

The Health and Social Consequences of the 2001 Foot & Mouth Disease Epidemic in North Cumbria



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Cover pictures: on-farm pyre; culled dairy cattle; Westmorland Show 2002; Keswick High Street 2001; disinfectant mat on A6; pro-vaccination demonstration, Carlisle.

Sources: local media, panel respondents, research team.

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Glossary

BSE	-Bovine Spongiform Encephalopathy
CADAS	-Cumbria Alcohol and Drug Advisory Service
CAP	-Common Agricultural Policy (of European Union)
CARL	-Council for Agriculture and Rural Life
CCRF	-Civil Contingencies Reaction Force
CP	-Contiguous Premises (status of culled farm)
CRE	-Centre for Rural Economy (University of Newcastle)
CSIN	-Cumbria Stress Information Network
DC	-Dangerous Contact (status of culled farm)
DEFRA	- Department of Environment, Food and Rural Affairs
DEFRA CSL	-DEFRA Central Science Laboratory
EU	-European Union
FMD	- Foot and Mouth Disease
GP	-General Practitioner
IP	-Infected Premises (status of culled farm)
LEA	-Local Education Authority
LSP	-Local Strategic Partnerships
MAFF	- Ministry of Agriculture, Fisheries and Food (subsumed into DEFRA, June 2001)
MP	-Member of Parliament
MEP	-Member of European Parliament
NCHA	-North Cumbria Health Authority
NGO	-Non-Governmental Organisation
NFU	-National Farmers Union
NHS	- National Health Service
NWDA	-North West Development Agency
PCT	-Primary Care Trust
RAZ	-Rural Action Zone
RRC	-Rural Regeneration Cumbria
RSAP	-Rural Stress Action Plan
RSIN	-Rural Stress Information Network
SEAC	-Spongiform Encephalopathy Advisory Committee
SVS	-State Veterinary Service
TB	-Tuberculosis
TIC	-Tourist Information Centre
VAC	-Voluntary Action Cumbria

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Executive Summary

This report demonstrates that the 2001 Foot & Mouth Disease (FMD) epidemic was a disaster for large numbers of rural people. By disaster we mean substantial and enduring distress and disruption. The research is based on systematic analysis of testimonies given by an (extraordinary) group of 'ordinary citizens', of their experience of living with and through the epidemic. It draws out evidence about the effects of the epidemic across a wide range of occupational groups. It makes recommendations for policy and practice which emanate directly from the longitudinal data and from the process of synthesising different kinds of evidence. Findings are informed by subsequent readings of background literature related to the analytical themes developed, and also by the substantive reports and documents which have emerged in the wake of the events of 2001. While the empirical research was carried out in North Cumbria, where the epidemic hit hardest and for longest, we have striven to follow events and reports from the other affected areas, and this report in no way seeks to minimise the severe effects on those other areas e.g. North Devon, South Wales and Northumberland. We believe that this report carries relevance for those other areas and for English (and UK wide) policy on responding to FMD and other disasters.

Through data collected over 18 months of weekly diaries kept by a large citizen panel, supplemented by in depth interviews and group discussions, this report shows the ways in which the FMD crisis impacted on the health and well-being of research respondents. This is done through analysis of the longitudinal data, and development of the analytical themes, Altered Lifescapes; Trauma and Recovery; Trust in Governance and Knowledges in Context, in which we also show the ongoing effects of 2001 on personal and community relationships and on chronic health problems.

It has often been noted that health and social services did not record any significant increase in demand during the FMD epidemic and subsequent months. 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 in health services research. We offer a different body of evidence about the impact of the FMD events which addresses the question of why demand for primary care and mental health services did not rise, as many expected.

First, movement restrictions for farming people were draconian: it is often not recognised that what movement was possible was hardly utilised; people did not go out, believing that mobility and social contact could spread disease. Funerals, weddings, even shopping trips were curtailed, visits to the doctor were similarly considered out of bounds. Others also moved around as little as possible for similar reasons, and to show support and consideration for what farming neighbours were suffering.

Second, we know that consultations in primary care, in particular nursing contacts, became more complex and lengthy, but that this experience was not formally recorded and has remained invisible.

Third, voluntary local help lines and rural support groups reported huge demand – showing that ‘health’ during the crisis was defined in terms of survival and practical support rather than medical interventions¹. In this context, formal NHS primary care, mental health and social services agencies, were not seen as immediately relevant.

Fourth, the enduring and complex nature of events taking place in often scattered communities may have prevented statutory agencies from ‘seeing’ the FMD epidemic as a human disaster. A ‘disaster’ in the more conventional sense (such as the sudden and horrific event at Lockerbie) tends to prompt pro-active and innovative approaches on the part of service providers, who feel able to dispense with ‘peacetime’ rules. There were some examples of innovative responses during the FMD crisis, especially in primary care, but these were scattered, informal, and not formally recorded; thus knowledge about them was hard to share.

Fifth, public health impacts were considered according to traditional norms: public health doctors and local authority officers initially perceived the human health risks to be either immediate environmental, or possibly zoonotic effects. The latter soon faded as a concern, while the former also appeared to be addressed once large-scale pyres were abandoned as a major disposal method following public protest. While concerns about longer term effects on mental health and well-being were sometimes raised e.g. at the local Health Task Group and in a number of articles and responses more widely such as in the British Medical Journal, it was not apparent how to act, due to the epistemological problem mentioned above of how to collect and produce evidence about this.

Recommendations include:

- **Developing non-pathological understandings of trauma**
- **Joint reviews of what counts or is recognised as a disaster**
- **Health and voluntary sector sharing of intelligence**
- **Regeneration funding for rural health/social outreach work**
- **Gathering expertise from front line workers; provision of debriefing and peer support**
- **More meaningful community involvement in disposal site management**
- **Wider and more flexible access to regeneration funding**

¹Local offices of the Citizens Advice Bureau (CAB), recorded increase in number of enquiries up by 45% on the previous year. (Cumbria Inquiry Report 2002, 78); Cumbria Stress Information Network (CSIN) (a multi-agency project based within the voluntary sector) set up a 24 hour telephone helpline. During the first six months of the epidemic over 2,500 calls were received, many from those acutely affected. (North Cumbria Mental Health Promotion Strategy 2002, 9).

Section 1 Introduction

'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'. (Erikson 1991)

The 2001 Foot & Mouth Disease epidemic involved a set of events far more complex and heterogeneous than was realised in its early stages. Far from being solely an agricultural problem, it precipitated a crisis in the rural economies of UK regions. As the year dragged on and the disease persisted, testimonies to the human cost of the epidemic began to emerge. For this reason we applied to the Department of Health for research funds to capture and understand the impact of these complex events. Our inquiry examines the health and the social consequences of the 2001 rural crisis. These are broad terms and some initial definitions are necessary here.

'Health' in this context is defined broadly: the sense of well being and quality of life which individuals experience. 'Social' we define as effects beyond the individual as they impact upon health, such as the character of social networks, mutual support, sense of community, identity and trust in social institutions. 'Consequences' we take to mean changes over time: the impacts of the FMD crisis during its early and later stages, but also any longer term effects and the nature of 'recovery', (a term we examine later). Clearly these definitions lay out a very ambitious research task and this partly explains the complex research design outlined below. Readers will judge how far we have succeeded in our task, but we believe our findings add to a number of important and diverse studies and inquiries. Together these form a growing body of knowledge about what was effectively a disaster for large parts of rural England and UK. This kind of knowledge was not available to policymakers, planners and practitioners who had to act in a complex world amid the unfolding crisis in 2001, since very little information had survived about the human health and social impacts of the most significant previous epidemic in 1967 (Woods 1999).

The 2001 FMD epidemic has been described as probably the most serious ever to occur in a previously FMD-free country² and by the Anderson Inquiry secretariat as *'a traumatic and devastating experience for all those who were affected by it. I was a national crisis and was probably one of the greatest social upheavals since the war'*³. The county of Cumbria suffered the largest number of confirmed cases (44% of national total). The DEFRA map below (Figure 1) gives a visual representation of the spread and concentration of the disease in the UK at the time of its (biological) end. Nationally, calculations of numbers of stock slaughtered vary according to source, estimates vary between 6,456,000 animals slaughtered for disease control and welfare purposes (National Audit Office 2002) to 10 million (EU Temp Committee).

² Cumbria Inquiry, executive summary 1. P9

³ Anderson 'Lessons Learned' Inquiry secretariat 2002



Figure 1. Spread and concentration of the disease (source: DEFRA, 2002)

Outbreaks endured in Cumbria from 28th February until 30th September, with individual farms continuing under restrictions into the spring of 2002. Again estimates vary, but a conservative total would be 1,350,000 animals, not counting lambs. There were 893 confirmed cases of FMD in the county, and in addition a further 1,934 farms had complete or partial culls of their livestock. In

the north of the county this represented 70% of farms⁴. Culling and disposal on this scale, together with the logistical exercise needed to carry it out, could not fail to have an impact on the communities involved.⁵ The increased isolation for farmers which was the inevitable consequence of the policy of slaughter, disposal and biosecurity; coupled with the huge numbers of non-farming people drawn into the crisis turned an economic crisis into a human disaster for large parts of rural Britain.

The effects of the crisis were felt locally and remotely; directly and indirectly; immediately and in the longer term. For example, locally, in parts of North Cumbria, farmhouses and farmyards are integral to the village, situated on the main street among other houses. It was therefore impossible for non-farming neighbours to escape the sights, smells and sounds of culling and disposal. Remotely, farmers in the high fells of the Lake District who traditionally send young sheep to winter on low land, (e.g. the Solway Plain or Furness Peninsula), were powerless to bring flocks back from infected areas because of movement restrictions, and so suffered multiple culls of over-wintering stock at different locations.

Restrictions on rights of way, and government advice to stay away from the countryside, led to a collapse in tourist numbers and Cumbrians themselves were deprived of the comfort of recreation in their own 'therapeutic' environment. Residents near designated mass disposal sites found their villages 'taken over' by high sided wagons and HGVs negotiating narrow roads and lanes, and some residents' homes were within horrifying sight of the large scale slaughter and disposal. For these residents, living with the environmental consequences of disposal through 2002/3, involved ongoing anxieties about the long term effects of living in close proximity to this new phenomenon.

Frontline workers who dealt with the day to day realities of the disaster likened this to 'war-work', which had immediate effects on health and well being, family contact, while the longer term consequences for this heterogeneous group were unknown. Children at all levels lost schooling, in some cases absences were for as long as six months, resulting not only in loss of formal learning opportunities, but also in possible complex long term effects, which remain unresearched and are largely beyond the scope of this study (Cumbria County Council 2002).

These complex features of the epidemic called in our view for a longitudinal and multi-method research design, detailed in Section 2. Through data contained in 18 months of weekly diaries kept by a large panel of citizens, supplemented by in depth interviews and group discussions, this report shows the ways in which the experience of the crisis impacted on health and well-being. In sometimes harrowing accounts, respondents articulate the direct trauma of experiencing culls at close hand; the 'collateral' impact of the culling on non-farmers who also shared a sense of communal crisis, and the repeated impact on front-line workers as they organised and carried out months of slaughter and disposal

⁴ Cumbria Inquiry, Part 1 p19

⁵ Ian Anderson, (Lessons Learned Inquiry Sec 5 p1) 'Numbers alone cannot capture the sense of what unfolded. The great epidemic of 2001 left an indelible mark on communities, businesses and people from all walks of life.'

Background and Policy Context

Even before the FMD epidemic there were grounds for considering the health consequences of a number of crises impacting on livestock farmers and their local communities; crises of both a direct economic nature (falling profit margins) and a public health nature (for example, E coli O157; BSE). Large-scale agricultural change was already happening. During the last decade, the UK agricultural sector suffered significant problems (Franks, 2002; Lowe et al. 2001; Policy Commission on the Future of Farming & Food, 2002; The Royal Society, 2002; MAFF, 1999). As the Royal Society Inquiry into infectious diseases in livestock states (2002:9), from the mid-1990s, 'much of the profitability has drained from the industry'. Contributory factors included the strength of Sterling, low livestock prices and the Bovine Spongiform Encephalopathy (BSE) beef market crisis. By the time of the epidemic, farm incomes were 'on the floor' (Policy Commission, 2002:13). Within Cumbria the epidemic massively damaged livestock farming that was already struggling to survive.⁶ This was particularly so in the more remote, upland parts of the county characterised by the lower income, smaller hill farming sector⁷, inextricably linked with tourism in areas of outstanding beauty (Bennett & Phillipson 2002, Lowe *et al.* 2001). A recent analysis of hill farm incomes in Derbyshire revealed a 75% drop over 10 years (Peak District Rural Deprivation Forum 2004). It is becoming recognised that health patterns in rural areas are similar to those in towns, with one in four people living in poverty (Tideswell Health Survey, 2002; State of the Countryside, 2001). The increasing sense of social isolation among livestock farmers as a result of a number of such agricultural 'shocks', has undermined farming as a way of life and the cultural identities of those working in the sector. It is known that rapid social and economic change has major potential consequences for public health.

Prior to 2001, concerns about rural health and mental health (Hawton et al 1998) have included concerns about the 'accessibility' of health and other services to those living in rural communities (Rural White Paper 2000). The restructuring of rural resources (schools, shops, health and leisure services) has required adaptation by those living in rural areas (Wood 2004). For some, this 'adaptation' might mean under-utilisation of primary health care, but in addition to distance constraints there is evidence (Gerrard 1998) that farmers in particular do not always make use of 'conventional' health services. Gerrard's work reveals a cultural gap between centralised, 'clinically efficient' health care, and local occupational values and needs. While her research related to farming people, her findings have resonance for cultural geographies of healthcare more widely.

Tourism is a key sector of the Cumbria economy, and is often sustained in close synergy with farming - for example farm accommodation and catering; the visual and recreational amenity of the farmed landscape. The virtual closure of

⁶ Cumbria suffered by far the greatest number of FMD cases in the UK (893 compared with the next nearest total of 176 for Dumfries & Galloway). Cumbria County Council has estimated losses to agriculture of about £130 million, and tourism losses of £400 million over one year.

⁷ These areas were in the main uninfected, but movement and trading and tourism restrictions meant a loss of income, coupled with increased costs for feeding extra stock and disinfection.

the countryside for almost a year brought much of this tourist industry to a standstill⁸. Distressing media portrayals of burning pyres compounded the problem. The reduction in visitor numbers to rural areas, coupled with predictions of further such losses that become self-fulfilling, meant hardship and anxiety for those running visitor-oriented businesses. Many village shops and pubs upon which rural communities rely all year round are themselves reliant on additional income from visitor trade for their survival, demonstrating the delicate interrelationship between these particular constituencies.

There is no doubt that rural communities in North Cumbria and elsewhere were hit hard, socially and economically, by the 2001 FMD epidemic (Bennett & Phillipson 2002). Yet the 'community' in reality comprises a number of diverse groups, with different sets of interests and varying capacities to voice those interests. Further, the 'community' and the groups themselves became divided in their responses to the FMD crisis; for example, farmers pressed for footpaths to remain closed in the interest of controlling disease spread, while the tourist industry wished them open in order to attract visitors to the hills. And divisions were created within the farming community itself: between those subject to culling and those whose livestock survived. The publicity given to the ostensibly high levels of compensation/compulsory purchase received by farmers whose livestock was culled led to a perception that all farmers had benefited substantially from FMD, whereas those who did not lose livestock, but were subject to months ongoing restrictions, claimed that they suffered severe financial hardship. We know that this put farmers and their families under greater stress and social isolation and further threatened the cohesion of local communities.

Social impacts of rural policy/disease control measures

It is acknowledged that rural contingency planning needs to become more inclusive: DEFRA's current FMD Contingency Plan is starting to involving a range of rural stakeholders, as can be seen in the work of the Rural Stress Action Plan Working Group, (DEFRA, 2003/4); (Donaldson et al 2002). However, there has been very little record of the social and human effects on individuals and on communities of large scale animal epidemics which means there is no tradition of doing this kind of work.

In 2001 FMD was not a new phenomenon. Between 1922 and 1967 and there were four major FMD epidemics with ensuing government reports in 1922, 1924, 1954 and 1968. Within these, it is hard to find any reference to the human health and social impacts of the disease. As Prempeh et al (2001) clinical specialists writing in the British Medical Journal note:

The health [of FMD] consequences are slight...Foot and mouth disease is a zoonosis, a disease transmissible to humans, but it crosses the species barrier with difficulty and with little effect.

⁸ Movement restrictions for livestock and signs discouraging tourists were still in place 3 months after the last FMD case was noted.

However, as this report will show, the health and social consequences of a slaughter *policy and practice* are significant. In 1968 speed of mobilisation against the disease was seen as critical:

In future, whatever the difficulties or inconvenience to rural life or the general public, the most drastic measures must be applied at the immediate commencement of even what might prove eventually to be only an isolated case. Never again must we run the risk of an outbreak swiftly developing into a national disaster.

(British Farmer, Jan 6 1968, Opinion, p.9)

Following the 1967-68 epidemic, The Northumberland Committee Report endorsed a speedy 'stamping out' policy (1968). The Cumbria Inquiry (2002) suggests that the rapid culling and disposal emphasised by Northumberland, was not achieved in Cumbria in 2001. The 'Lessons Learned Inquiry' (p.22), noted central issues running through the government FMD reports prior to the 2001 epidemic which Anderson argued also featured in the 2001 outbreak such as contingency planning, speed of response, animal movements, role and supply of vets, liaison between central and local governments, movement restriction after markets, tagging of animals and the use of swill as a source of infection.

But as our study highlights, most of these issues and the slaughter policy from which they stem, have profound social and human impacts. The trauma of losing generations of work in building up pedigree herds and flocks at a stroke; the effect on rural businesses threatened by the economic impacts of restricting livestock and human movement; the social impacts of closing auction marts, cancelling seasonal rural social events and isolating 'infected premises' (which means isolating human beings); the public health concerns of carcass disposal methods including landfill, mass burial and burning on pyres; all these may have health and social consequences. As the Cumbria Inquiry notes, the environment and the lives of local rural communities were transformed:

. . . these events caused a huge level of trauma and distress for many in the population, and brought attendant concerns about short-term and long term-problems of health.

(2002, p.57)

The inquiries that followed the 2001 epidemic focused on the government handling of the epidemic (Lessons Learned Inquiry, Anderson, 2002); disease control strategies in livestock (Royal Society Inquiry, Follett, 2002), and survival of the industry (Policy Commission on the future of Farming and Food, Curry 2002). The European Parliament formed a temporary sub-committee on FMD that reported on prevention and control strategies (EU Temp Committee, 2002). These inquiries highlighted that the scale of the 2001 epidemic and the massive slaughter and disposal operation led to logistical, implementation and communication problems and control measures resulting in an upsurge of public concern. Yet like earlier FMD inquiries, they afforded little insight into the impact

of the upheaval on human health and well being at individual or community level.

County led FMD inquiries such as those carried out in Northumberland, Devon and Cumbria reported to some extent on the health and social impacts of the 2001 epidemic using evidence taken and meetings held with local people. The Cumbria Inquiry (p.21), in addition to its formal hearings, held meetings with representative groups, organisations and businesses as well as six evening public meetings held in different parts of the county. A small study commissioned by County Durham & Darlington Health Authority and Northumberland Health Authority highlighted ongoing anxiety about risks associated with mass carcass disposal sites and mistrust around location policies. It called for 'more equal, reciprocal dialogue and sharing of information, even in the context of crisis situations, in which stakeholders can contribute rather than being passive receivers' (Bush 2002; 2003). The Welsh Assembly commissioned a study into the impacts of the 2001 epidemic on the mental health and well-being of the people of Wales in which Deaville et al (2003:2) note: 'There is a paucity of literature on the human health impacts of foot and mouth disease from previous outbreaks in the UK'. The Welsh study used the largely statistical and medically orientated methods common in health services research and which are often inconclusive for socially complex fields of study. Nevertheless it concluded that the post FMD situation in Wales did raise concerns about general and emotional health, in particular anxiety and depression, and called for further research into the long term effects on child health and well being (Deaville, 45/6).

During the crisis, it was largely 'traditional' public health impacts which 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 the former also dropped from view once large scale pyres were abandoned as the principal disposal method following public protest⁹ (North Cumbria Health Task Group 2001/2002). 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 (BMJ Letters 2001-2002), little action followed, due to the epistemological 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.

In diabetes care, disruption to routines, both of self care and access to health services, began to be noticed as the crisis took hold. The Cumberland Infirmary Diabetes Centre consultant, Dr David Large, instigated a study of blood glucose control collected from laboratory databases before, during and after the FMD epidemic, amongst those who said they were affected by FMD and those non-affected service users. The study is being completed as we finalise this report, but draft findings indicate that those affected showed worse glucose control

⁹ Longtown Community Centre (2001) Public Meeting convened to discuss pyre burning with representatives from the Army, Maff, the Environment Agency and local Health Services, 11th April 2001.

during and just after the epidemic, than before it, in comparison with the non-affected group. (Large et al in preparation; Syed et al 2002).

We also note that DEFRA's FMD contingency plan (version 3.1, Dec 2003) identifies that 'any future outbreak may result in significant social, economic and personal emotional impact' (p.42). It proposes tackling these issues through consultation with the 'Rural Stress Action Plan Working Group' (RSAP). RSAP was funded by MAFF as part of the Government's Action Plan for Farming, announced on 30 March 2000. A partnership, multi-agency organisation, both voluntary and industry related, it has enabled farming charities to provide helpline support, produced a small 'Farming Help' card which promoted rural help lines and which providently was launched in the farming press on February 16th 2001. RSAP had been in operation some six months preceding the FMD crisis and important partnerships had begun to emerge.

The literatures we have drawn on for this study reflect the heterogeneous nature of this field of inquiry, including the history of FMD in the UK; local and government sponsored inquiries; health related FMD publications; disaster studies; clinical and other literatures on trauma and Post Traumatic Stress Disorder; rural health studies. Within 'FMD literature' we also reviewed some of the large body of textual and other cultural products which have arisen since the epidemic but are not referenced here. We have also drawn on the methodological literature relating to the use of diaries in health research.

Section 2 Research Design

Methodology

In designing the study it was felt there was a need to look beyond questions of *what* regarding the 2001 FMD epidemic to questions of *how* and *when*¹⁰. A wide range of perspectives and some way of capturing these over time were required. We considered a number of alternatives which could provide large scale and longitudinal data whilst remaining predominantly qualitative in nature. This led us to look at diary based methodologies in health research.

Meth (2003:201) emphasised how diaries offer 'longitudinal personal insight into day-to-day processes...(diaries) provide rich detail on the everyday context of health and illness.' Diary keeping brings the task of data collection into the person's own everyday world (Elliot, 1997; Verbrugge, 1980, Zimmerman & Wieder, 1977). They provide the opportunity to study change over time and offer direct insights into a person's everyday experience and how they perceive it (Hayes, 2000). We were also influenced by the work of the Mass Observation movement, which produced a kind of 'anthropology of selves'. In this work Harrison, Jennings & Madge recruited a national panel of diarists from 1939-1965 writing about everyday life; this work now constitutes an invaluable resource¹¹.

The use of both citizens' juries and standing panels as a consultative mechanism is well known in health and multi-agency groups, and has been used in assessments of health needs, (Kashefi & Mort 2004). This procedure has been used by others formulating citizens' juries in other contexts (Coote & Lenaghan 1997). However, whilst highly deliberative, these have been criticised for their lack of 'follow-through' and opportunity for learning (Dowswell et al 1997); (Harrison & Mort 1998). It was felt that in order to utilise this approach in a *research* context, a longitudinal approach, rather than a discrete event, would be more productive.

Our design was also underpinned by action research (AR), a philosophy that is carried out *with* research respondents rather than *on* research 'subjects'. Because of the sensitivity of the post FMD situation, it was felt that a style of research which could both generate knowledge of health and social impacts and inform policies to address the potential consequences of these impacts, was ethically appropriate. The 'participants' in this study therefore included the members of the project steering group representing a wide range of stakeholders, as well as those who directly contributed the data – the 54 members of the citizen panel (respondents)¹². All had regular opportunities to guide the research process and later comment on the emerging themes and findings. As Hart & Bond (1995) describe, there are many modes of action

¹⁰ 'What' questions have, we feel been exhaustively covered in the main government and agency inquiries referred to in Section 1.

¹¹ The Mass Observation archive is maintained by the University of Sussex, see <http://www.sussex.ac.uk/library/massobs/history.html>

¹² The 54 members of the project panel are referred to in this report as 'panel members' or 'respondents'. The number of panel members fluctuated slightly, as detailed in Section 3.

research, from the managerialist to the emancipatory. Our approach was largely practical in that the 'action learning set' was constructed as the project steering group, which represented the sorts of agencies which needed to understand more fully the effects of the disaster and to work on drafting recommendations to mitigate these effects and to respond to any future disaster. The role of the 54 respondents then, was as co-researchers but also more traditionally as respondents, providing data.¹³

To assist with this a number of 'feedback loops' were created:

- Quarterly steering group meetings
- Regular newsletter to panel members, inviting comments and contributions
- Annual reports (Dept of Health) circulated to steering group for comment
- Panel group discussions a) to introduce and start project; b) to gather responses to interim analysis
- Monthly visits to all panel members
- Dissemination conference: invited audience of policy, practice, voluntary and public sector
- Panel member project evaluation

Here there was also a large element of learning and the opportunity for respondents to present alongside the researchers at the major conference in Carlisle and to the Health Overview & Scrutiny Committee of Carlisle City Council. As in the nature of AR, the cycle of inquire, intervene, evaluate may continue indefinitely. Appendix 7 outlines further the outcomes of the action research approach including the panel member evaluation of the project.

Project Steering Group

In any action research project, the role of the steering group is central. It comprised representatives from key agencies involved both in the management of the epidemic and post-FMD recovery: 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 and other health professionals, veterinary practices. As recommended by the Dept of Health, this was chaired by Dr Peter Tiplady, former Director of Public Health for (the then) North Cumbria Health Authority¹⁴.

Composition of the project panel

The task of the first steering group meeting was to agree the occupational and demographic profile of the panel of respondents to be recruited to the study. Discussions were held about the relative merits of random sampling and purposive sampling, and it was agreed that if the purpose was to gather longitudinal in-depth data

¹³ For example, the steering group helped us draw up the panel profile and later take decisions about using the EuroQol; the panel members directed us to inquire about 'effluence' at one of the mass disposal sites (Great Orton), and also commented on the EQ-5D and on the process of diary writing.

¹⁴ This met first on 30.11.01 and quarterly thereafter; a full set of minutes is available.

from a large panel of respondents about the effects of FMD, a structured purposive sample, carefully selected, and recruited independently and anonymously would be most appropriate. It was decided the panel of 54 citizens should be recruited from 6 occupational groupings which were affected in different ways by the crisis; a detailed profile for each group was then drawn up to guide the recruiter:

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

Table 1 Occupational groups included in the panel

Group 2: Micro businesses¹⁵			
	Arts and crafts	Hospitality	Retail
	Riding schools, photographers, film makers, pottery businesses	Including hotels, guest houses, public houses, restaurants, taxi firms, coach firms and caravan parks	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 men and 4 women		
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, <i>accessible rural</i> (relatively low unemployment levels, good road networks and better access to services and facilities.); <i>remote rural</i> (located in very remote area, limited road network, access to services) and <i>urban</i> (towns such as Penrith)		

Table 2 Example of detailed profile within each group

¹⁵ This group profile 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

Recruitment of the Panel

The six group profiles were forwarded to an independent professional recruiter. The groups were recruited in order, individual names being held by the recruiter and only released to the research team once the researchers were satisfied that the profile had been matched. The resulting panel composition is given in the following section (Table 3).

Once the panel was recruited we used a range of methods to capture data at individual and collective levels, introduced in order:

1. Group discussions (taped & transcribed)¹⁶
2. Weekly project diary over 18 months containing structured and free-text sections (see App1)
3. In depth semi-structured interviews (taped & transcribed)
4. EQ 5D instrument (quality of life questionnaire)
5. Documentary material e.g. local agency reports, Cumbria Inquiry, Anderson Inquiry

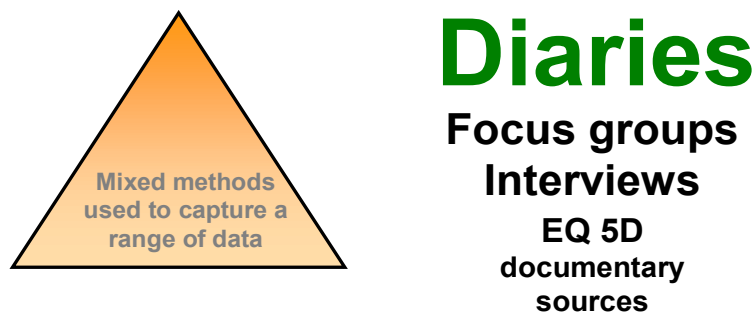


Figure 2 Weighting of data collection

Ethical approval was given by both East and West Cumbria Local Research Ethics Committees.

The study timeline at the end of this chapter gives an overview of the activities and collection of research data over the course of the project.

¹⁶Each respondent gave their written consent to be part of the study for 18 months at the first group meeting.

Discussion groups and interviews

Questions were developed to help prompt the group discussions:

- What impact has FMD had upon the sense of community felt by individuals/groups on the panel?
- What have been the main personal resources/community assets which have helped sustain individuals/groups through the crisis?
- What strengths and weaknesses in health, social and economic support have been highlighted by the crisis?
- To what extent have those living in the worst affected areas suffered either from loss of employment, or fear of employment loss?
- To what extent have those working in tourism/small business been able to recapture business, compared with those working in farm-related employment?
- What have been the impacts on: self-reported health; mental health and health behaviours, of those individuals/groups affected by the FMD crisis?
- How do the impacts vary according to age, gender, occupation and locality?
- Are younger people affected differently from older adults?
- Are others relatively 'cushioned' from the longer-term impacts?

As each panel group was recruited a group discussion was held, followed as soon as possible by in-depth interviews in respondents' homes (occasionally workplaces). These taped interviews were generally between 45 minutes and 1 hour 20 minutes duration, most lasted around an hour. Interviews began with broad, open questions ('What was your first memory of the FMD outbreak?') and many transcripts contain long, uninterrupted stories about living with the epidemic. During this visit the first four paper diaries were distributed and respondents could raise any queries which had not been resolved at their group meeting. Monthly visits were made over the succeeding 18 months to collect diaries and offer the small agreed payment. The EQ-5D instrument was distributed 6 months into the study¹⁷. A regular project newsletter for panel members was produced and ran to 10 issues (see example Appendix 4).

Designing the diary

The project diary was the principal research tool and an initial design was piloted with a small group of volunteers for comment on comprehensibility and usability¹⁸. To encourage those respondents who might not be used to writing, the diary begins with a few simple weekly questions: to rate quality of life, relationships with family and work colleagues, and health. These questions were also constructed to yield some symmetrical data across respondents and across the groups, while the main part of the diary, the free text section, was not prescribed in any way.¹⁹ Since respondents enter studies with different levels of health and perceptions about health, it was important to look for changes over time within the body of individual diary entries, a point we discuss later. Diary

¹⁷ It was originally planned to distribute this three times during the course of the study but this later proved impractical, a point we discuss in detail in Section 4

¹⁸ The Pilot Group consisted of a vet, a health worker and two farmers from outside the study area. They made a few minor comments on the diary layout, but as the diary is predominantly free text, they offered views about how respondents might be encouraged to fill these in – e.g. to make sure we emphasized that there was no 'right' or 'wrong' way to complete a diary

¹⁹ See Appendix 1, blank project diary.

writing began with Group 1 in Christmas week 2001 following their group discussion.

The diary and interview material were also later interrogated for insights into these questions, but these were not explicitly asked. We believe that a strength of our design is the *absence of structured questions*. We wanted respondents themselves to articulate what was important, so that we could follow their identification of priorities and how these changed over time. Our largest body of data is contained within the free text sections of the diaries. We argue that the themes we have identified (Figure 6) have greater reliability and validity because the data supporting them was *not* generated from explicit questions.

Additional data

The EQoL-5D instrument was distributed six months into the study.²⁰

We set aside time for additional interviews with agencies or individuals. This material was collected first to fill any 'gaps' not covered by the panel profile, such as army and police personnel; secondly we responded to issues which arose during the course of the study, and carried out interviews accordingly. Examples include local government, police service, army, NGOs and voluntary sector agencies. Many of these interviews were also taped and transcribed and were later interrogated for the themes identified from the panel data. Details about this additional data are given in Appendix 3.

Useful comments and suggestions were made by both steering group and panel members throughout. In addition, interim findings were discussed with different stakeholders: e.g. participation in the EU Temporary Committee on FMD; Cumbria Inquiry; participation at Carlisle City Council Health Overview & Scrutiny Committee reviewing action taken following the Cumbria FMD Inquiry; The Voices of Experience interim findings conference; discussions with research colleagues and health practitioners about how our synthesis of the qualitative and quantitative material (Ethnoplots, Figure 7) might apply in other public health contexts.

Panel member evaluation

When respondents had finished keeping diaries we carried out an informal written survey to ask them about their experience of writing the diary and being part of the project. Questions included whether they had kept a diary before, what kept them going with the writing, whether the small payment helped and if so in what way, whether they shared the diary with family members (see Appendix 7).²¹

²⁰ . It was originally planned to distribute this three times during the course of the study, but this later proved impractical, a point we discuss in detail in Section 4.

²¹ There is no doubt that payments helped keep some respondents 'on board'. This is partly because payments allowed some tangible recognition of the respondent's expertise, it conveyed a sense of value of their contribution, and we would argue dignified it. For others suffering acute financial hardship, the possibility of gaining £40 per month made a significant difference to the household budget. (Some respondents chose to receive supermarket vouchers instead of money). Others spoke of giving their funds to charity or saving up to buy presents for grandchildren. We believe that long term commitment to providing data for research should be the subject of some recompense and, rather than bias the results, can

Researcher commentary

Researchers kept field notes during their 18 months of contact with panel members to maintain a critical view of the longitudinal process. These notes reveal some ethical and epistemological questions raised by this kind of data collection, such as what could and could not be included as data, and how panel members responded differently in different formats, i.e. diary, individual interview and group discussion.

During fieldwork visits, conversations were wide ranging, from local and national FMD developments and initiatives, to everyday talk about families, paid work, past and future events, hopes and fears. Researchers occasionally sought clarification of what had been written. Respondents sometimes made great efforts to communicate detail about the imperatives of their circumstances, such as a respondent describing his working practices as a livestock haulier – *so's you knows exactly what it's like for us, what the pressure's like dealing with all the paperwork.*²²

Respondents approached the project in different ways, sometimes finding one method of communication suited them better than others. Some panel members who in interview indicated that they had been severely affected by the events of 2001, rarely mentioned these in their diary; others, living near disposal sites for instance, articulated in their diaries continuing concerns directly related to FMD. Over time we came to recognise the way in which each diarist was applying 'benchmarks' to their own health and well-being in the structured part of the diary. For one respondent a score of 'Average' for health/quality of life indicated normality - no problems, no highlights; while for another, the change from a regular entry of 'Good' to 'Average' occurred at a time of personal anguish and psychological crisis.

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 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, the duration and intensity of the research process in this study led to the development of trust between researchers and respondents, which we believe lies behind the very high commitment of respondents to the study, (see Section 3).

At times such issues were challenging. During visits, in the course of informal conversation, significant information was sometimes divulged. While these confidences informed the general understanding of researchers, they could not be included as research data. Similarly other family members sometimes became unofficial respondents, but if their comments were not alluded to either

actually free the respondent and researcher from certain biases created around potentially exploitative relationships or respondent fatigue/attrition.

²² Our fieldwork is described in greater detail, see Bailey et al (2003)

in interview or diary by the project respondent, then these also could not be included.

Lancaster Study Timeline²³

1 st FMD case confirmed Cumbria	29 Jan 01
Last case Cumbria	30 Sept 01
Royal Society calls for evidence for its Inquiry into Infectious Diseases in livestock	11 Oct 01
	30 Nov 01
	Lancaster Project Steering Group inaugural meeting
17 Dec 01	1 st Panel group meeting: <i>Farmers & farm workers</i>
Framework document for Anderson Inquiry published. Inquiry aimed to report to PM and Sec State DEFRA in mid-2002	Dec 01
EU International Conference on FMD Brussels	12/13 Dec 01
Dec 01 - Feb 02	Respondents begin weekly diaries following panel group meetings
Restrictions and cleaning/repairs/restocking going on into 2002 (some did not re-stock until 2003)	2002 and 2003
UK declared free of FMD	22 Jan 02
Jan 02	DIARIST ²⁴
Jan 02	Programme of interviews with respondents begins
23 Jan 02	Panel group meeting: <i>Small business group</i>
Post-FMD conference Rheged Penrith (DEFRA NWDA)	25 Jan 02
29 Jan 02	Interviews Cumbria County Council
31 Jan 02	Panel group meeting: <i>Agricultural related group</i>
EU lifts meat and animal export restrictions	05 Feb 02
Feb 02	DIARIST
13 Feb 02	Panel group meeting: <i>Frontline workers group</i>
21 Feb 02	Panel group meeting: <i>Community group</i>
26 Feb 02	Steering group meeting
28 Feb 02	Panel group meeting: <i>Health and veterinary group</i>
Evening 'public' meeting of Anderson 'Lessons Learned' Inquiry Carlisle	12 March 02
March 02	Interviews with respondents completed
20 March 02	Action Group meeting Penrith
8 April 02	Interview Radio Cumbria broadcaster: FMD
16 April 02	One-day conference Skipton, Farming/FMD documentation: Littoral Arts
EU temp committee on FMD Inquiry meeting at Gretna (respondent writes report for the DIARIST)	18 April 02
Team presentation to EU temp committee in Kendal	21 April 02
22 April 02	Meeting with CSIN (FMD helpline)
22 April 02	Meeting with Cumbria Community Legal Services

²³ Events concerning respondent panel/data in RED
National/International/'Official' events shown in BLUE

²⁴ DIARIST is the study newsletter.

22 April 02	Interview Cumbria Drug and Alcohol Service
24 April 02	Interview Business Link Cumbria
May 02	DIARIST
Team attend Kendal public hearings of Cumbria FMD Inquiry. Presentation to Inquiry.	7 May 02 – 31 May 02
Team attend informal public meetings of Inquiry at Workington, Ulverston, Appleby and Longtown.	
09 May 02	Steering group meeting, Penrith
14 May 2002 – 19 May 02	Conference paper at Kansas USA
23 May 02	Team attend seminar on FMD carcass disposal in North East
28 June 02	Team presentation at conference Rising From The Ashes (Institute for Rural Health), Wetheral, Cumbria
July 02	DIARIST
15 July 02	Interview: manager of slaughter team, March – Aug 01
Team presentation to EU temp committee on FMD Strasbourg	02 Sept 02
Agricultural shows in South of county have livestock with strict bio-security. Other Cumbrian shows through summer had no livestock	05 and 12 Sept 02
Cumbria County Council Foot & Mouth Disease Inquiry Conference, Rheged Penrith	06 Sept 02
27/27 Sept 02	Atlas Ti training, Lancaster University
10 Oct 02	Presentation to rural health conference, Masham Yorks
14 Nov 02	Steering Group meeting Penrith
18/19 Nov 02	Data clinics, Lancaster University
21 Nov 02	Paper presented to Occupational Health Conference, Baltimore USA
Littoral Arts: Documenting FMD conference City Art Gallery Manchester	27 Nov 02
Dec 02	DIARIST
Jan 03	Data clinic, Lancaster University
Feb 03	DIARIST
11 Feb 03	Steering Group meeting
March 03	Data clinic, Lancaster University
May 03	DIARIST
April – June 2003	Weekly diary keeping ends
9 May 02	Steering Group meeting
15 May 03	Panel group Penrith (presentations to respondents to elicit their feedback on research methods and interim findings)
21 May 03	Panel group Penrith (see above)
21 May 03	Team attend seminar on research ethics Lancaster University
04 June 03	Panel Group Penrith (see above)
11 June 03	Steering Group meeting
11 June 03	Panel Group Penrith (see above)
21 June 02	Interview women's refuge worker, (domestic violence)

03 July 03	Panel Group Penrith (see above)
Aug 03	DIARIST
Aug 03	Data clinic, Lancaster University
Sept 03	DIARIST
03 Sept 03	Paper at Royal Geographical Society-IBG Annual Conference London
14 Oct 03	Lancaster Project Conference, Carlisle Racecourse
15 Oct 03	Kai Erikson seminar, Lancaster University
14 Nov 03	Steering Group meeting
18 Nov 03	Team presentation at N Cumbria Health Research Conference, Newton Rigg, Cumbria
20 Nov 03	Interview, Cumbria Constabulary
25 Nov 03	Team members attend archive workshop: Economic & Social Data Service, London
Dec 03	DIARIST
22 Jan 04	Steering Group meeting
6 April 04	Interview army: FMD NW Chief of Staff
23 April 04	Steering Group meeting
30 April 04	Draft research report submitted to Dept of Health
30 July 04	Peer reviews of report (5) received
22 October 04	Final (revised) report submitted to DoH

Section 3 Overview of the Data

As expected from a purposive sample, all panel members experienced the FMD epidemic in some way. Respondents were affected in different personal ways and extents, but also in terms of variation in experience. This variation became very important in the study - two members report that while being located in the geographical 'epicentre' of the FMD activity, e.g. Penrith, they were personally not affected by what was going on around them in terms of occupation, business or other kinds of suffering. Two other members report being caught up in the crisis intermittently, only through occasional contact with people suffering severely. The diary contributions of these four respondents are however, very revealing about what it was like to be relatively unscathed when so many were deeply affected. The rest of the panel reported a range of different experiences of the crisis, all of which show they were significantly affected. Table 3 below shows the total actual panel recruited, giving ID number (to preserve anonymity), age, sex, occupation and group number.

Record of changes to panel composition

One respondent, aged 17 from Group 1, left the panel very early, soon after the first group discussion, and was quickly replaced by a respondent from the recruiter's 'reserve' list, so is not recorded below. 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 from Group 4, 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, also from Group 4, 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 from Group 2, found that family difficulties and financial collapse became so overwhelming that diary writing became impossible. For these reasons the panel number fluctuates between 51 and 56 at different times during the study, though most often 'settled at the target of 54.

Diarist Number	Sex	Age	Occupation	Group Number
54	M	58	Farm owner (stock culled, infected premises) ²⁵	Group 1
53	M	49	Farm owner (stock culled, infected premises)	
52	M	32	Farm owner (form D restricted) ²⁶	
51	F	43	Farmers wife (contiguous cull) ²⁷	
50	F	24	Farm labourer (contiguous cull)	
49	F	44	Farmers wife (stock culled, infected premises)	
48	F	53	Farmers wife (form D 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	
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	

²⁵ Infected premises (IP); stock identified as being infected with foot and mouth disease and culled.

²⁶ Stock movements restricted by DEFRA *form D*.

²⁷ Stock culled as part of DEFRA contiguous cull programme (farm was bordering an IP).

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	

Table 3 The Panel

The map below (Figure 3) shows the locations of the panel members plotted using their postcodes. This plotting reveals a distribution 'shape' which reflects the spread of cases of FMD in Cumbria (Figure 4).

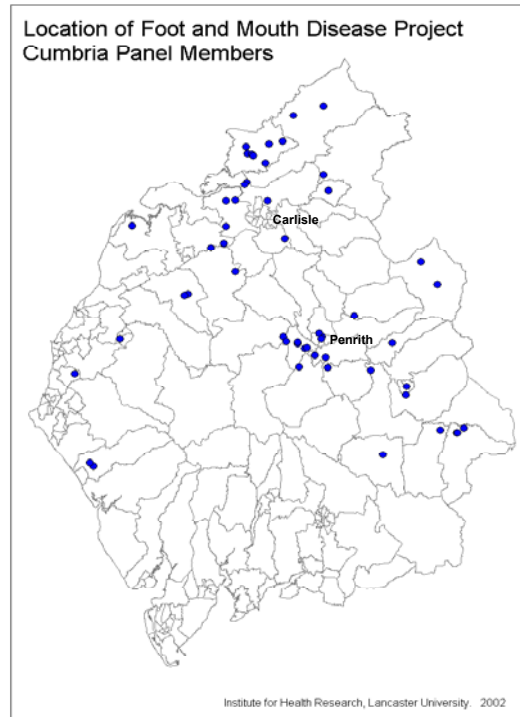


Fig 3 Location of Panel Members.
Source: Lancaster study 2002

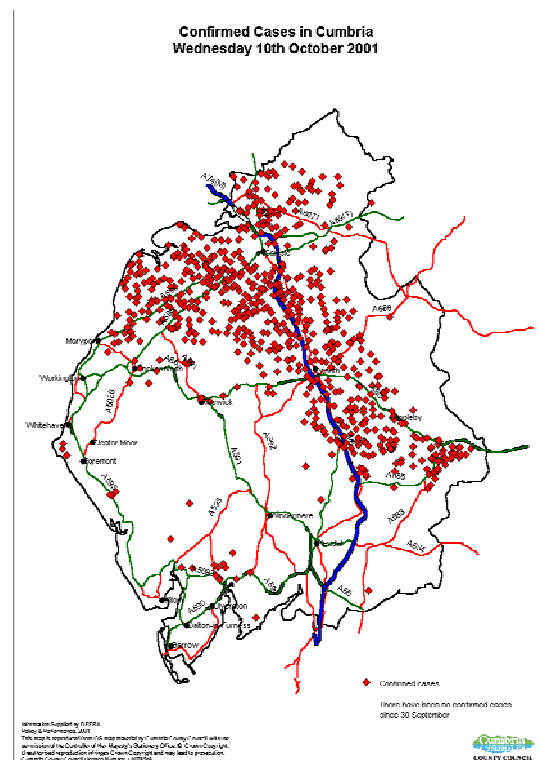


Fig 4 Spread of confirmed cases
Source: DEFRA and Cumbria Inquiry 2002

The Panel Dataset²⁸

The diary method proved to be remarkably successful, resulting in a dataset of 3,071 weekly diaries contributed by a final panel of 51 members. In addition we collected 52 panel members in depth interviews and held 12 panel group discussions, taped and transcribed for analysis.

	Group 1	Group 2	Group 3	Group 4	Group 5	Group 6
Focus Groups	1	1	1	1	1	1
Interviews	9	8	9	7	9	9
Weekly diaries	601	394	576	380	533	587
EQ 5D	14	8	12	6	11	7

Table 4 Panel Dataset

²⁸ See paragraph 2 of this Section for discussion of withdrawals, see also appendix 2

Section 4 Analysis

All interviews and group meetings were transcribed from audiotape; diaries were transcribed from the original (usually hand written) format. In addition to personal reading and initial coding of material, eight all-day 'data clinics' were held to identify emerging themes, using a constant comparative approach. The data is held in ATLAS Ti software, and once the themes were refined following agreement that 'saturation' had been reached according to the principles of grounded theory, coding was undertaken. Before each clinic all four researchers read and analysed the same interview and diary material, at the 'clinic' they discussed their individual analyses, looking for new and recurrent themes. This analytical approach is well established in the social sciences (Charmaz 1997) and a methodological literature has developed to accompany its use (Barnes 1996; Glaser 1992; Strauss & Corbin 1994, 1998). Constant comparison entails breaking down, examining, comparing, conceptualising and categorising the data so that central, recurrent and robust, analytical themes or categories emerge. Because of the importance of free text in our study, we detail this process below.

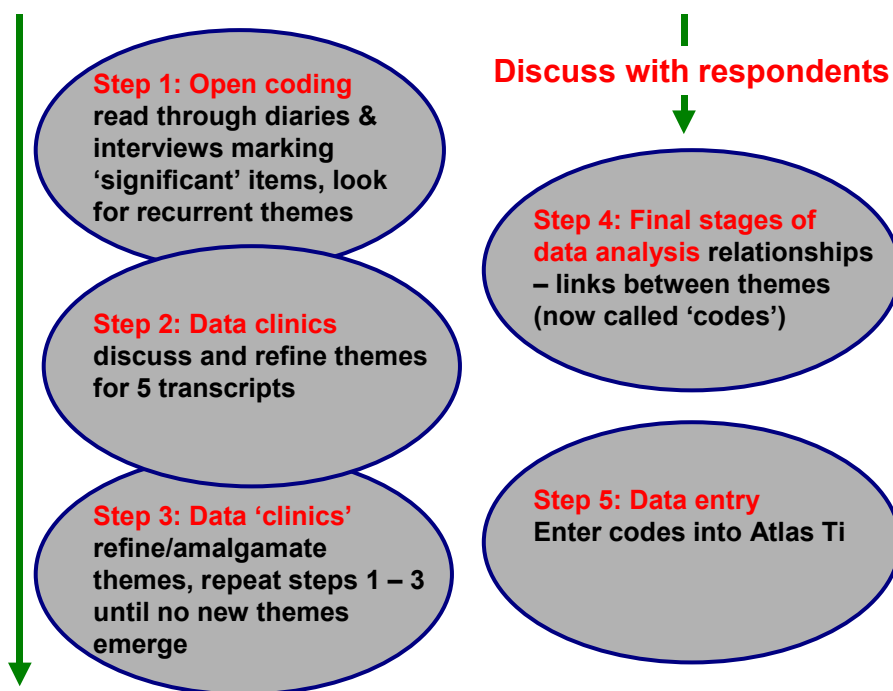


Figure 5 Process of Analysis

Step 1 - Open Coding.

Researchers each read the same transcripts (interviews and diaries), marking text which appeared significant:

Data

They daren't come out because I mean, we had folk in X and we used to go and meet them at the road end and take them groceries and because they daren't. They were so frightened that they were going to catch this. They daren't come out, so a lot of our lads were the same. Any of them that had anything to do with farming went home and stopped at home or else they come to work and they stopped elsewhere and they just stayed well clear of the farm. They daren't do anything else.

(Agriculture related group, interview)

Open Codes

'FMD virus/spread'
'Trapped'
'Social/community'
'Work/home'
'Fear'
'Job disruption'

Step 2 – Data Clinics

Here different data extracts that had the same code were compared, in order to substantiate it, or to identify and verify emerging codes and to make links between them.

- **'Interpreting science'**

I mean trying to disinfect a farm is just the most ludicrous idea I've ever heard of. . .

(GP, interview)

It felt in a way like a war zone if you like, because you didn't like moving around because you were terrified about spreading the virus. . .

(Front line worker, interview)

- **'Different epidemiologies'**

Farmers were beginning to get the idea that it was being spread by the smoke from the fires

(Agriculture related, interview)

This is a fragile virus, change the temperature, change the PH, it's dead

(Vet, interview)

- **'Lay/Professional'**

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

(Agriculture related, field notes)

Or it was all, 'sorry we know to do differently next time but we've done it now'. So that was kind of the attitude from them.

(Community resident living near disposal site, interview)

- **'Conflicting knowledge/perspective'**

Oh God yes. People were well they're reading on the news that everywhere's [our emphasis] closed and stay off the fells. And then

Tony Blair would be coming on telly saying, 'the Lake District is open for business so don't stay away' and all this.

(Rural business, interview)

It was quite annoying when Nick Brown was saying that everything was under control and it wasn't.


(Front Line Worker, interview)

These were eventually subsumed under a substantiated code:

Open Code

Substantiated Code

'Interpreting science'
'Different epidemiologies'
'Lay/Professional'
'Conflicting knowledge/perspective'



Epidemiology

Steps 1 & 2 were repeated several times with different data.

Step 3 – Validating and Saturating Codes

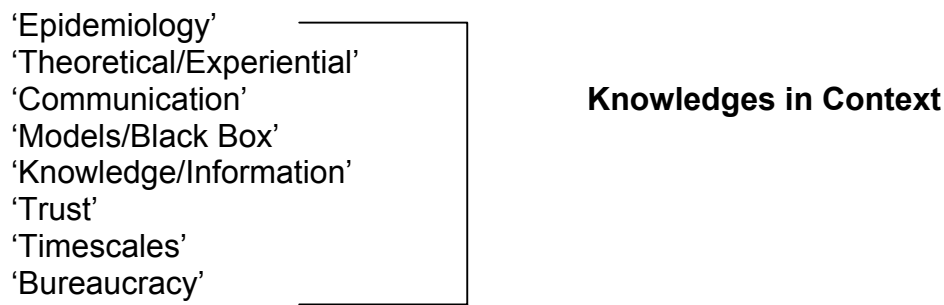
This process continued until no new or relevant data seemed to emerge and the relationships between codes were well established and validated. In this way successive data both formed the basis for the creation of codes and confirmed their importance.

Step 4 – Analytical Categories

In order to organise and make sense of very complex data we subsumed similar substantiated codes under overarching analytical categories:

Substantiated Code

Analytical Category



In this way four key analytical categories emerged:

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

So each category is underpinned by several substantiated codes, in turn underpinned by open codes which lead directly back to the data. Whilst codes and categories have been ordered in this way, they are of course inter-related and indeed some substantiated codes link to more than one analytical category. For example, aspects of trust underpin 'Trauma and Recovery', 'Knowledges in Context' and 'Trust in Governance.'

Figure 6 below is a visual representation of the relationships between the codes.

The different colours were originally related to different phases of the process, but as the 'map' was refined, these lost that significance; they have been partially retained to make the map easier to read.

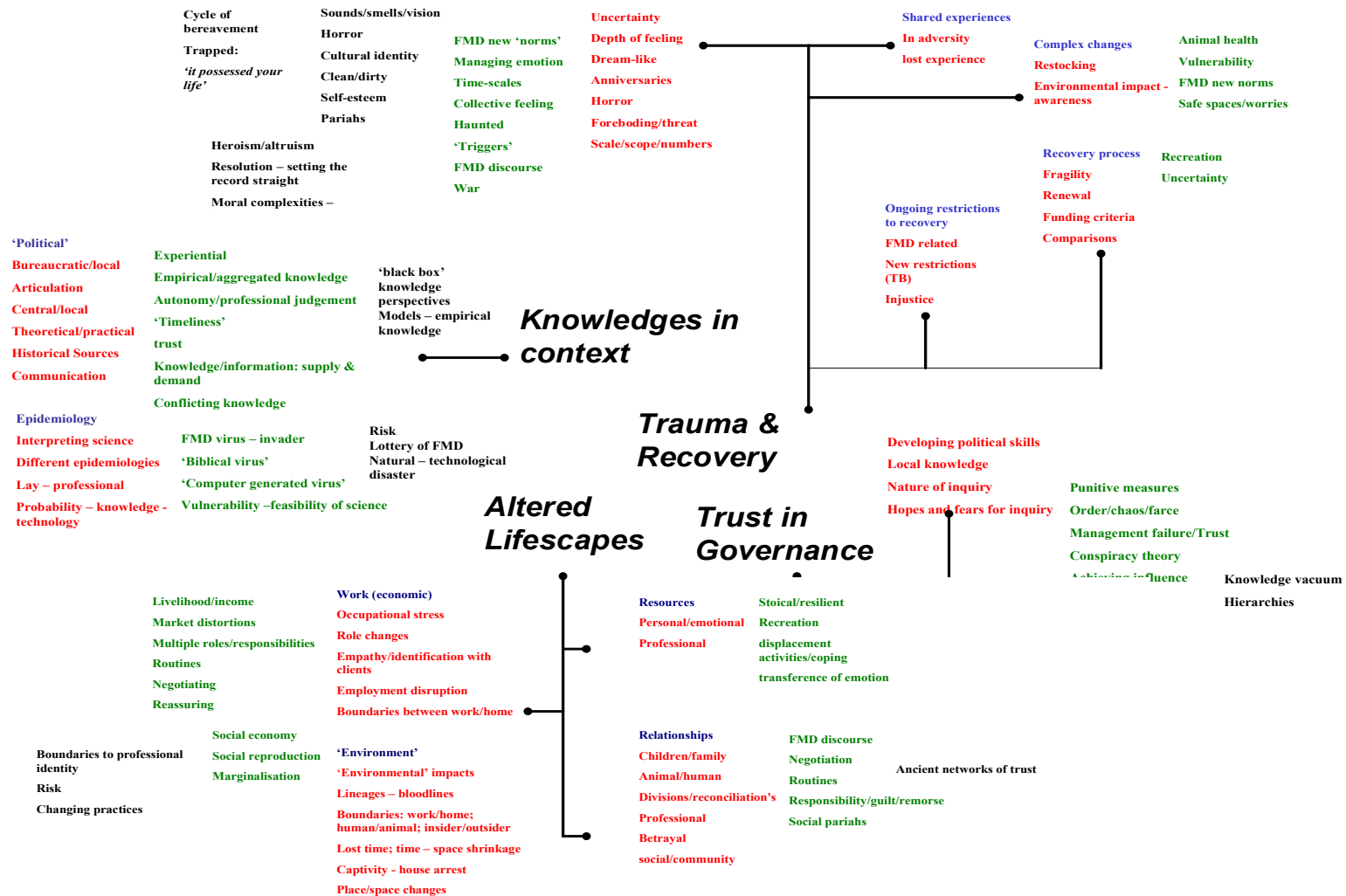


Figure 6 Map of codes and analytical themes

Step 5 – Storing and retrieving the data

We have transferred our coding into ATLAS Ti, creating ‘electronic tags’, involving re-reading all the data and assigning codes to all the material.

Consultation with respondents²⁹

As diary writing was ending in sequence, the analytical categories and their codes were presented at the second round of group discussions where respondent were asked whether these adequately reflected the different kinds of material they had supplied. Comments and suggestions were made and some respondents who still had a few weeks left of diary writing, referred to the meetings in their last entries:

Really good evening at Penrith re the discussion, it was so good to talk to the other diarists and realise and be able to relate so closely to what they said. It was poignant to see what other people had written and interesting to see what you had done so far with the data collected. . . I can see now how it comes together.

(Veterinary Practice Manager, diary)

I thought it was interesting to see how much people still are willing to talk about some of 2001 at the meeting on Wednesday night. [...]. There were so many themes that you have all come up with on the "electronic tags" sheet that it seems impossible to comment on them all. Some of them seem very relevant to me, others not so much.

(Vet, diary)

Reading through the electronic tags they seem to have covered every aspect of people's feelings, what happened and how things have changed.

(Resident near disposal site,

diary)

Very interesting to hear how our diaries had been analysed by the team. I must confess that I often wondered how the information we recorded would be utilised. Obviously no two diarists compiled their diaries in the same way but the outcome was certainly quite impressive. Comments made by people who worked alone or in a tight environment made me realise that my task had been made easier by the people I was in contact with daily through my work and by my close involvement with customers who had had FMD. [...] our comments and suggestions had been structured into different categories and certainly enabled me to fully comprehend what the team had been working on and the conclusions they were reaching.

(Agriculture related trade, diary)

²⁹ See also Panel evaluation Appendix 7

Developing Ethnoplots

It was originally planned to administer the EuroQol (EQ-5D) quality of life instrument three times during the life of the study. This proved to be impractical for two reasons, first the unavailability of sufficiently matched baseline comparative data and second, the unpopularity of the instrument with study respondents. This is explained in Appendix 5 along with the results from one round of EQ-5D which was completed and analysed.

In deciding not to pursue the EQ-5D further, we considered how we might compare the answers to the structured questions about respondents' self reported health or quality of life contained in the first few pages of the diary template (see App 1) with the narratives which members gave in the free text. The Ethnoplots, (Figure 7 below) brings together two of these questions with diary free text plotted over time. This way of combining qualitative longitudinal information with quantitative measures within one visual field could, we believe, be used both in other longitudinal research, particularly in public health, and in practice e.g. management of chronic illness. In deciding not to pursue the EQ-5D further, we considered how we might compare the answers to the structured questions about respondents' self reported health or quality of life contained in the first few pages of the diary template (see App 1) with the narratives which members gave in the free text. The Ethnoplots, (Figure 7 below) brings together two of these questions with diary free text plotted over time. The Quality of Life and Self-Reported Health questions were chosen as the two most appropriate measures for this purpose given the project's decision to discontinue the EQ-5D (see also App 6)

This way of combining qualitative longitudinal information with quantitative measures within one visual field could, we believe, be used both in other longitudinal research, particularly in public health, and in practice e.g. management of chronic illness. However, there is still much work to be done developing the analysis of the ethnoplots produced both in this study (App 6) and in investigating the possible applications this approach might have in other research and practice domains. Such areas might include dermatology where interactions between conditions, emotional states and/or food might be tracked over time; diabetes where self-care/control of blood sugar is known to relate to daily living activities and food practices (Taylor 2004); bereavement, where different phases such as shock, grief and anger, require different approaches in counselling or self care.

We are currently exploring what work this kind of representation can do in helping understand the complex relationship between the 'external world' and the subjectivities of research respondents. The Ethnoplots has been likened to a 'fingerprint'.³⁰ For those respondents who carried on completing the structured part of their diaries for a significant amount of time ethnoplots have been constructed and are grouped in Appendix 6. However, while all respondents

³⁰Kai Erikson, personal communication, October 13th 2003

wrote free text diaries through to the end of the study, the numbers which filled in the structured question boxes dwindled over time.

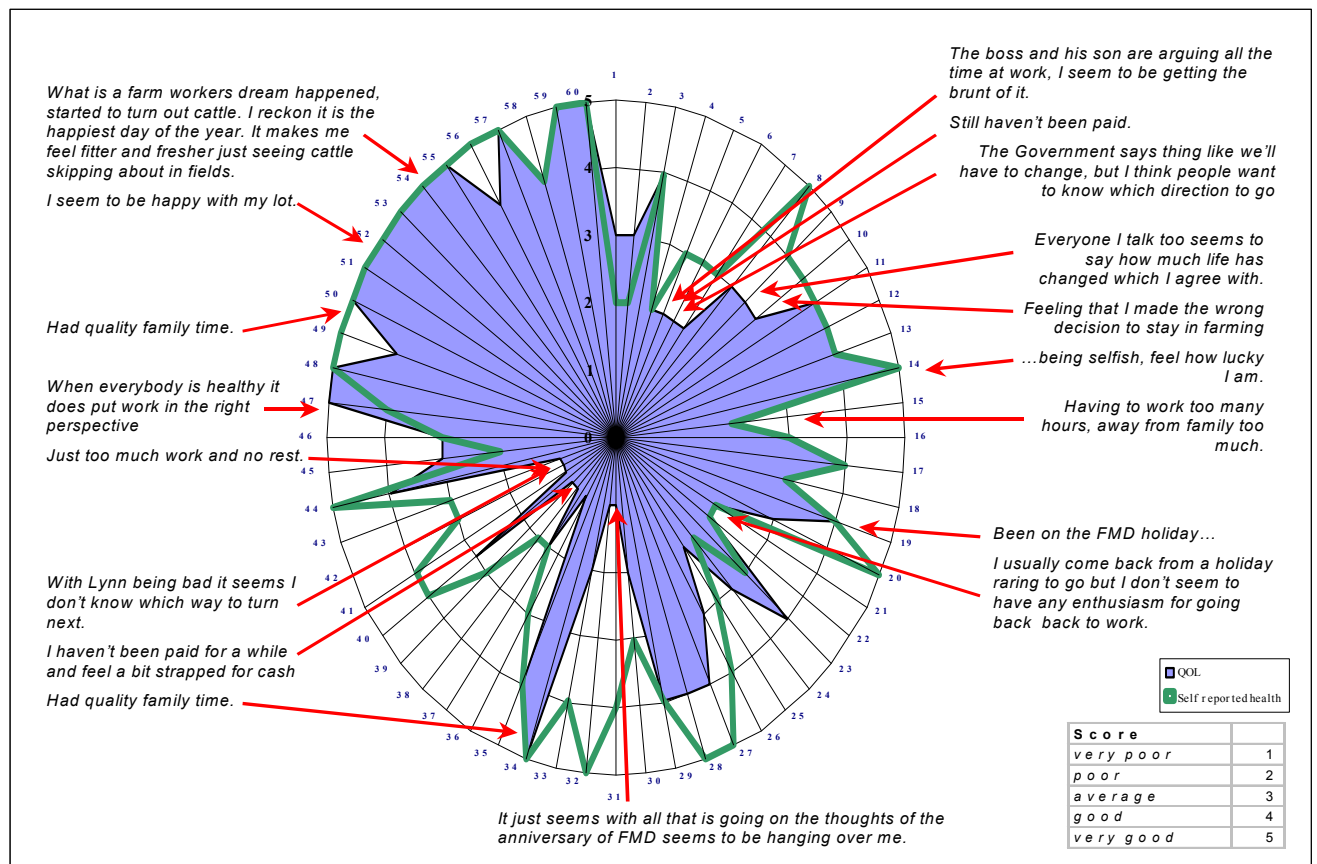


Figure 7 ‘Ethnoplots’ - responses to quality of life & self reported health questions in the structured diary section plotted alongside free-text entries from the same week (the numbers around the outside of the plot represent completed diaries, plotted chronologically from December 2001 to May 2003).

The ethnoplots above is developed from the diaries of a farm worker from Group 1 who had reported severe distress and disruption during the epidemic in the first group meeting and in his interview. Diaries however, began in December 2001 (Point 1 on the ethnoplots), and early in 2002 he speaks of arguments at work (the farm) and about his wages not being paid, and uncertainty around the future of farming. These all correspond with times when he reports poor quality of life and changes in self reported health from poor to very good. Quality of life remains low when he says he feels he had made the wrong decision to stay in farming. This occurs again when he is reporting working very long hours and not seeing his family (wife and young sons). Next he reports going on ‘the FMD holiday’.³¹ This corresponds to better health but is followed quickly by: *I usually come back from a holiday raring to go but I don’t seem to have any enthusiasm*

³¹ This was a scheme offered by the Hadfield Trust which provided short breaks in bed and breakfast holiday accommodation, usually within Cumbria, for people who had suffered distress during the epidemic.

for going back to work. Quality of life is at its lowest (and health is fluctuating) at the anniversary of the cull on his farm of animal he had reared. It just seems that with all that's going on the anniversary of FMD seems to be hanging over me'.

A brief episode of 'quality family time' is linked with marked improved health and quality of life, followed by two very difficult months when lack of money (not being paid), his wife's illness and very hard work, combine to give much lower scores. There then follows a gradual climb in health and life quality which is sustained and linked with wife's recovery, spending time with family and finishes with:

What is a farm worker's dream happened, started to run out cattle. I reckon it's the happiest day of the year. It makes me feel fitter and fresher just seeing the cattle skipping about the fields.

We can also see in this respondent's 'fingerprint', that there are points where quality of life and self-reported health do not overlap but are perceived or experienced differently. Quality of life at weeks 1-11 rates between 'poor' and 'average', yet self reported health climbs during this time to 'very good'. This divergence occurs again at weeks 30 - 33 and 40 - 44. Taken with the free text entries, the relational picture which can be shown in the Ethnoplots offers, we believe, a more nuanced view of 'health' than approaches epitomised by standard instruments such as EQ-5D and SF36. A characteristic of these standard approaches is the assumption that quality of life and self-reported health are convergent (Mallinson, 2001, 2002).

Section 5 – Findings

In April 2002 we were invited to give evidence about our research to the Cumbria FMD Inquiry. At that point we had about five months diary and interview data collected, but not analysed. Each researcher therefore reviewed the data for their 'own' respondents, searching specifically for examples of talk or writing about health/mental health. As can be seen from the simple figures below, most respondents were living with the impact of their experiences of 2001 without seeking formal medical help. Out of 54 panel members:

- 16 had reported on-going health, financial or social problems which they attributed directly to the FMD crisis
- 24 reported feelings of anxiety or stress which were not being addressed
- 11 had reported signs of post-traumatic experience (i.e. flashbacks, nightmares, sleeplessness, lack of concentration)
- 6 of respondents were undergoing medical treatment for depression or anxiety
- 4 had mentioned a family member who had been treated for depression or anxiety³²

Since this overview was produced, we have been able to develop the large themes discussed in Section 4 in far greater detail, (e.g. Trauma and Recovery). Some respondents who had not mentioned e.g. seeking professional help for depression, did so later in the year and reported finding this beneficial. Three others later withdrew from the study, reporting that participating in the study triggered FMD related negative feelings, which in turn impacted on other areas in their lives. The in-depth data later available indicates that the health/mental health of those who experienced traumatic events in 2001 remains in some cases fragile. Those respondents report an increased sensitivity to stress, manifested in mood swings, over-reacting to new problems, increased use of alcohol, fears and pessimism for the future, and lower tolerance thresholds.

As already stated, respondents were not asked specific questions, so the themes were developed out of readings of free text diary material and interviews. In this way, examples chosen to illustrate the themes below, have been sampled from many other utterances and reflections grouped within that category, (see also Section 4). This Section is in six parts. First, Multiple Effects conveys the interconnectedness of living and/or working in rural areas. Second, the four themes arising out of the data: Altered Lifescapes; Trauma & Recovery; Trust in Governance; Knowledges in Context; and third, Health and Social Consequences gives examples of the form in which these multiple effects on health have taken.

³² A few respondents appeared in more than one of these categories.

Multiple Effects

This concerns the relational aspects of respondents' experiences. The interrelations of rural networks have been examined by Donaldson et al (2002) who discuss the effects of the FMD epidemic on rural governance. In our study, by analysing people's work, social and personal networks at a very local level, we can show how these inter-relations occur in everyday life. The two examples given below illustrate first how workers have multiple roles, and second, how their lives interact with others and this meant they experienced the crisis on many levels. (Figures 8.1 & 8.2).

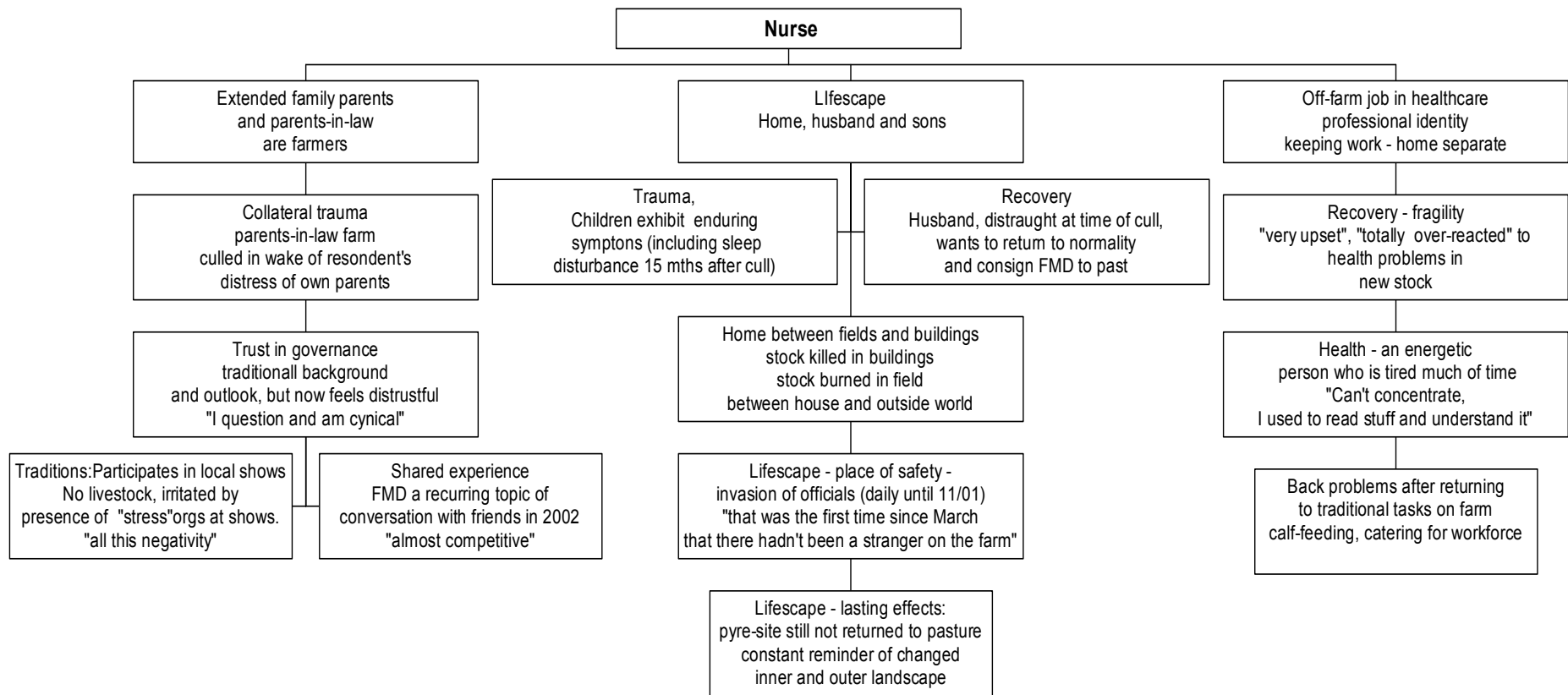


Figure 8.1 Nurse

The Nurse works at a large rural GP practice and is also the wife, daughter, daughter-in-law and sister of farmers. She has 2 sons at primary school. Her primary care work was important to her during FMD and she describes 'my life at work' as being 'minimally affected' by FMD compared with her life at home. She says this made her hesitate to join the research panel; however she wrote in her first diary:

After a few days thought I decided it would be good for me to do this diary thing. It may help me come to terms with what has happened, and in years to come I may regret not writing this. FMD has brought about enough regrets without adding to the regret list.

Her interview revealed traditional attitudes to women working off farms:

(My husband) was never ever very keen on me working and, he still isn't really (laughs), but he sees, he could never see the business working unless they had me as a side-kick.

FMD made her rethink her nursing career and take up further clinical training after the cull on the family farm:

I have wanted to do the [primary care] course. But until FMD never had the time. Sometimes I feel this is positive result of FMD. Other times I feel despair about this course. I struggle with the coursework and can't fit everything in....

Wednesday tried to study for [...] exam, no concentration. I used to read stuff and understand it - why can't I do this any more? Feel very anxious today, want to run away. Just get into the car and drive.

The following month, with the support of colleagues, she decided to give up the course:

Feel better today than I have in over a year!! I feel like I have been on a ship in a storm and have now got off it.³³

Since theirs was a big farm where stock was slaughtered in the buildings and there was a large pyre, they had 'strangers' on their farm for months:

I can remember being off work one day in November time, [...] and I was about to go and get the kids from school and I thought 'nobody has rung my doorbell today', and that was the first time since March, that there hadn't been a stranger on the farm, for some reason or another.. ... I was sick of, [...] the invasion of privacy I think.

She talked of a dividing line between her work at the surgery and her experience of the cull, how she maintained a professional distance and did not talk about her own experience when patients would attend with problems:

... I would hate to think that anybody came to see me and couldn't have told me things 'cos they would distress me.

But indicates there were times when she used strategies for dealing with difficult matters:

³³ In 2003 she began different professional training and is now doing well.

...there's things that people have come with that, I've sort of put them in another direction.

She is involved with church, school, farming, sport and community activities; has a busy social life and wide circle of friends. Yet she expresses deep disillusionment and loss of trust in government:

...they have no credibility at all in my eyes now, because I know what they used to say to the Press in London and what was actually going on in reality up here, and you know it's, it's very very sad that you've lost, it's lost its mystique of always being there in a crisis or coming up sound and what have you, when it let you down badly.

In May 2002 she attended a public meeting of the Cumbria FMD Inquiry:

Strange experience. Felt we had heard all this stuff before+++++ SICK OF FMD. Pleased when meeting was over. Had gone out of duty only. Feel all the inquiries will have little impact or the impact they SHOULD!

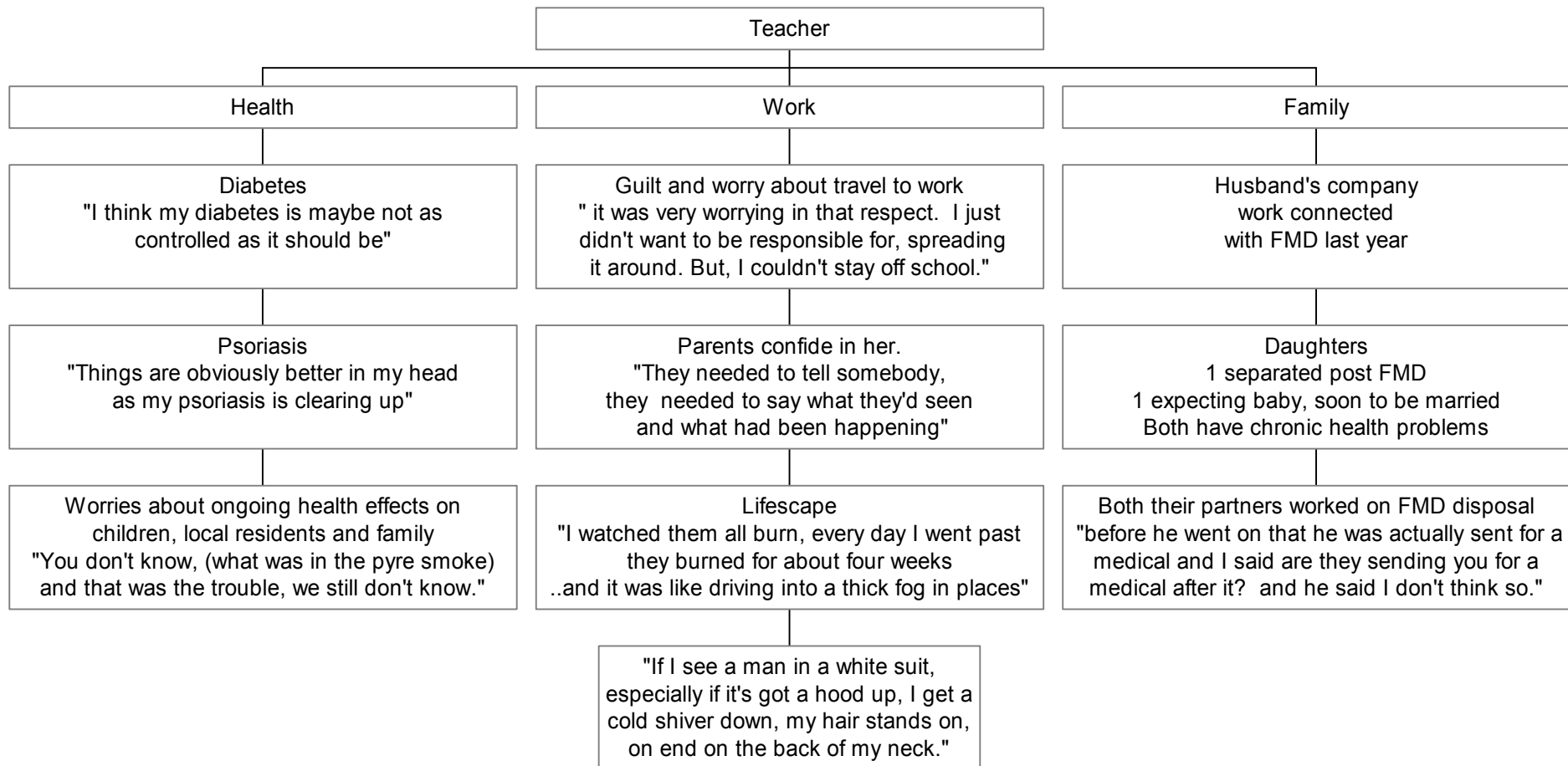


Figure 8.2 Teacher

The Teacher lives with her husband in a rural area and drives 12 miles along narrow roads to work. There were many pyres along the route:

I drove down here one beautiful spring day, and counted twelve pyres on my way down to Longtown, twelve!

Driving in such a sparsely populated area she saw the same people every day:

...early in the morning you see a lot of people in tractors and you, you know you get to the point where you recognise people and I've been doing it five years so I recognise everything

Although not involved in farming herself she was emotionally affected by what she saw, describing how a farmer had cared for his sheep during lambing:

....he'd really worked and worked and worked and I went past one day at the [...] and there was two heaps and they were just lying by the side of the road waiting to be collected one day, and I cried then. (upset here).....and I see the farmer's wife sitting crying and the farmer sitting crying and we were just wondering what on earth's going to go on? How's it all going to end?

Sometimes she was unavoidably caught up in distressing circumstances:

And I was stopped like that several times, different farms, and just had to sit there while they got on with stuff. The worst one was later when they had killed them all and then had to pick them up and take them to the different places, because that was just, the stench [...] some of those animals were left ten days before they were picked up

At school she could not avoid the FMD narrative of parents who had been affected:

They needed to tell somebody [...] and you've got to listen

She worried for the children in her care:

...there was a few, good few days where, when it was playtime we just didn't take the children outside because, of the smell as much as anything. I mean it was making them gag.

Her daughters' partners worked on the disposal of carcasses and of ash:

...he spent three days once just chopping cows in half with a bucket on his machine.

She worried for their long-term health and tried to advise:

...watch what you're doing it's not worth getting a week's salary now to end up with, a severe illness in your early forties, or late thirties'.

She feels that she will never find out 'the truth' about FMD:

*I find that really hard that they can, hide things for thirty years, I think that's dreadful. I want that changed. It might be supposedly for, I suppose it's probably for our own benefit. Not sure that that's going to wash, might wash if you're a politician with things to hide, but not if you're a member of the public who wants to know...
(all extracts interview Feb 2002)*

Altered Lifescapes

There was no normality, normality had gone³⁴.

For many respondents, everyday places changed dramatically during FMD, some of these have altered in the longer term or permanently. While the pre-FMD 'lifescape' undoubtedly contained hardships (see Section 1), our data shows that the alterations brought about by the epidemic affected respondents' sense of identity, self-esteem and well-being. Respondents report on journeys to work past pyres, mounds of dead livestock and the logistical traffic that went with the culls. In later diaries they continue to be reminded of scenes at particular points on their journeys. The sense of FMD identity is mentioned in reminders such as tarmac strips where disinfectant mats were laid on roads and how only those who lived through it would know what these represented.

We elaborate the concept of 'lifescape' developed by others (Somé & McSweeney 1996; Howorth 1999) as a way to help articulate the spatial, emotional and ethical dimensions of the relationship between landscape, livestock, farming and rural communities. As part of the developing sub discipline of health and place, 'Lifescapes' here is a way of framing the social, cultural and economic interactions that occur for people across the landscape. Lifescape articulates the being-in-the-world attachment to place and landscape, highlighting that through familiar fields and woodlands, roads and paths, people create a sense of self and belonging (Ingold, 1992 & 2000). The link between place and well-being is discussed in much of the literature on therapeutic landscapes for example in the work of Wil Gesler who states that these are places with an enduring reputation for achieving physical mental and spiritual healing (Gesler, 1993:171). However, much of this work has focused on the healing properties of physical places such as shrines, spas, baths and hospitals. Recent work by Wilson (2003:84) examines the interconnections between place, identity and health and argues that the (therapeutic landscapes) research overlooks both the culturally specific links between well-being and place, and the significance of *everyday places* and *taken-for-granted* spaces in people's lives. Our data is intimately concerned with this aspect of health and place.

³⁴ Interview 2002

Identity

The data shows disruption to place, occupation, family, education and culture and an articulation of the view that Cumbria was 'too far away to matter'. There is a sense of new cultural identities appearing, such as 'culled and uncultured'; 'front-line and office-based'. Above all there is the strong sense, (well known in disaster studies), that unless you were there, it is impossible to explain, and this gap in comprehension/empathy is a continuing sense of frustration.³⁵

I try to explain what it was like to be here through last year but am still unable to articulate thoughts and feelings accurately. It is so hard to try to enable people who weren't here to get a real grasp of it. The fear, the anger, the frustration.

(Rural vicar diary April 2002)

'New FMD identities' engendered black humour, as this respondent shows describing the signing of the guest book at a wedding in June 2001:

.... so we went to the Church do and then we went back to milk [...] and there were lots of Longtown folk there lost the lot and, when we got up to milk, they said 'You mean you have got stock?', and everybody said how lucky we were to be able to go away in the middle of the wedding back to milk [...] Everybody had to sign a book to say who they were and they said 'Why don't we put our [FMD] case number next to our name?' [...] We had a good day, it was our first mixing amongst folks since February.

(Farmer, group meeting Dec 2001)

A farmer whose stock survived and who did not leave his farm for 10 weeks during the epidemic, speaks of meeting with extended family in Christmas 2001:

...they didn't get foot and mouth, [. . .] so the family party was the first meeting we had when nobody had foot and mouth. [. . .] So we could have a good conversation without offending anybody, [. . .] 'Cause there wasn't a foot and mouth victim sitting next to us, and we were just, you know, In some ways makin' fun of them, 'Oh look out here's a foot and mouth victim coming, he's got a new Range Rover', or this sort of thing like, and we could say that without actually offending anybody.[. . .].

(Farmer, interview, Jan 2002)

Occupation

There are many references to disruption of work patterns, including money, time colleagues/relationships. For vets, changes continued as they caught up with routine testing visits which could not take place in 2001.

There has been a big backlog to clear after testing was stopped during FMD last year so we have to catch up with those farms who didn't get the disease but are due a test, as well as testing the restocking farms.

(Vet, diary May 2002)

³⁵ That disasters create 'insiders and outsiders', a kind of collective identity, is discussed by Erikson (1994) from his work in many different disaster settings.

They also report addressing new and increased animal health problems consequent to re-stocking. TB testing and re-testing with its associated anxieties was continuing as dairy writing closed in May/June 2003. Field officers and other front-line workers from within DEFRA and seconded from other agencies (e.g. Environment Agency) speak both of very long hours and arduous conditions in 2001, but then experienced difficulties of settling back into routine work after the fevered pace of the epidemic.

Levels of wages paid during FMD led to market distortions which created resentments. A slaughterman says of a former fellow worker:

*He phoned up yesterday, and they're still on standby from DEFRA.
Never done a day's work since September and he gets £220 a week.
For lying³⁶ abed.*

(Frontline, interview Feb 02)

After a re-stocking check a vet records:

The farmer is convinced he was given FMD deliberately and on arrival I was given his weekly tirade regarding DEFRA, Tony Blair, how I must have made thousands of pounds out of it etc

(Vet, diary March 2002)

Yet some vets, like this one, were seconded from their practices on their normal salary, the balance of the funds going to sustain the practice as a whole. Certain employment underwent re-distributions, here a slaughterman made redundant from the abattoir due to FMD, joins an FMD slaughter team:

We went back the next day on the Thursday and we never done anything and he called us all intil like a meeting eh, and there was about maybe 60, 65 of us. And he just says 'I'll have to pay you all off', so that was it. ...and then he phoned on the Tuesday night and he asked if I'd go back and work for him. Going round farms, slaughtering.

(Frontline, interview Feb 2002)

An agricultural supply business tried to keep its staff on:

.... because we didn't know how long it was going to last we, we kept all our sort of staff on. But as the number of cases grew [...] we lost eventually about ninety percent of our customers, and it was obvious that it was going to take a long time to recover, so we then decided we make 4 people redundant, so we dropped down from 12 staff to 8, I went onto half pay...

(Agricultural related, interview Feb 02)

They lost over 300 clients through confirmed infection (1/3 of Cumbrian cases.) His role as supplier changes to confidante:

Frequent discussions during each working day (or evenings) with customers who lost stock. They all seem to want to confide in other

³⁶ lying

people [...] this can be wearying as they all demand a level of attention and they are all different

(diary, as above)

Income from tourism in the marginal areas was severely reduced and remained so throughout the whole of 2001. Small businesses report taking out bank loans to keep afloat during months of uncertainty.

Our foot and mouth loan has another three years to go, [...] It just goes out of the bank so you know that every month it doesn't matter how much you make, you're not making as much as you did before, and you're still paying back the money that you borrowed to get over the time when nobody came.

(Small craft business, group discussion June 2003)

However businesses in towns and villages in the central areas of Cumbria fared better. While hospitality providers on the *fringes* and in farm settings lost almost all their business, the hotels and guesthouses in towns in the worst hit areas gained business from incoming vets, field officers and slaughter teams. DEFRA alone spent over £4m on staff accommodation.³⁷

Some rural businesses in marginal locations suffered severe isolation and hardship:

..the silence, no it gets sad sometimes when you're in here [...] to be in here for a whole year every day to see nobody every [...], you begin to hate the place, you begin to hate the very thing you love... for me to have walked out of that door (emotional at this point) not because of the Foot & Mouth epidemic but because the lack of awareness by our government to realise the human dilemma, the psychological effects that something like that can have on people's lives, aside of the finance, the economics, everything, people matter.

(Small craft business, interview Jan 02)

Conditions of work changed. Those on the 'front-line' speak of long hours, sporadic meal breaks, keeping going on adrenalin, exhaustion. Wagon drivers faced new imperatives when collecting milk or delivering feed and were under constant scrutiny as to bio-security. Community nurses report having to take medical histories and make assessments 'over a gate'.

We then had somebody who was quite immobile stuck in their farm in the middle of the fell who wanted advice and assessment [...] So the only way I could do it was over the farm gate. [...] there was a yard with about 40 cows in between us [...] And we're shouting at each other and I thought this is [...] ludicrous, I was really annoyed for allowing myself to be put in the position.

(Community nurse, interview Feb 2002)

The cultural importance of livestock auctions in Cumbria cannot be underestimated -for farmers the absence of auctions meant loss of social contact and a radical and complex change to trading, with animals going straight to slaughter often with no agreed final price. Farmers also report frustration and anger at perceived inefficient, bureaucratic and

³⁷ Cumbria Inquiry Report, part 3 p 65

uncomprehending (sic) licensing arrangements. In the longer term, the re-stocking of farms has brought animal health problems and continued stress and reminders for farmers as they get used to new stock. Some report feeling less involved in their work, others say they over-react to problems among stock.

Family Life

Integral to this theme are family, house, garden, holidays, money, recreation and access to transport. Families remained isolated and separated for months because of fear of spreading/acquiring infection or through working away from home. However there were many references to respondents' pleasure in their children, and the 'hope for the future' that children afforded them. There were children who did not attend school for weeks, sometimes months, missing both education and social interaction

Spoke to a friend who is having a really tough time with her [teenage] daughter, she won't go to school. They think it's delayed shock from last year's F and M. She hoped she would go back in September but she didn't, it is so hard for them.

(Farmer's diary Dec 2002).

One respondent taught her children at home using materials delivered by the school. There are references to 'lost time' and guilt of family members who feel they missed seeing or paying sufficient attention to their elderly relatives. Women reported in interview at the beginning of the project how they felt distracted and unable to concentrate on home/housework, others reported how they had 'discovered' gardening as a therapeutic activity. Incomes among respondents varied widely - those on lower incomes appeared to have a generally lower (self-reported) quality of life and health. (see Figure 11)

Culture

This includes the importance of social events, planned and unplanned; sense of community; work; recreation; traditions. There are repeated, frequent references to the cancellation of familiar events during 2001 – often when the respondent is writing of their resumption. From large scale (horse trials; county show) to indoor bowls in a village hall and outdoor religious services. The loss of social contact and recreation is very significant for people and is known to affect well-being. There was also 'collateral' loss of charitable/local income from cancelled events.

Divisions sometimes appeared between the culled and uncultured farmers, sometimes unspoken:

It's like there's us and there's them....

(Farmer [uncultured] interview Feb 02)

sometimes overt/violent:

[farmers with large compensation payments] had gone in pubs and been shouting their mouth off and getting people's backs up... he went in the pub ... but three hidings he got in two or three weeks.

(Agric related group meeting Jan 2002)

Some believe that where these divisions occurred they were the manifestation/exaggeration of existing relationships. Those who were the only farm left 'standing' or the only one infected in an area suffered particular problems. Conversely panel members speak also of the kindness and support they received and how helpful and affirming this was:

I think at the beginning neighbours were good, especially in villages. Everybody took food to farms. You could see it outside farms there were little packages, presents and flowers and as it escalated and it got more I suppose that was lost, but at the beginning...

(Agric related group meeting, Jan 2002)

One of my neighbours rung me up one day and she said there is a queer big box of groceries on your front doorstep. Because I had never been out of the house I didn't know that they were there even. We received all sorts of things that were just left at the doorstep – groceries, flowers, [...] it was overwhelming.

(Agric related group meeting Jan 2002)

We have received over 100 letters and cards

(Agric related group meeting Jan 2002)

They write of their own efforts to telephone friends and offer support. The option of group or in-person activity/support was not possible because of the voluntary restriction on movements which gripped the worst affected areas. War imagery is often used:

By the 25th March we were the only one left, all our neighbours had gone, and we wondered why we hadn't got it. [...] we didn't dare go out because everyone that did go out was getting foot and mouth. [...]...Then there was one Sunday in September, there was a ploughing match we'd went to and I thought God this is the first time I'd seen farmers, there'd be no shows nothing to go to, no meetings, nothing. [...] We came out as if we were coming out after a bombing raid, and you were just seeing what had been bombed.

(Farmer interview Jan 02)

A rural vicar's normal practice was to visit and be with those in trouble:

The only way you could be with the farming community was on the end of the phone.

(Community group meeting Feb 2002)

Major life events were affected as (some) funerals had to be held in private 'to spare people making a decision whether to go or not' (interview Jan 02); some weddings were postponed and birthdays and anniversaries went uncelebrated:

We missed three weddings this summer because of foot and mouth. Just not gone. When my nephew got married in July [...] people were ringing him and saying if we were coming to the wedding, they weren't coming.

(Farming group meeting Dec 2001)

But these events happened somehow, coinciding and interrelating with the traumatic events of FMD, as a vicar relates:

Some parishioners were having their golden wedding and they were having a service of blessing [...] and then they were having a do at the (village) pub. So the night before [...] I had been to lock the church up and I popped in the pub for a pint. It was [Aug 2001] about quarter past nine, and there was a vet and I thought, hello trouble. The vet didn't come at quarter past nine unless there was trouble. So I came home and said to [my wife] I think [...] has gone down, there was a vet there. And we got this golden wedding and people coming from all over the country and all over the world. [...] We had the blessing and I asked people to leave their cars by the church and walk up to the village, it was only 500 yards, wherever possible and they were very good about that. And there was this celebration going on and I just couldn't be part of it, we couldn't be part of it somehow. And we went out, the sun shone and the guns went off, you could smell the blood in the air and the wagons came and then the word came that [neighbouring farm] had lost them all, killed all as contiguous and his wife had died at home. They had culled all the lambs and she had died during the night. Unbelievable, it was just unbelievable and we just couldn't celebrate. Villagers came and stood on the cross by the post office and we just stood, there weren't any words. [...] Dreadful, dreadful day.

(Rural vicar interview March 02)

Ongoing local traditions were sources of comfort, offered a sense that some things would remain in the face of mass slaughter and loss:

The one thing that survived FMD last year was the annual 'Dole Ceremony' at the Countess Pillar on the A66 at Brougham [...] as far as we can tell it has taken place on the same day at the same time every year since Lady Anne Clifford inaugurated it in memory of her mother in 1654. There are some things that even foot and mouth could not kill off.

(Rural vicar diary April 2002)

Mother's day [...] We went to [...] churchyard to put flowers on my Mum's grave. It was pouring down with rain. Then on the way to Castle Sowerby church (where husband's Mum is buried) we passed 2 sites where carcasses were burned, the ash has been removed, the ground levelled and reseeded [...] The physical traces of what happened are easier to erase than the mental ones.

(Community member diary March 2002)

Place

This includes 'where you live' i.e. home, parish, town, county; where you 'recreate', take pleasure and renewal. Place is also about situated social dynamics and is multi-dimensional, holding different meanings for different social groups. It is also about safe spaces and settings for health and health practices. For those living in the worst affected areas their immediate surroundings changed and became hostile, bleak, beleaguered, and (from their perspective) unhealthy. Familiar places were described as: unreal, *bizarre*, *crazy*, *surreal*.

We noticed that when we first started killing the stock as soon as they lit the fires everything went silent. There wasn't a bird singing in the sky, there was nothing and it was just an eerie feeling. [...] there was nobody in the streets.

(Group meeting Jan 2002)

A teacher said children told her they didn't like being at home because it was *spooky ...there's no noise*'. Some changes were still palpable in 2002:

Things still don't look or feel 'normal'. There's too many unpleasant associations in the fields and pyre sites; it still seems too recent.

(Community nurse diary March 02)

...fields are very quiet in North Cumbria, a little sad feeling. It's amazing how activity i.e. animals in fields, affects you.

(Self-employed, community group May 02)

With footpaths closed the possibility of refreshment in the landscape was denied. For those living near disposal sites the roads were a reminder of the disposal of carcasses with constant streams of lorries and a feeling of being invaded, even violated (Bush 2002). Yet other places were unprecedentedly quiet, with footpaths closed, even walking on the roads in other areas made some feel guilty and they spoke of *ghost villages*. For many, this landscape and these spaces are changed forever:

The sheep, cattle and ponies are no longer grazing the fell, so no longer meander into the village in the colder weather. We always knew when a cold snap was due because the fell ponies came down to the village. I guess that I miss that aspect of life. The unexpectedness of it, instead of now where the rural aspects of life are boxed away, the traditions broken and farming is separate, like any other industry. I guess the feelings that I have are about being witness to an ongoing heritage of rural life, and one of the side-effects of FMD is that it is now destroyed. We hoped everything would get back to normal after FMD was over – but much of it has changed to a different 'normal', a less inclusive one.

(Community nurse diary, Dec 2002)

A respondent living near a disposal site writes of how this change in her landscape has brought about irretrievable loss:

R and I still remember back to when the airfield [where the burial site is] was still there and it was a lovely place to go walking and to relax by getting away from everything. It used to be lovely and quiet and was also

so nearby. We do actually quite miss it sometimes as there is nowhere else like that round here now.

(Community resident, diary, Nov 2002)

Trauma and Recovery

This has been a bereavement for individuals and communities. You have got to look at a minimum of 2 years to work through it.³⁸

In the initial group meetings, respondents often became upset either when articulating suffering or hearing about the suffering of others. Because of movement restrictions for many it was the first time they had met with others outside of 'survival mode'. At the interviews, many were suffering emotional anguish which they had become used to controlling; they often chose to sit with a table between themselves and the interviewer. Many respondents exhibited acute distress and it was not unusual to break down during interview. However, some would refuse to stop the tape and rather than seek comfort or sympathy would plough on telling their story.

Collective Trauma

A major theme emerging from the analysis is that of a shared sense of shock, horror and endurance, characteristic of other disasters. The FMD 'year' represented a *collective trauma* in Cumbria, a term developed by others (Erikson, 1976, 1991, 1994; North & Hong 2000 & Sideris, 2003). We know that a wide range of livelihoods were threatened or destroyed; in farming generations of bloodlines and breeding stock were lost; family relationships were disrupted and damaged and many frontline workers were deeply traumatised by their experiences of working on slaughter or disposal, many farming families were divided for almost 12 months, many children lost months of schooling and relationships with neighbours were severely damaged by the imposition of clean/dirty regimes. Importantly, for some respondents the particular trauma of FMD is inextricably linked with processes of recovery.

In 2002, many respondents were forced to revisit the events of the FMD year through anniversaries of culls, of financial disaster or of their reluctant participation in the mass killing. Respondents write of anniversaries rather as a rite of passage. Painful and distressing images and some degree of 're-living' the events of the past year may be part of the recovery process. For example, a slaughterman speaks of his feelings one year after being involved in the mass culls:

It's a year since I went away killing. I feel a bit funny with myself today. It was our wedding anniversary on the 10th, but this sticks in my mind more.

(Frontline worker diary March 2002)

A DEFRA worker writes of his relief at signs of renewal:

³⁸ Rural vicar, diary March 03

It was good to see sheep back in the fields and even the first lambs were appearing again. The last lambs I saw last year were being given lethal injections by a vet and we laid them out in rows to spray with disinfectant till they were taken for disposal.

(Frontline worker diary April 2002)

In one of her last diaries for the project, a health worker revisits her worst memories of 2001:

My worst memories.... taking my daughter and her friend home (from a show in Carlisle). It was the same evening that her father's pedigree sheep were being taken to the voluntary cull. By mistake I took them through a closed road – the sign having fallen down to the side of the grass – in the dark we went past a burning pyre only yards from the hedge separating the road and the field. We could see the charred, rigid bodies of the cows and the sparks from the fire and the smell permeating the air and the silence of the two young girls.

(Community nurse, diary June 2003)

Traumatic stress is often represented as the 'normal' reaction of those people exposed to an abnormal disaster event (Yehuda et al 1998; Alexander & Wells, 1991). Our definition of trauma has been developed within the context of this particular disaster and related to both the events and the reactions to those events. Trauma was widespread, both acute and chronic, and respondents have reported feelings of shock, depression, including thoughts of suicide; loss of concentration and interest; recurrent thoughts and flashbacks, broken sleep, avoidance of and obsessive attention to details, problems requiring medical intervention, a sense of being misunderstood, and anxiety about the effects on children (e.g. witnessing culls). While such 'symptoms' accord with more clinically based definitions of post traumatic stress disorder (PTSD); we maintain that the experience of trauma in this context (while in many ways exacerbated by the long duration of the epidemic), should not be seen primarily as a disorder.

Situations which may promote severe reactions are classically those where the actor or group cannot flee or fight the horror or terror, i.e. cannot follow the instinct either to escape or confront the threat or danger. Being caught in such situations is believed to place the individual involved at risk of developing PTSD. An example of such a situation from our data involves a farmer who was prevented by movement restrictions from feeding his condemned sheep for three days and having to watch them starve in a field near the house. Many of these sheep were heavy in lamb at the time.³⁹ Although the circumstances were particularly distressing in this case, this was not uncommon among those affected and similar situations have been related to us. Horrific as it was, these events took place within a collective context of distress. Therefore individuals did not necessarily become 'ill' and many respondents and others found their own psychological or social resources which offered them some protection against this.⁴⁰ As McFarlane (1988, 2000) observes, there does not necessarily

³⁹ Respondent 54 (interview Jan 02).

⁴⁰ We would add a note of caution here – long-term stress and its effects may indeed be a serious problem and we believe this should continue to be researched (see recommendations). The point here is about personal and collective resources which were brought into play at the time and in the following months.

appear to be a simple relationship between distress and psychiatric illness; distress need not be translated into psychiatric morbidity (Alexander & Wells, 1991).

Experiencing the culls

The culls were completely outwith ordinary experience and for many, the memory is enduring. A respondent from Group 3 (also a farmer) never refers directly in diary or interview to what took place on her farm during the cull. She refers instead to *that day*, shorthand which assumes an understanding of a wealth of meaning:

Those people that didn't lose their stock, they don't have their memories of that day ... from the cull onwards we were lucky if we had three, four hours of constant sleep, [...] you were just lying there, you know just thinking of, about what had gone on really.

(Agric related, interview Feb 02)

As in times of war, sources of information become critical, she becomes distressed when she remembers:

.... we got all our information from Radio Cumbria [hourly bulletins] and often you knew 8 out of those 9 people and you know it was hard to deal with (upset)

(as above)

When she returns to work:

A very emotional week, especially on Tuesday. [...] Saw many people whom I have not seen for 12 months. Very good to see and chat to them, but when some asked 'Did your stock survive?', then memories all came flooding back.

(Diary Feb 2002)

She describes the anniversary of the cull:

Anything we do this weekend will be better than last year. A couple of sleepless nights as the memories come back

(Diary April 02)

A year later she says

Don't look forward to this week in the end of April. 27 - 28th April 2001 has awful memories

(Diary April 03)

A farmer becomes upset in interview by memories of his son's distress at losing his own stock:

And he's bred them [...] When we were fetching them in to slaughter like [...] you know, he was in tears, [upset here] ... That was the worst.

(Interview Jan 02)

He describes enduring the experience of the cull:

you just have to, block it all off as far as I was concerned.

And the realities of decomposition:

And the smell you could hardly breathe like. [...] by the Saturday they were just all coming apart like, [...] they were that heavy in lamb, if you just touched them like they just exploded.

(as above)

A year later his memories are still vivid, when every week for 5 weeks he recalls the events of the previous year in his diary:

This time last year the nightmare had begun [...] it was certainly the worst week of my farming life.

(Diary March 2002)

A health professional/farmer describes in some confusion the large scale cull at her home and indicates physical symptoms of shock:

...then it was just days of culls after that, [...] and then the pyre was going on, it was just, I can't even say what it was like...and it was so cold as well, in fact it always, oh I feel really cold even talking about it, ...oh it was just really weird.

(Health group, interview March 2002)

In her diary she describes a flashback on seeing a Damien Hirst piece at an exhibition:

Reminded me of the calves we used to see in their mothers' bodies when their abdomens split open on the pyre. Felt sad.

(Diary 2002)

Front-line workers and occupational distress

Many co-opted workers were poorly prepared for the work they found themselves doing. A 'field officer' on secondment from Environment Agency to work for MAFF/DEFRA spoke of recurring traumatic images:

I kind of switched off... my reaction was, just thought this is absolute chaos, this is madness

(interview Feb 02)

He felt morally compromised:

I resented myself and I resented, the government and the fact that the only way I could comfortably resolve the situation was to er, leave my job

(as above)

And extreme anger:

I vividly remember, the last farm I was on, [...] I was penning up cattle and, I would have been quite happy to have seen (politicians) getting penned up and getting popped in the head [...] which I don't think was a very healthy state of mind to be in, but...that's how I felt at that time....

(as above)

He speaks of flashbacks and suicidal thoughts:

I'll never be able to look at a cow or a sheep again without seeing blood pouring out of the hole in its head, [...] maybe I will in time...I walked, walking along the pier one night [...] I did actually think about jumping in... I felt so bad about myself.

(as above)

A DEFRA field officer describes withdrawing from social contact at home:

I was coming home (very late at night) and I didn't want to talk to anybody [...] I was just ignoring [my boyfriend] I wouldn't talk to him. I wouldn't phone my parents, I wouldn't phone any of my friends. [...] I just wanted nothing to do with anybody.

(Interview Feb 02)

'Collateral' trauma

A teacher from Group 5 (Figure 8.2) heard the stories of parents. A mother told her: *All she could see was pieces of animals all over her yards and the smell was horrendous.* Her daughters' partners both found work on carcass disposal and they too told their stories:

One was handed a big long sharp piece of metal and told to run through a cattle shed and stab each one in the stomach as he went. [...] he started having nightmares.

(interview March 2002)

A sole trader in a craft business located in a marginal area told how he was affected by a cull next to his work premises:

MAFF came and knocked on the door [...] they sort of asked a few questions and I explained that I live on a farm 10 miles away and they let me know that I couldn't return home there and weren't really able to offer alternatives...I had I don't know, £50 in my pocket and the clothes I was stood up in and nowhere to go basically, the first 2 nights the Saturday and Sunday nights, I slept in the car

I found a lay-by away from, far away from here, I just sort of driving aimlessly keeping warm most of the time [...] I tried a few helplines that MAFF had handed me and the [...] conversation with a lot of them was 'I'm sorry it's a sort of unusual circumstances, there's nothing we can do to help you'. ... the last one, [...] suggested I get in touch with the local authority which I did on the Monday morning and they housed me in a guest house [...] I was there for 2 weeks, that two week period was a nightmare. [...] ...you almost hit a point where you're almost delirious and nothing matters. You don't care, nothing matters in the world and that was a comfort, that feeling was a comfort. You just switched off. And to a point I am still fairly well switched off.

(as above)

He later developed symptoms:

When I'm lying in bed I get palpitations, [...] you're thinking the thoughts of the day, thoughts for tomorrow, what's going to happen next, am I still going to be in business, what if I don't, what am I going to do next? [...] and then the panic attacks set in you can't I remember first time I saw the doctor [...] he said, 'look there's lots of classic signs of anxiety and panic attacks, I'm going to prescribe you some more anti-depressants'.

(Recorded diary June 02)

A health visitor describes her work with clients some of whom she feels to have been affected by FMD in indirect ways such as stress related illness, domestic violence, redundancy and consequent housing problems:

...a family separated due to domestic violence. This apparently had been an issue for some time, but was exacerbated by the effects the foot and mouth.

(Diary May 02)

(A client who) having lost her farming job she has great difficulty getting work now. Also she has the difficulty of arranging childcare. Her problems are very complex and despite all the help available I cannot find any more avenues to explore with her.

(Diary July 02)

And visiting:

....a farmer who was recovering from a myocardial infarction. I follow these patients up to identify problems that may affect their recovery [...] He was very quick to identify stress as a problem to him, this he largely put down to the foot and mouth outbreak.

(Diary Nov 02)

The way that many families were incarcerated for months, and the clean/dirty regime imposed on workers and many other rural citizens, also weakened the ability of communities to 'pull together'. But many accounts of traumatic stress are accompanied by accounts of how individuals found a way to contextualise this, or gain strength from the knowledge that many others locally were experiencing similar horrors. For example, an Environment Agency worker says:

...any shared experience [...] you can only appreciate it through having experienced something similar... And I think for a long time I was looking for that kind of support, rather than going back into the office and, people [...]without really having a, a clue of, of what it was like.

(Interview Feb 02)

Recovery

Respondents' diaries are full of signs of recovery and renewal. But there is also evidence that their confidence is fragile. Early diaries from across the different groups showed collective dread when there were new FMD scares. Even happy occasions carry overtones of shared history:

[after a christening] Every new beginning and every special occasion it seems to bring with it FMD baggage, so small is our community and so heavily affected were we, that there is no escape. But I expect that it is all part of the healing process.

(Rural vicar diary, June 2002)

Farmers report over-reacting to ill-health among their stock and we also found significant levels of hurt among those who felt that they had worked hard during FMD but who felt that their efforts had not been acknowledged:

. Had my job review done, not happy with it, hardly mentioned the FMD work last year. It is almost as if last year didn't happen.

(DEFRA worker diary June 2002)

I suppose it's human nature we want some acknowledgement that we did something during that time and we haven't had that, we haven't received that [...], its not just acknowledging what we've done, its acknowledging that there was a problem and a lot of people are still in sort of denial to it really I think. My number one priority really [...] was the staff, cause I think because I know what it was like you know, having your head chewed off every ten minutes all day [...] there were a lot of very angry people out there and there still are...

(Tourist information worker interview Feb 2002)

However there is a wealth of evidence of the importance of family and community activities, sport and traditional events in the lives of the panel.

This week ended with an art exhibition in the village school. This was of the children's excellent work, guided by their art co-ordinator [...] She has helped them work through F&M with their art works. [...] The school was full of villagers coming together for this joyful occasion and it makes me feel very emotional just to write about it.

(Nurse diary April 2002)

The local village hall had a Jubilee fun night at the weekend. It is the first real 'Do' that we have had in the hall since the start of FMD. [...] It is good to see the countryside pulling together, as the national government seems to have washed their hands on us.

(Farmer diary June 2002)

Trust in Governance

You find yourself having to trust people or agencies you know little about and just hoping everything will be alright.⁴¹

This theme was developed from a large body of data about trust, or lack of trust, in decision making during and following the crisis. The discourse spans all levels of 'authority', decision making and management and many respondents were concerned about ways of resolving these problems and preventing any recurrence of the disaster. The widespread perception of government and management failure in the early stages of the epidemic, led to mistrust in governance as a whole, which manifested in conspiracy theories, viewing 'clean up' operations as punitive and the questioning and challenging of more contentious policies such as disposal methods.⁴² Differences between reports from London about the epidemic being 'under control' and what local people could see happening on the ground such as piles of dead animals lying uncollected for up to ten days, undermined credibility and trust in governance. The extract below is from a diary entry as the research was closing, i.e. summer 2003, indicating that the erosion of trust in governance continues to be a problem.

I don't think it will happen but DEFRA London, or where ever, will have to trust local knowledge and locals will have to trust DEFRA or whoever is in charge. The reason I don't think it will happen because after all that has happened over the last two years, all trust has gone.

(Agricultural industry, diary, June 2003)

Order/Chaos/Farce

The unprecedented scale and scope of the crisis, coupled with the delay in initial response, meant that at times, implementation of disease control oscillated between order and chaos:

It just felt like it was a shambles to be honest that is what it felt like to me [. . .] It was all reaction to what was happening. There didn't seem to be any plan as to how to get on top of the problem.

(Front line worker, interview, Feb 2002)

There just wasn't the organisation. Yes the sheer volume. MAFF got terribly behind at the start.

(Agricultural business, interview, Feb 2002)

As the crisis took hold, central agencies seemed overwhelmed and operations became farcical:

⁴¹Community resident, interview, February 2002

⁴² A finding of Anderson 'Lessons Learned' Inquiry is 'the extent of the breakdown of trust between many of those affected directly or indirectly and their Government'. (Inquiry report Sec1 p2)

The week we lost all our animals to foot & mouth was the longest week ever. On the fourth day they came for some [...]. The driver they sent hadn't been on a machine like that for 9 yr. He didn't come back. The next day they didn't come until late afternoon. There was no driver for the telescope handler. [...]. We didn't see anyone for 2 days. I kept phoning to see what was happening. They kept saying there was no lorries. The army liaison officer kept coming out to see us. We were bothered about our next door neighbour, because they could see the cows beside the wall, they looked out onto them. The wall was cracking with the weight of the cows. On the 7th day they came.

(Farmer, diary April 2002)

Local front line workers, often known and trusted by the farming household, could create order out of chaos:

Initially it was just chaotic. I mean luckily where I was working the contractors were local and some I knew and they were very good and they knew the farmer as well so there was no problem whatsoever, they tried to help them as much as possible.

(Front line worker, interview, Feb 2002)

Punitive measures

The bio-security measures, of microscopic disinfecting and 'washing out' of infected premises for weeks following a cull, were described by some panel members as punitive:

You started thinking of all sorts of strange things in your mind washing out. I said prisoners wouldn't have done it.

(Farm worker, interview, Jan 2002)

And again, not even just that [having stock culled], but then being frustrated and irritated by the mechanics of the clean up operation and all the rest of it. It was turning the knife in a wound for a lot of them.

(Rural GP, interview, March 2002)

The distress of enforced captivity on an infected farm was compounded by the chaos:

Once they were confirmed, that was them confined to barracks for however long it took. It took them ten days to a fortnight before they even started to build his fire, then they made a mess of that, they couldn't get it to light or to burn....Yeh, horrendous time of it.

(Agricultural business, interview, Feb 2002)

In 2002, a vet reflects on the 'science' behind the enforced captivity, in this case for a farming household who did not trust the contiguous cull policy:

The self-imposed isolation of not sending kids to school etc is just stupid but to go against the flow is very difficult. [. . .] They were not allowed to leave the house for 3 months. They just view this as a punishment imposed because they refused to let the hefted flock be culled. (They were right not to.)

(Local vet, diary, June 2002)

In later diaries there is also a sense that ongoing bio-security restrictions and regulations, particularly in the livestock industries, are punitive, partly because they are unworkable and do not make sense:

Now they [DEFRA] want to minimise risk by regulating animal movements so draconianly (sic) that they are making it impossible for us trade. 'Don't even try to argue' we were told, 'it won't change a thing'.

(Agricultural industry, diary, Feb 2002)

Health fears about disposal methods

Given the scale of culling there was unease about disposal methods. For those living near landfill and burial sites there were immediate and ongoing environmental health and safety concerns.

The pyres, seeing the pyres built and some of them were in public places on public roads and seeing them burning. And I remember going over a main road and counting them and I could see 14 pyres burning in one go and the smell yeah, was horrible.

(Agricultural business, interview, Feb 2002)

...What is being tested for in the surrounding streams? what exactly is classed as a danger? and if problems did arise, how would they be monitored and resolved. All these issues do tend to make you anxious.

(Resident near disposal site, diary, March 2002)

Diaries written in 2003, do acknowledge some disposal site management initiatives as helpful, including 'Open Days' and distributing regular newsletters to local communities:

I have included this newsletter in with these diaries as it contains quite a bit of information on a few different aspects, I think it is good about the wildlife which is emerging on the site.

(Resident near disposal site, diary May 2003)

Anxieties about disposal were exacerbated by a lack of credible information, this respondent writes about a local public meeting with a panel of 'experts':

I felt rather angry by the way in which the questions are handled. The answers are often vague, have no supporting evidence or are dismissed with 'I'll have to get back to you on that' or, 'I can't comment'.

(Resident living near disposal site, diary, March 2002)

And another respondent from Group 2:

. . .as I say when we were at the meeting these kind of things were brought up, and you're being told, no no, there's no harm, they [the pyres] won't cause any harm to health or anything else. [. . .] but somebody else stood up and had all these sheets and things, and said it causes this, it causes that.

(Rural tourism business, interview, Feb 2002)

Panel members spoke of public health advice about pyres in general being inadequate. Residents were advised to 'keep their windows closed' and people with asthma to 'ensure adequate supply of inhalers'⁴³. Despite reassurances that health risks from smoke particulates, dioxins and sulphur were not significant, panel members who lived with the daily reality of the sight and smell of the pyres reported health concerns:

We certainly have had more colds, wheezing coughs and things like that. I'm more inclined to say well, it's probably because we've just spent winter in a caravan, which although it's got heating and things like that, it isn't ideal. But certainly my husband thinks there's more to it than that. If the smoke and everything was going to cause something, there's no way being in this area there's no way we could have avoided it...

(Rural tourism business, interview, Feb 2002)

. . .there was some anxiety in the community, and there still is, over the long term effects of that smog. It was over the town for six weeks, it was terrible, I mean it was blowing over the churchyard; it must have been like Auschwitz. I mean it was a terrible smell.

(Rural vicar, interview, March, 2002)

...the smoke is very heavy and oily, and, and it just settles and it was like driving into a, into a thick fog in places. [...] And it was just the feel of it, was just as nasty as anything else really, I mean you just felt dirty

(Teacher interview Feb 2002)

By April 2001, public opposition eventually led to the ending of pyres as a disposal method.⁴⁴ In particular, opposition to a mass pyre in the north of the county with a capacity for 1000 cattle per day, acted as a catalyst. A panel member, living near the proposed site, questioned public consultation:

Nobody knew anything about that until some of the residents nearby saw these things coming in, you know, saw the wagons coming in, and the army there and everything, and someone said 'what's going on?', 'what's all this for?'

(Rural Tourism business, interview, Feb 2002)

A public meeting held after the mass pyre had been lit, proved to be the turning point. A panel of experts failed to convince the 'public' that the large pyre was safe, particularly after a member of the public disputed the science:

We had a public meeting [. . .] J [a research scientist working within carbon chain degradation processing] spoke, the old sleepers they were using had gone the course and got chemicals in them that were coming over the town, and there's a sort of health anxiety over that actually.

⁴³ Advice and information about the health implications of carcass disposal, including pyres, was posted on a Carlisle City Council web site by the North Cumbria District Control of Infection Committee, on the 30th March 2001 (www.carlisle.gov.uk/_3/fandm_5.htm); accessed, 26th March 02.

⁴⁴ Following local newspaper reports of a large pyre being erected in the North of Cumbria, a public meeting was held in Longtown on Wednesday 11th April 2001. Representatives from the army, MAFF, the Environment Agency and local health services, formed an expert panel who could address the concerns of the public. Local residents made clear their health concerns about the continuation of a large burn and activities were discontinued.

(Retired vicar, interview, March 2002)

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

(Agricultural industry, field notes, June 2003)

Hopes and fears for public inquiries

The anxiety which respondents have expressed, in particular fears that another epidemic will strike, with equally devastating effects, indicates that there are health and social consequences of 'Trust in Governance'. As the research went on, panel members also commented on hopes and fears for FMD public inquiries and future 'regeneration' policies.

I was about to sit down after a really bad week to write some comments for the lessons learned inquiry [Anderson Inquiry] and thought I should check the web site for an update. I found out to my considerable annoyance that the inquiry was coming to Cumbria to meet with DEFRA and hold the open meeting on Tuesday night, and if you wanted a ticket to attend, then you had to apply by a week ago. The overall impression is that the government do not want to learn lessons.

(Vet, diary, March 2002,)

Driving around today I've been trying to listen to what the Euro inquiry people have been up to [. . .] I was talking to an old farmer in the afternoon and he wasn't impressed either [. . .] what has been learnt, and what will be different next time because the one thing that must be prevented is the effects on people, nobody really got that.

(Veterinary Practice Manager, diary, May 2002)

Cumbria FMD inquiry report out – nothing we didn't suspect really, 'confusion disorder and delay' were the local newspaper headlines. However, Cumbria County Council seemed determined to do their best to encourage the Government to take heed of the conclusions of the inquiry for the way ahead.

(Tourism business, diary, Sept 2002)

'Rural regeneration'

Trust in governance also applied to issues relating to recovery funds and regeneration initiatives⁴⁵ set up in the wake of the epidemic:

⁴⁵ For example, long term recovery and regeneration strategies of rural Cumbria began to emerge through a Cumbria FMD Task Force and a Rural Regeneration Team, which led to a Rural Action Zone Programme (see, 'Next Steps Strategy, June 2002 - <http://www.cumbria.gov.uk/business/ruralactionzone/>). This is a multi-agency partnership, funded from a range of existing resources and overseen by a not for profit company, Cumbria Rural Regeneration Company (<http://www.ruralregenerationcumbria.co.uk/index.htm>)

There is a great deal of talk about grants for regeneration schemes [. . .] Maybe I'm cynical but these things look good on paper but aren't so easy in practice. A really good practical idea doesn't often fill the criteria or of these grant givers. Let's hope I'm wrong.

(Health Practitioner, diary, summer 2003)

A walking festival planned for May 2002 is cancelled

People say, 'well why have you cancelled it?' But it's things like the inflexibility of the authorities to be able to give us the grant, you know we have to put in the grant application so far ahead we can't take the risk of saying 'well we can do it now'.

(Tourism information worker, interview Jan 02)

I am feeling bitter as there is all the money in the rural recovery fund to help rural Cumbria and rural economy yet my future seems so insecure as ever.

(Front line worker, diary March 2002)

I feel like I've been degenerated!

(Agriculture related, group meeting May 2003)

Knowledges in context

Knowledge is passed down generations, it's not learned by somebody coming from nowhere into an office and reading a textbook.⁴⁶

This theme broadly illustrates the body of data about a 'gap' between on the one hand knowledge of 'everyday practices' i.e. situated, local understanding of these practices (proximal knowledge), and on the other bureaucratic, centralised or theoretical understandings (distal knowledge) which emerged during the epidemic. The data shows that proximal and distal knowledges are different in character, and that the context in which knowledge is generated is central to its credibility. For panel members, particularly in the agricultural related and front line workers' groups, difficulties arose when central directives were perceived to be stripped of context, of 'what if' scenarios, unable to adapt to what was happening 'on the ground' and therefore, unable to mobilise stocks of local knowledge and expertise. Instances where such knowledge could be mobilised, are remembered with a strong sense of 'everyone pulling together' and of 'making the best of it'. A knowledge gap was also created by frustrating problems with obtaining reliable, up to date advice and information that 'made sense' and didn't 'frighten the reader with alarming words.'

⁴⁶ Agriculture related business, final diary June 2003

Science at a distance

These contributions show a conflict between central control and local initiative; laboratory science and 'field' science:

...she did all the trillions of paper work and organised the slaughter team, and they arrived and she says, oh I haven't heard from Page Street yet whether or not I can kill them. So they waited three hours and they were querying it, and she was sort of saying look, they've no skin and they're blistering and they're septic, oh no they said, you'll have to wait another hour, so she put the phone down and she said, 'get on with it'.

(Veterinary Practice Manager diary, March 2002)

The older vets who were round from the '60s, they just knew that was the only way to stop it. [. . .] early on you've just got to get on and cull to stop it.

(Farmer, interview, Jan 2002)

Communication

Farmers sought advice about culls, from their vet, auctioneer, haulier, who in turn, were desperately seeking information from government agencies:

So I tried all the other numbers that we had that I didn't like to give out to everybody, but couldn't get anybody [. . .] After that they did put the later hours on [because they had only been available from 9 to 5].

(Veterinary Practice Manager, interview, March 2002)

Actually the decisions were altering all the time from up above as to what went and what didn't go, [speaking of contiguous culling] but I was told that they were going to go, the sheep I was looking after.

(Farmer, interview, Jan 2002)

A panel member who manages a Tourism Information Centre spoke of having to deal with the public's anger and frustration, as well as his staff's feeling of inadequacy:

I had to ring DEFRA for some definitive advice on paths which didn't seem to be obtainable anywhere. DEFRA were unable to help really. They did get back to me in the end but I thought they were pretty slow at it. . .

(Tourism information, interview Jan 02)

A manager of an outdoor equipment shop speaks about dealing with rumours and counter rumours about business grants:

And I mean, there's rumours going round, you know friends that are in business in different parts of the country, that are; 'have you heard about this and have you heard about that.' And I'd be on the phone to Business Link [agency offering advice and support] everyday after I'd heard a new rumour, and quite often they'd say; 'oh I don't know about that, I haven't heard about that'.

(Small business, interview, Feb 2002)

Local organisations reached out to offer information and support:

... we rang people up and we pushed all the information we could into the parish magazine because we couldn't visit anybody. So that became a source of information for things like the Addington Fund [relief crisis funding] and all of those advice lines . . .

(Rural Vicar, interview, March 2002)

Panel members spoke of local media, in particular local radio coverage as being more up to date, trusted and reliable:

. . .the presenters and that they were all very much involved you see [. . .], and the presenters all lived in villages and all these villages all had fires, they knew what was going on.

(Farmer, interview, Jan 2002)

Our interviews with local media staff, suggest that they worked at 'translating' what panel members spoke of as impenetrable 'Ministry-speak':

. . .there was quite a lot of correspondence from the Ministry, but you just read the first page and thought this was written by a fella in an office and got sick of it...

(Farmer, interview Jan 02)

Local knowledge and control

The State Veterinary Service is very, very centralised, and power is in London, and they wouldn't let it go.

(Vet, interview, March 2002)

This led to local expertise and knowledge of the local geography, of road networks, of local contractors and suppliers, being ignored⁴⁷. Here a respondent speaks of mapping 'clean' and 'dirty' road networks:

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 someone else.

(Agricultural industry, interview, Feb 2002)

Also in a manner resembling the mismatch of knowledges which undermined central agency credibility in the management of the Chernobyl fallout in (Wynne 1999) local practices were not taken into account:

⁴⁷ Anderson Inquiry (ibid) notes '*The FMD outbreak of 2001 had a profound impact on all those communities and individuals involved. Collective learning from such a massive experience can have great value if it is carefully analysed and then well used*'. (Sec 3 p2) and '*It is essential that the high level of knowledge and expertise about FMD that has been generated during the 2001 epidemic is not lost but maintained for future generations to use*'. (Sec 17.2 p4)

... they went around in helicopters looking for sheep because they thought that this other half million sheep was there, but this was like in May in lambing time. They were going on Figures in June from two years previous, which there would be that many more sheep, because all the ewes are on then and the lambs would still be running about, but try to tell them, they just wouldn't have it.

(Agricultural industry, interview, Feb 2002)

... they was saying this is stuff that they burn at Sellafield but DEFRA weren't listening and the mess that some of these lads were making on farms, trying to build pyres, fetching coal and then fetching it back again, you've no idea.

(Front line worker, interview, Feb 2002 – re using incinerator coal for open air pyres)

Interestingly, the following comment acknowledges that the army did effectively utilise local knowledge:

When the army were brought in they wanted somebody with local knowledge of the farms and the farmers and the countryside to help the army with getting settled in and dealing with the problems.

(Agricultural industry, seconded to the army, interview, Feb 2002)

'Hands off' and 'hands on' knowledge

Many front line workers were local people whose livelihood had been severely curtailed by the FMD control strategies and who had practical knowledge of handling livestock; others were seconded from local government agencies or unrelated branches of the Civil Service:

.....they were literally taking anybody on but some people had no knowledge of livestock whatsoever... .because, as far as they were concerned, we would be standing, in full waterproofs with a clipboard, at a gate directing traffic basically, licensing folk in and out, err, making sure they were disinfected properly, err, basically getting in the bloody road.

(Frontline worker, interview, Feb 2002)

But being a Field Officer involved much more than paperwork:

I mean, in between all this [culling of cattle] I was keeping an eye on the sheep and I was lambing some of the sheep! I know it sounds completely silly, but I just couldn't walk past and, and leave them.

(Frontline worker, interview, Feb 2002 – the sheep were unlikely to be culled until the following day)

A Field Officer with milking experience recounts a slaughter team arriving for a large cull at 3.30pm:

.... and they had to be back up in Edinburgh for ten o'clock so they were going to stop at half past seven [. .] I mean, we were going to shoot the little milkers first because I'd seen them suffering with not being milked and what have you...

(Frontline worker, interview, Feb 2002)

Diaries written into 2003 suggest that 'loss of control' is now manifest in ongoing restrictions and regulations, many of which seem to panel members, to be driven by bureaucratic requirements rather than by common sense understanding of agricultural industries:

I would like to see some of these people in a field counting sheep because I don't think they would know where to start. They expect every farm to have pens and runs and loading banks for sheep. Real life doesn't work that way. Normal people don't have the money.

(Agricultural industry, diary, June 2003, writing about a discrepancy on a form)

Health and Social Consequences

In this section we highlight what respondents have told us specifically about their health, health related matters, health of family members over the duration of the study. (Themes discussed above are of course relevant here too, such as the ongoing anxieties about living near mass disposal sites). Here we also draw out role changes accelerated or affected by the FMD crisis, particularly in relation to gender. Reflecting the theme of the inter-relatedness of rural work, social and personal networks, that which we introduced at the beginning of this section, we consider how change and uncertainty may have multiple and potentially long term social impacts on rural communities.

Self reported health/mental health

A GP suggests that animal movement restrictions increased workload for farming patients:

I mean he was never really bad [with stress] but again I think what was more important for the farmers was the practicalities, movement restrictions and things like that. I mean he was having to work twice as hard basically, to do his normal jobs because he couldn't move his stock around as he would normally be doing.

(Rural GP, interview, March 2002)

He reflects on how during the FMD crisis, farming patients became hugely frustrated by a sense that their tacit knowledge was being undermined:

. . . just absolutely bubbling over with frustration and irritation, and again, hugely independent people, and this is their farm, they've inherited it, worked on it all their lives, and suddenly some pip-squeak from MAFF is coming in telling them what to do and it just became completely intolerable for a lot of people I think.

(Rural GP, interview, March 2002)

In June 2002, a veterinary practice manager notes that one of her customers is still displaying health problems:

Chatted to farmer who started getting up at 4:30 am during FMD, because he couldn't sleep. He is still doing it now!! He still has not got

any sheep in [restocked] because he can't face it. He lost his sheep to the cull but kept his cattle.

(Veterinary Practice Manager, diary June 2002)

A front line worker requests that we do not continue with an interview in which she recalls her FMD experiences. In March 2002 she begins her diary:

(I stopped the interview with C as I) Realised that insufficient time has passed since FMD to be able to reflect on events of last year with a stranger without reliving them. Reliving them is not good for my peace of mind.

(Front line worker, diary, March 2002)

During the crisis a vicar ignored/postponed his own health problem as he was preoccupied supporting others. In May 2002 he finally has surgery:

He [surgeon] has removed 3 polyps, otherwise nothing sinister. If test shows problems then will check me in 3 years, otherwise I am clear. Relieved.

(Vicar, diary, May 2002)

In October 2002, a fatal farming accident triggers, difficult FMD memories for one respondent. He is distressed by the incident and has a 4 week break from diary writing. In January 2003, he retrospectively explains the 'link' between the accident and FMD:

He was killed while driving a tractor back from where they had been testing [the restocked] cattle [. . .] I know you cannot look at history and say what if... But if the cattle had not been culled, there would have been no blood sampling to do and no reason to be on the road that day at that time.

(Vet, diary Jan 2003)

The teacher Figure 8.2 notes in her diary that her control of her diabetes is deteriorating. This accords with observations which were made by staff at the Cumberland Infirmary Diabetes Centre (Large et al in preparation) during the crisis (see Section 6).

There is widespread concern⁴⁸ that it may be difficult to assess psychological effects for children and for many respondents this remains a concern:

. . .the farmer's wife was saying that the kids were all off school and nursery with 'Hand foot and mouth'⁴⁹. She had taken the youngest who was ill, with the middle kid to the doctor. The doctor had said what it was

⁴⁸ Cumbria Inquiry Report p, 82.; Carlisle City Council Health Overview & Scrutiny Committee FMD report March 2004, Cumberland News (Letters, Hendrie, 16.04.04)

⁴⁹ 'Hand foot & mouth disease' is a common, highly contagious, mild childhood illness that is caused by the coxsackie virus A16. It can cause painful blisters to form on hands, soles of the feet, and buttocks. See <http://www.dermnetnz.org/index.html>, accessed 09.04.04

and the middle kid burst into tears as he thought they were going to take her baby brother outside and shoot him!! It is funny but also very sad.

(Vet, diary, June 2002)

Another child remembers a significant FMD event, Good Friday, one year on:

'...you did that last year as well Mam. Do you remember Grandma phoned to say she had got the letter about the sheep being killed on the farm?'. To think that an 8-year old remembered it took me by surprise, but she was right.

(Agricultural industry, diary March 2002)

There were also 'FMD babies'⁵⁰, those born during the crisis and for some panel members whose home lives were disrupted by long working hours, there is a sense of losing a significant period which can never be regained:

G's 1st birthday [. . .] Feel very glad I bought the video camera because after the last year on FMD, I feel as if I've missed out on him growing in his first year of life – which makes me feel sad.

(Frontline worker, diary, April 2002)

Children and young people - emotional expression

Children and young adults witnessed, and in some cases were part of, distressing scenes of loss, suffering and grief, scenes which perhaps challenge traditional gender roles. A respondent, a farmer's daughter, described what happened when she, with her mother and 15 year old son were rounding up her parents' healthy sheep that were to be slaughtered off farm as part of a voluntary cull.⁵¹ Her father who had major heart surgery the previous year, had agreed to stay inside:

My dad had come out and I says, 'oh Dad', and he went away, he turned and went back to the house and then my son said, 'I'm going to see granddad', he says, 'I'm just worried about granddad', so he went and he sat and he held my father while he cried, and then my father, he went out to the wagon [transporting the sheep] that was ready loaded on the road and he talked to them.

(Interviewer) This must have been very hard for your 15 year old son?

Yes. He was very good, he was very supportive⁵², I mean I was in a state and he just held me and we just cried together and then he held

⁵⁰ Babies born either during the epidemic or during the lifetime of the research

⁵¹ Earlier in the interview, the respondent recalls that her parents had originally refused to permit their sheep to be part of a voluntary cull. However: *and then this letter came to say that they had refused the voluntary cull and that they would be coming to kill them [off the farm] on the Friday* (Agricultural industry worker, interview, February 2002).

⁵² The grandson had a very close relationship with his grandparents. Most week ends and during school holidays he helped them run their small farm, mainly sheep with some dairy cattle. Later in the study, the respondent speaks of her now 16 year old son moving in with his grandparents who had restocked. He continued with his studies but was able to, *help Mam with the heavy jobs seeing as Dad is getting more frail.*

my Dad and he held my Mum and we just stood and cried. And they say about the emptiness. I've heard that from so many people after the cull. Normally the cows are blaring or something is happening but they said it's different; it was an eerie feeling, nothing you know.

(Agricultural industry, interview, Feb 2002)

A farm worker respondent worries about his younger son:

I have a young son who, round about that time (the cull), got to have a nervous problem at school and we had a struggle getting him to school. In fact, we let him stop off about 3 week, this was before we got it, but he couldn't go off the farm, and we were all concerned. He actually still has got a little problem but he is settling down quite well now and going back to school.

(Farmer, interview, Jan 2002)

Here a mother speaks about a cull next to her son's school:

In fact they were going to have a pyre over the back of the school here and some neighbours complained and said the effect of the smell would affect them, so they didn't do it in the end, they ended up taking them to a burial site [extremely upset at this point].

(School secretary, interview, March 2002)

the respondent also describes the events at another school which had its own animals which were culled and then...

we were worried that it was going to happen during term time, because the children were coming in every day and they were use to seeing the pigs and the sheep and everything...sheep, lambs, and they had a huge pig with piglets, who was gorgeous.

(Interviewer) So will the school restock?

Yes, hopefully shortly. But what worried us was that we were going to have to shut the whole school down while the animals were in cull but we got round it by blocking off the agricultural block...and it was all fenced off...

Gender roles – controlling emotion

A respondent suggests that he needed to help others 'control' their emotions:

Normally you go out on a farm and you have a laugh and a joke, you value the stock for them and you do your job professionally. This was different; this was trying to keep the farmers upright, trying to stop them from bursting into tears, or to control it if they did burst into tears. I had times when I had farmers in tears, vets in tears, and slaughter men in tears, and that's bloody hard to know what to do.

He describes his own way of dealing with this:

I felt it was very important that I should never be seen to be upset. The only times that I did get upset [. . .] some week old lambs were taken off the moors to be injected through the heart, and that got me, and so I made the excuse that I had to go and do some totting up, and I walked

away about 60 yards or so, looked over the fence, composed myself. And I've got to say there's been a couple of times when I've come home late at night sat in a chair and had a good blub, it actually makes you feel a slight bit better.

(Agricultural industry worker, interview, Feb 2002)

Role changes in long term relationships

A respondent talks about how her husband could not cope with working (washing out pens) at a disposal site:

...he said, 'I couldn't do it', he says to me, 'well I lasted the morning because they were bringing the sheep in, but you're right next to the killing pen, and in the afternoon,' he said, 'well the trailer loads of lambs that were coming in [...] 'I just couldn't stick it.'

Her husband's agricultural fencing work had been curtailed by the FMD crisis. The respondent puts this in context:

He has a history of depression and so I really didn't want him to go. I said, 'I don't think you could stick it', you know, and he said, 'well I can't afford to sit at home, I've got to do something'

(Agricultural industry worker, interview, Feb 2002)

A year after this incident the respondent notes in her diary:

[a colleague] handed in his notice. He called in at lunchtime to tell me. It was a big blow [. . .] I was upset and cried. This wouldn't have affected me much before FMD but this year I seem to get upset and cry at the least little thing. D [husband] can't seem to understand as I have been a solid rock since he met me.

(Agricultural industry worker, diary, Feb 2002)

It is not unusual for men to be continuing to show distress a year after the traumatic events:

I visited two farms this week on which both farmers burst into tears. One lost his sheep but kept his cows. He cried buckets telling me how they slaughtered his lambs. The other is restocking and I went to see his new cows. He sobbed when talking about the dreaded day.

(Agricultural industry worker, diary, Feb 2002)

Some men suggest that their female partners are better at offering emotional support to others:

She really [my wife] cares about folk and all our friends and neighbours it seemed as they were going down and it affected her quite a bit, a bit more than me. I am one of them, I am doing my best and feel sorry for them but can do no more. But she takes things a bit deeper wishing she could go to help and make a cake as you do in villages, things like that whereas you can't. She could ring people up that had a disaster but I couldn't. I know I should have done more but I found it hard. I was frightened of saying the wrong thing.

(Farm worker, interview, Jan 2002)

Men and women found ways of supporting each other:

I think you go into auto-pilot, ... We seemed to take it in turns, so when I was down he was alright, and when he was down I was alright, so we'd sort of you know, if you're both down at the same time you just say, 'well sorry it's not your turn it's mine'.

(Veterinary practice manager, interview, March 2002)

Men seeking help/healthcare

Extracts from the diary of a worker on a farm (culled in August 2001) show the relationship between the effects of traumatic experience, health status and the role of formal/informal nursing support:

Wk 27(July 2002) *I feel myself as though I am not as happy about quite a lot as I was before, it seems as though the tension we went through just won't leave our minds alone. Everybody I talk to seems to be either in a haze or trance or something like that, still difficult to explain simply and properly.*

Wk 33 *I feel as though I probably need someone to talk to at the moment, but my emotions are so mixed up at the moment that I probably wouldn't know where to begin.*

Wk 38 *There seems to be an edginess to me at the moment that seems to be building up in me I think it probably has been for probably a month or just over, can't say for definite what it really is. It might be a year since the F&M the state of things at the moment I just feel I haven't got full control but I might be able to explain as it unfolds in the future.*

Wk 42 *It seems I go one way quickly down and then I seem to pick myself up faster than I used to. I used to be very laid back but seem to be a lot more anxious about things since F&M. It seems to have come in my mind that I am different to what I was before.*

Wk 43 *Me and [wife] have been squabbling about having an MOT (health check). I say I feel fine but I will go if she goes first, but she says she feels fine so it's a bit of a stalemate. Anyway, our M [son] has to go for his asthma test and I have to take him so I will just go and keep the peace and hope everything is all right.*

Wk 50 *I had a good talk to the nurse about my asthma check and we got talking about lots of things and it seemed to help a lot just talking to someone different about things. I have got to slow down and unwind.*

Long Term Social Consequences of the FMD crisis

Within farming - Loss of control from within farming and agricultural related industries appears to be an ongoing state because of rapid changes, new restrictions and regulations. It has taken farmers and those who work with animals about two seasons to get used to new stock, with the attendant

increase in farm injuries and anxieties about new diseases brought into localities with new stock, such as TB. There has been therefore an undermining of 'taken for granted' tacit knowledges which has fuelled further uncertainty about future.

A woman farmer describes the continuing emotions of re-stocking:

I lost my cows, which were my friends as I've said before, I am replacing them. These are not my cows these are somebody else's cows and I have to learn to love them really. (group meeting Jan 2002)
Turned dairy cows out into the fields. They were pleased to see grass again – had to get all family members to help – these cows do not know the way to the fields. (diary, May 02) *Those farmers who survived FMD do not realise what it is like as restocked cows do not know their way to the fields, and just follow the leader. (diary July 2003)*

Some respondents believe that FMD has accelerated the pace of the younger generation moving out of farming.

He [farmer] has definitely decided to sell [. . .]: This has all been very sudden but his son is no longer interested [. . .] With all the new regulations and paperwork a lot are finding it hard.

(Veterinary Practice Manager, diary, August 2002)

A vet writes about the 'new normality':

In some ways it is like after the FMD epidemic, before and after, everything is the same, but nothing is the same. Part of you is trying to find where you fit in the new reality, part of you wants the safety of the old ways. Slightly dislocated from your surroundings, but the physical surroundings are the same, but I suppose you have changed, and the old certainties, that were not certain but seemed it, have made way for new changeable ways that are not certain, and you know that they are not certain.

(Vet, diary, Jan 2002)

A vet considers the impacts for farmers a year after the crisis:

Several [farmers] were saying that this year was harder to cope with than last as there was no crisis or adrenalin to keep them going. And that the toll from last year was beginning to tell on them and their nerves.

(Vet, diary, Sept 2002)

There's a suggestion that small farms will be hardest hit:

FMD only seems to have made it harder for the smaller farmer, especially the ones that didn't get FMD.

(Agricultural industry, diary, June 2003)

Within tourist related business A camping caravan and fishing business in the north of the county reported huge economic losses:

I would have said Caravan wise we lost 95% of the business; people just didn't want to know. To the point where, had it not been for the shop [fishing] in X managing to keep going, we would have lost this anyway [the caravan site] 'cos we took out a mortgage to buy this anyway in the first place.

(Rural tourism business, Interview, Feb 2002)

In August 2002, this business is still struggling, the family of five has been unable to build a family home and is living in a static caravan. A diary entry also suggests that whilst there are post FMD funds for farming these are not forthcoming for tourism:

A pull out section on farming gave details of no less than four different schemes to help farmers overcome foot and mouth related loss of business, all of which involve grant funding of some description. One or two seemed as if they might be relevant [. . .] but when I contacted them, they only apply to farms. Maybe I'm missing something somewhere. I can't seem to find anyone remotely interested in helping our type of business.

(Rural tourism business, Diary, Feb 2002)

Also same business owner feels penalised because of particular location. Already on periphery of popular tourist centres, she now feels blighted by association with FMD:

I'm having a difficult time persuading people to come here, as soon as they hear X mentioned I can hear the change in tone

(Rural tourism business, Interview, Feb 2002)

In contrast, a gift shop owner trading on the periphery of popular tourist destinations, suggests that money generated by the 2001 FMD crisis has helped to keep his business buoyant:

Our business really was most fortunate in the end not to have been affected but as remarked before, much of the money earned from working for DEFRA I think found its way back into the Cumbrian economy at Christmas and in the New Year.

(Rural tourism, diary, May 2002)

He also suggests that some farmers who had lost stock used compensation money to buy fitting 'memorials':

... selling for instance figurines of farm stock, many of them sort of limited edition things we then started getting people in who had lost their animals, had had compensation and were then wanting to buy something to sort of remind them of the animals they'd lost, you see. [. . .] So we would have like a Texel Tup and Texel lamb and people would be buying these to remind them of stock they'd lost. Sometimes it might be somebody who'd had perhaps several hundred [or] a young person who'd had perhaps one tup and half a dozen ewes.

(Rural tourism, interview, Feb 2002)

Within family and social domains In 2002, a respondent attributes being overweight, frustrated and angry to ongoing FMD related stress, fuelled by a work situation where he feels that his everyday practices are being tied up in post FMD livestock movement restrictions and bio-security regimes that do not

make sense. Throughout 2002 and well into 2003, he suggests that a difficult work environment has negative impacts on his home life.

When is it my turn to have some fun, some joy, a little praise perhaps. I am dog tired, sick-fed up.

(Agricultural industry, diary, March 2003)

There may be permanent changes which might never be attributed to FMD when decisions are made, but this respondent reflects on a potential loss:

All my churches struggle at the best of times and are heavily reliant on visitors and fund raising. Last year had a devastating effect on all of that and money has become incredibly tight. In fact I am not sure how long my parishes can go on as they are

(Rural vicar, diary March 2002)

Discussion

The themes outlined above show responses to complex events in which what we see are predominantly *normal* reactions to *abnormal* events. These reactions may be exacerbated or alleviated by a number of factors: the sources of strength called upon to cope with emotional and severe practical difficulties; the support networks (formal and informal) which emerged; influence of place/particular location on business recovery; the burden of dealing with new regulations which demand cultural change; the fear of the epidemic returning and the stress of living with uncertainty (the 'new normality'). While this argument is supported by related studies ranging from the sociological (Erikson 1976 & 1994) to the psychological (McMillen, Smith & Fisher 1997); this also means that statutory and voluntary organisations have a more complex and enduring role than has perhaps been understood. People who have suffered a terrible blow, shock and enduring distress, may not be sick as a result, but they need careful and appropriate support to rebuild lives and regain confidence. A district nurse puts it like this:

No [nursing] visit to a house during that period was simple. Emotions were near the surface and every day brought fresh news and concerns. I'm sure that if an audit of the medical and nursing registers were undertaken for that period, there would be little evidence of any increased formal counselling. This wasn't because it didn't happen but because it became the norm. But what happened to all that stress and tension? Where are we now? I think that's the biggest unanswered question. Some people may have resolved their experiences but I feel for the majority, it was put on the back burner and gradually buried in the day to day realities of living. This does not mean that it's gone. For many people it's like an unexploded bomb. At some point in their individual lives, some event will trigger its detonation. Stress can also be detrimental to physical health and it plays a large contributing part in many conditions. Yet the effect of the stress of that period will remain undocumented and unappreciated as it will be hard to allocate blame to one specific time frame.

(Respondent contribution to Voices of Experience conference 12 October 2003)

Section 6

Conclusions and Recommendations

...when the community is devastated...one can speak of a damaged social organism in almost the same way that one would speak of a damaged body.
(Erikson, 1991)

The studies we have examined which attempt to understand the cost to human health of the 2001 disaster have struggled to produce the kinds of evidence their methods addressed. We suggest this is because what counts is what is counted, (Bloomfield 1991) and emanates from a form of domination in knowledge production about health, described as: ‘...a culture, mindset and training scheme which stresses the epidemiology and science of public health’ and which has for too long been ‘...an uncritical handmaid of an implicitly bureaucratic, rational and utilitarian approach’ (Heller et al 2003). Longitudinal diary based methods have enabled the production of evidence about the human health effects of the disaster:

- Deterioration in chronic conditions and diseases due to disruption in personal routines and access to health services
- Sleep disruption, flashbacks, nightmares, uncontrollable emotion, loss of concentration
- Reported pyre effects: headaches, respiratory problems, nausea
- Sharp increase in anxiety across different sectors
- Longer term stress relating to loss of confidence
- Ongoing health fears of residents living near carcass disposal sites
- Increased number of injuries relating to handling new stock
- Workplace health: risks and hazards (short term), change, uncertainty (longer term)
- Loss of physical exercise and recreation for a year

Wider social effects found:

- Tensions and conflict within communities
- Loss of amenity and recreation
- Communities experiencing permanent changes in land use
- Loss of confidence in organisations’ ability to control crises
- Loss of trust in governance
- Increased social isolation
- Uncertainty, confusion and lack of continuity in public life
- Bitterness (collective and individual) linked to lack of resolution of pain and suffering
- Increased sense of fragility in employment

Immediate distress, feelings of bereavement and ongoing suffering by many different groups is a feature of the 2001 FMD disaster. But suffering is not a health problem unless it becomes pathological, when it is re-categorised as

'depression' or 'PTSD' and subjected to treatment. If it is treated it is counted. Otherwise those who are suffering are expected to get over it, and recover using their own resources and networks (Morse 2003). In the rural communities affected by the disaster, it was the world which was disordered, not local people or those drafted in to help. Yet the effects on this large group of people were painful and disabling and there remains a simmering sense that this is not understood by 'outsiders'. The demands and expressed wishes of those who have experienced a disaster need to be given special attention because these impact on the possibilities for recovery. This is reported in a number of other studies such as the recent re-examination of Aberfan by McLean & Johnes (2000)⁵³. It has been shown that when the response of 'authority' is not appropriate, or when it underestimates the scale, duration and impact of disasters, or does not acknowledge its own mistakes, recovery is much more difficult (Giner-Sorolla 2004)⁵⁴.

Our definition of trauma is therefore a situated one, within the context of the FMD disaster, and encompasses both the events and how those events were experienced by both individuals and communities. Trauma is associated with the inability to fight or flee, i.e. being trapped in the stressful environment and unable to take control over events. In this way we can see how the 2001 FMD epidemic with its severe movement restrictions on people, exacerbated the distress caused by particular events such as the culls. It is known that the length of time people are exposed to traumatic events can be a risk factor for developing enduring problems. Again, the FMD epidemic culls alone (let alone the restrictions) lasted for nine months in Cumbria, another factor not sufficiently understood by 'outsiders'; in terms of disaster studies, exposure in this case was very long indeed.

Recovery is subject to many influences and stages including how the disaster is perceived by those affected and those who are not. Erikson (1994) notes that it appears much harder for people to recover psychologically if the disaster appears to be 'produced by human hands'. McMillen et al (1997) in a study of a range of very different types of disaster, found that a community of people with existing networks of support was more likely to experience recovery from disaster than examples where ad hoc or random groups (i.e. train passengers) were hit by disaster. North & Hong (2000) found that recovery was more effective if local people received support, practical help and training from

⁵³ McLean & Johnes revisited the 1966 Aberfan disaster in which 144 people were killed, 116 of whom were children, buried when a coal slag tip slipped down onto the local school. Here a local chapel was used to house the bodies and was where parents came to identify their children. Later local people requested that the Coal Board (which was apportioned liability) should fund the demolition and rebuilding of the chapel as they felt they could no longer worship in a place which had such a traumatic association with their loss. This was initially refused and is given as an example of how those outside of the disaster view such requests as 'irrational', while for insiders it is a normal reaction to an abnormal event.

⁵⁴ In their ESRC funded study into the after effects of the Prestige oil spill off North West Spain, Giner-Sorolla et al reported: 'Compensation without feelings can be seen as an insulting hand-out or buy-off; but expressing appropriate emotions of shame, guilt or compassion sends the message that the compensation is based on a genuine social relationship'. Anderson 'Lessons Learned' Inquiry report says 'a first step is for DEFRA simply to admit that government made mistakes during its handling of the crisis and that all involved are determined to learn from these mistakes'.

professionals to counsel *each other*, rather than experience the direct intervention of 'outside' health practitioners or social workers.

We have shown that the post FMD suffering is accompanied by fear of a new disaster, by loss of trust in authority and systems of control, and by the undermining of the value of local knowledge. This legacy is ominous, and one which we have endeavoured to make visible to those agencies who will read, reflect and act on our findings. Just as suffering has to be *documented rather than counted*, our conclusions imply recommendations for change mostly in attitude and emphasis, rather than the creation of new bodies or yet more specific targets and protocols. We want to argue for *more flexibility* in e.g. disaster planning, and for *less tightly coupled systems*, since such systems arguably themselves carry further and more elaborate risks as Charles Perrow in his study of risk and accidents (1999) has shown. For this reason, not all the insights provided by the research translate neatly into recommendations for operational change, however we urge the authorities and agencies who have a role in disaster management, care and recovery to assist in this work of 'insight translation'.

Nine conclusions and recommendations were drawn up in consultation with the project steering group:

1. Conclusion

Many human reactions to the disaster, such as experiencing of flashbacks; emotional triggers; life now measured by pre and post FMD events; irretrievable loss; anxiety about new problems, are *normal reactions to abnormal events*. (See Section 5, Trauma & Recovery p50)

Recommendation

Organisations in healthcare, recovery and those working on the Rural Stress Action Plan need to disseminate this message widely so that those who seek help, whether practical, financial or emotional, realise that this is because of external circumstances and not because of personal failings or pathologies. RSAP working group has contributed to the current DEFRA FMD Contingency Plan and the Haskins Rural Delivery Review to raise awareness about stress. But existing plans still talk in pathological terms, therefore the work of this Group should be extended to develop a non-pathological understanding of trauma as indicated in this report.

2. Conclusion

During the crisis voluntary sector helplines were inundated with distressed callers. Statutory agencies seemed paralysed by a new and complex phenomenon which they did not recognise as a 'disaster'. (See Summary p6)

Recommendation

Health, social care and voluntary organisations need to review jointly what counts as a disaster and how this is recognised. The definition should be broadened beyond professional definitions or what can easily be counted or measured and should include developing and long-term phenomena. In crisis situations, practitioners from all agencies need support so that they can take initiatives according to needs which they encounter on the ground.

3. Conclusion

During the crisis, voluntary sector organisations rather than statutory agencies responded quickly and flexibly to help alleviate severe practical and emotional needs. They understood that practical needs, e.g. fodder to prevent animals starving, were inextricable from emotional distress. (See Section 5, Knowledges in Context, Appendix 3)

Recommendation

Health services and voluntary sector organisations need to develop ways of sharing 'intelligence' about needs. Ways to do this without breaching confidentiality should be developed. The sectors have different, but closely related roles, both during and after disasters.

4. Conclusion

Rural health services were disrupted and many patients and clients did not access help for chronic conditions. (See Section 5, Discussion)

Recommendation

Enhanced outreach working initiatives in rural areas would help alleviate some of the ongoing problems resulting from poor access during the disaster. Additional funds to support this should be made available through regeneration agencies so as not to damage existing provision in other areas. 'Health' and 'non-health' agencies need to work within a broad definition of health to facilitate this.

5. Conclusion

Health consultations became more complex and lengthy during the crisis. Rural health practitioners had to improvise new ways of working. (See Section 5, Occupation)

Recommendation

Practitioners 'on the ground', e.g. health visitors and community nurses, should be consulted regularly during a crisis to see what changes in working practices need to be accommodated (extra visit time, phone time, home visits), as it may be more effective to adapt existing networks of trust rather than draft in new 'emergency' workers.

6. Conclusion

FMD Front-line workers were recruited at speed for the emergency. Some were transferred or seconded from existing unrelated posts, or hired through agencies/employment service. They had little or no training for what was an unprecedented situation. They amassed critical expertise, 'learned on the job', which is still not being sufficiently recognised or recorded so that it may be used in future contingency planning; e.g. veterinary; emergency planning; community health; transport; police. Lack of recognition of this knowledge has contributed to poor morale. (See Section 5, Recovery; Local knowledge and control)

Recommendation

Agencies that employed front-line workers should make a record of skills and expertise acquired and ensure ways to access this in future. Strategic and operational knowledge and experience about FMD should be brought together, rather than separated hierarchically.

7. Conclusion

Many respondents reported how taking part in the research provided a sense of relief and release within a 'safe conversation' (in diaries or interviews). There is little evidence of de-briefing and counselling offered to *workers* who undertook horrific tasks over long periods of time. Positive regular mental health promotion for workforces should have higher priority within the larger organisations, and be available also for sub-contractors. (See Appendix 7)

Recommendation

All agencies need to review this aspect of provision. In particular, where a temporary workforce (or seconded one) is concerned, these can be the people worst affected, but receive the least care. Great care needs to be taken over the kind of support which is offered, with emphasis on guided de-briefing models and peer support, rather than stigmatising or pathologising approaches.

8. Conclusion

Residents living near disposal sites have had their environment affected and changed in ways about which there is little knowledge or precedent. Anxieties prevail, and currently the extent to which residents and communities are consulted and involved varies greatly between inclusive and exclusive practices. (See Section 5 Trust in Governance)

Recommendation

A need for greater community involvement in disposal site management and contingency planning more widely. Those involved in such planning (local government and other agencies) need a regular programme of outreach meetings, held within local community centres at times which most suit a working population. These need to be strongly focused on listening, negotiating and learning, rather than 'imparting information. Local residents may be willing to act in an advisory capacity on decision making bodies with post-FMD remits. Such community involvement may help alleviate some of the mistrust, particularly of government agencies, that has followed the epidemic and the fears about future animal disease outbreaks again becoming disasters.

9. Conclusion

Post FMD regeneration funds have been widely publicised in affected areas but the experience from individuals and small local organisations is largely negative. Small businesses have great difficulty finding their way around the recovery funding, and in some cases, feel excluded by their geographical location. There are too many 'new', unrecognisable organisations and little continuity, ironically making help seeking itself stressful. Eligibility criteria are perceived as stringent, even punitive, inviting applicants to make themselves into 'victims' to qualify, or transform their activities in ways that are alien to their purpose. (See Section 5, Trust in Governance)

Recommendation

Post FMD rural regeneration support needs to be simplified, made more accessible and with less stringent/punitive eligibility criteria. A greater recognition is needed of inequalities and of how differences in location may influence the rate of recovery. One-stop events, with advisors to hand can save time and anxiety. Regular events for voluntary and community groups, but which also focus on local businesses and recognise the inter-relatedness of rural economies, would create more meaningful access, than expecting applicants to struggle with complex criteria alone.

References

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.

Allan, S. (2003) *Arts residency project for rural primary schools - in the areas of Cumbria hit hardest by the 2001 foot and mouth epidemic*. Eden Arts, April 2003.

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* (X1) No 1&2 37-46

Barnes, D. (1996) An analysis of the grounded theory method and the concept of culture *Qualitative Health Research* 6 (3), 429, 41.

Bennett, K. & Phillipson, J. (2002) The effects on village, business and household life in the Northern Fells. In, *Coping with Crisis in Cumbria: the consequences of foot and mouth disease*, (Newcastle, Centre for Rural Economy).

Bloomfield, B. (1991) The Role of Information Systems in the UK National Health Service: Action at a Distance and the Fetish of Calculation, *Social Studies of Science*, Vol 21, 701-734.

British Medical Journal Letters (2001/2002):

Gibson, G. (2001) Human consequences of foot and mouth disease are more than described *British Medical Journal* **322:1491** (16 June).

Hunter, D. (2001) Public health concerns grow over foot and mouth outbreak described *British Medical Journal* **2001**;322:881 (14 April).

Mayor, S (2001) UK investigates possible human cases of foot and mouth disease *British Medical Journal* **322:1085**.

Nicoll, A. Wilson, D. Calvert, N. Borriello, P. (2001) Managing major public health crises *British Medical Journal* **323:1321-1322** (8 December).

Petrie, K. & Wessely, S (2002) Modern worries, new technology, and medicine, *British Medical Journal* **324:690-691** (23 March)

Weldon, F. (2002) Why scare stories are good for the NHS *British Medical Journal* **324:9284** (20 April).

Bush, J. Thompson C, Phillimore, P. and Pless-Mulloli, T. (2002) Perception and communication of risks to health from foot and mouth carcass disposal sites', presented at the Institute for Health Research, University of Lancaster, May 2002.

Bush J, Pless-Mulloli ,T. Phillimore, P. Thompson, C. (2003) 'If they'd just asked for some local knowledge...': a critical examination of risk communication practices in the context of foot and mouth carcass disposal sites in the UK, *Epidemiology*, 14 (5) S119.

Carlisle City Council Health Overview & Scrutiny Committee (2003), *Evidence at hearings of the committee on Post Foot and Mouth Disease Environmental and Health Matters Subject Review/Inquiry*: 28th October 2003; 23rd November 2003; 17 December 2003.

- Charmaz, K. (1997) 'Identity Dilemmas of Chronically Ill Men' in Strauss A Corbin J (eds) *Grounded Theory in Practice* (Thousand oaks, California: Sage).
- CN Research (2000) *Health Care Opinion Survey*, March 2000, on behalf of the North Cumbria Health Care Authority.
- Coote, A. & Lenaghan, J. (1997) *Citizens Juries: Theory into Practice*. London, IPPR.
- Cumbria County Council (2002) – Education Service, school absences data (report in preparation)
- Cumbria Foot & Mouth Disease Inquiry (2002). *Inquiry Report*. Cumbria County Council.
- Deaville et al (2003), *The impact of the foot and mouth outbreak on mental health and well being in Wales*, Report for Welsh Assembly Government, Institute of Rural Health, Gregynog, Wales.
- Department for Environment, Food & Rural Affairs (DEFRA) (2003) *Foot and mouth contingency plan* (version 3.1, December 2003)
<http://www.defra.gov.uk/corporate/consult/fmd-contingency> - accessed January 2004.
- DEFRA: FMD Data Archive, data warehouse. <http://footandmouth.csl.gov.uk>
- Denzin, N. (1989) *Interpretive Interactionism* London, Sage.
- Devon Foot & Mouth Inquiry (2001) *Crisis and Opportunity*. Final Report. Chaired by Professor Ian Mercer CBE Devon Books, www.devon.gov.uk
- Dolan, P. (2000) Affected Age on Health State Valuations, *Journal of Health Services Research and Policy* (5) 1, 17-21.
- Donaldson, A P. Lowe, P. & Ward, N. (2002) Virus-Crisis-Institutional Change: The Foot and Mouth Actor Network and the Governance of Rural Affairs in the UK, *Sociologica Ruralis*, Vol 42, No 3, p 201-214.
- Dowswell, T. Harrison, S. Mort, M. & Lilford, R. (1997), Health Panels – A Survey. Final report of a research project funded by NHS Executive (Northern & Yorkshire) Project No HSR 015. Nuffield Institute for Health, Leeds University.
- European Parliament' Temporary Committee on Foot-and-Mouth. European Parliament resolution on measures to control foot-and-mouth disease in the European Union in 2001 and future measures to prevent and control animal diseases in the European Union (2002/2153(INI)) P5_TA-PROV(2002)0614. Foot-and-mouth disease: 2001 crisis
- Elliot, P. (1997) The Use of Diaries in Sociological Research on Health Experience, *Sociological Research Online*, vol. 2, no. 2.
- EQ-5D study carried out in Cumbria in 2000 (commissioned by the former North Cumbria Health Authority Public Health Unit).
- Erikson, K. (1976) *In the Wake of the Flood*. George Unwin and Allen, London, UK.

Erikson, K. (1991). Notes on Trauma and Community. *American Imago*, Vol. 48, No. 4, p.455-472.

Erikson, K. (1994). *A New Species of Trouble*. New York: W.W. Norton & Company.

EuroQol Group (1998) *EQ-5D User Guide* – EuroQol, version B 1998.

Farming and Food a sustainable future. *Report of the Policy Commission on the Future of Farming and Food* (The Curry Report). London: H.M.S.O, 2002 (Chairman: Sir Donald Curry).

Franks, J. (2002) *Farming after Foot and Mouth*. University of Newcastle upon Tyne, Centre for Rural Economy Working Paper 66.

Gerrard, C. (1998) Farmers' occupational health: cause for concern, cause for action *Journal of Advanced Nursing*, 28, 155-63.

Gesler, W. (1993) Therapeutic landscapes - theory and a case study of Epidauros, Greece. *Environment and Planning D*, Vol.11, No.2, pp.171-189

Glaser, B. (1992) *Basics of grounded theory analysis* Mill Valley CA Sociological Press.

Giner-Sorolla R, Espinosa P & Brown, R, (2004) 'Saying sorry can win support', presentation at British Psychological Society, Social Psychology Pre-Conference Workshop. Imperial College, London, 14 April 2004.London.

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

Harrison, S. & Mort, M. (1998) Which Champions, Which People? Public and user involvement in health care, *Social Policy & Administration*, Vol 32, 60-70.

Hart, E. & Bond, M. (1995). *Action Research for Health and Social Care: A Guide to Practice*. OU Press.

Hawton, K. Simkin, S. Malmberg, A. Fagg, J. & Harriss, L. (1998) *Suicide and Stress in Farmers*, DoH report, London Stationery Office.

Hayes, N. (2000) *Doing Psychological Research: gathering and analysing data*. Open University Press.

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

Howorth, C. (1999). *Rebuilding the Local Landscape*. Ashgate, Aldershot.

Ingold, T. (1992) Culture and the perception of the environment, in (ed.) Croll, E. & Parkin, D. *Bush Base: Forest Farm. Culture, Environment and Development*. London: Routledge.

Ingold, T. (2000) *The Perception of the Environment: Essays on Livelihood, Dwelling and Skill*. London: Routledge.

- Jowell, T. (2000) Community development and the Government's policy agenda, in Ashton, P. and Hobbs, A. (eds) *Communities Developing for Health*, Health for All Network.
- Kashefi E & Mort M. (2004), Grounded Citizens Juries: a tool for health activism? *Health Expectations*, 7, 1-13.
- Kind, P. Dolan, P. Gudex, C. Williams, A. (1998) Variations in population health status: results from a United Kingdom national questionnaire survey, *British Medical Journal* 316: 736 - 741.
- Large, D M, Messersmith R, Aldred A & Tiplady P, Effects of Diabetes Control of the Foot and Mouth Disease Epidemic in North Cumbria, 2001, (In preparation). Carlisle, Cumberland Infirmary.
- Lowe, P. Edwards, S. and Ward, N. (2001). *The Foot and Mouth Crisis: Issues for Public Policy and Research* University of Newcastle upon Tyne, Centre for Rural Economy Working Paper 64.
- Mallinson S, (2001) Listening to Respondents: A Study of Standardised Health Measurement, Unpublished PhD thesis, Institute for Public Health Research & Policy, University of Salford, UK.
- Mallinson, S. (2002) Listening to respondents: a qualitative assessment of the Short-Form 36 Health Status Questionnaire.
- McFarlane, A.C. (1988) Relationship between psychiatric impairment and a natural disaster: the role of distress. *Psychology and Medicine*, Vol. 18, 129-39.
- 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.
- McLean I, & Johnes M, (2000) *Aberfan: Government and Disasters*, Cardiff, Welsh Academic Press.
- McMillen J, Smith E & Fisher R (1997) Perceived benefit and mental health after three types of disaster *Journal of Consulting and Clinical Psychology*, Vol 65, No 5 733-739.
- Meth, P. (2003) Entries and Omissions: using solicited diaries in geographical research *Area* (35) 2 195- 205.
- Ministry for Agriculture, Fisheries and Food (MAFF) (1999) *A New Direction for Agriculture England Rural Development Plan* London: MAFF.
- Morse, J, (2003) Innovative Inquiry, Editorial, *Qualitative Health Research*, Vol 13, No 4, 447-448.
- National Audit Office (2002) 'The 2001 Outbreak of Foot and Mouth Disease, Report by the Comptroller and Auditor General. The Stationery Office, London
http://www.nao.gov.uk/publications/nao_reports/01-02/0102939.pdf

- North, C. & Hong, B.A. (2000). Project CREST: a new model for mental health intervention after a community disaster. *American Journal of Public Health*. Vol. 90, pp.1057 – 1058.
- North Cumbria Health Task Group - *Health and Social Care Action Group*. Minutes 17 April 2001 to 4 January 2002
- North Cumbria Public Health/Health Development (2002) North Cumbria Mental Health Promotion Strategy, February, NHS, Cumbria
- Peak District Rural Deprivation Forum (2004) *Hard Times: A research report into hill farming and farming families in the Peak District* Peak District Rural Deprivation Forum
- Perrow, C (1999) *Normal Accidents*, Princeton, Princeton University Press.
- Prempeh, H. Smith, R (2001) Foot and mouth disease: the human consequences *British Medical Journal* 322:565-566.
- Rural White Paper (2000) *Our Countryside: The Future – A Fair Deal for Rural England* the Stationery Office.
- Sideris, T. (2003). War, gender and culture: Mozambican women refugees. *Social Science & Medicine*, Vol. 56, pp.713–724.
- Stanley, L. Wise, S. (1993) *Breaking out again: feminist ontology and epistemology* London, Routledge.
- State of the Countryside, (2001) Countryside Agency, April 2001 www.countryside.gov.uk accessed 29.04.04.
- Strauss, A Corbin, J (1994) Grounded theory methodology: an overview. In (eds) Denzin, N. Lincoln, Y. *Handbook of Qualitative Research* Thousand Oaks CA, Sage, 273-285.
- Strauss, A Corbin J (1998). *Basics of Qualitative Research Techniques and Procedures for Developing Grounded Theory* (2nd edition) Sage.
- Syed, A.A. Tiplady, P. Large, D. M. (2002) Human Consequences of foot and mouth disease: a diabetes perspective *Diabetes Today* 5 (3) 75-76.
- Taylor, L.J. (2004) Innovation in Diabetes Care: A 'Telephone Ethnography', Unpublished Masters Dissertation, Institute for Health Research, Lancaster University, UK
- The Northumberland Committee Report (1968) *Report of the Committee of Inquiry on Foot-and-Mouth Disease 1968*, chaired by the Duke of Northumberland (Cmnd 3999), HMSO.
- The Royal Society (2002). *Inquiry into Infectious Diseases in Livestock*. Plymouth, UK. (Chaired by Sir Brian Follett, 2002)
- Tideswell Health Survey (2002) Farm Out Health Project, High Peak and Dales PCT.

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

Somé, S. and McSweeney, K. 1996. Assessing sustainability in Burkina Faso. *ILEIA Newsletter*. ETC Leusden, The Netherlands.

Verbrugge, L. M. (1980) Health Diaries *Medical Care* Vol. 18, p. 73 - 95.

Weldon, F. (2002) Why scare stories are good for the NHS *British Medical Journal* 324:9284 (20 April).

Wilson, K. Therapeutic landscapes and First Nations peoples: an exploration of culture, health and place, *Health & Place*, Vol. 9, pp. 83–93.

Wood, J. (2004) *Rural Health & Healthcare: a North West perspective*, Public Health Information Report for the North West Public Health Observatory, Lancaster, Institute for Health Research. www.nwpho.org.uk/reports/ruralhealth.pdf

Woods, A. (1999) *From occupation hazard to animal plague: Foot and mouth disease in Britain, 1839-1884, Unpublished MSc Thesis, Manchester University.*

Wynne, B. (1996) 'May The Sheep Safely Graze? A Reflexive View of the Expert-Lay Knowledge Divide' from Scott Lash, Bronislaw Szerszynski and Brian Wynne eds. *Risk, Environment and Modernity: Towards a New Ecology* London: Sage 45-83.

Yehuda, R., McFarlane, A.C. & Shalev, A.Y. (1998) Predicting the development of PTSD from the Acute Response to a Traumatic Event. *Biological Psychiatry*, 44, 1305-1313.

Young, A (1995) *The Harmony of Illusions: Inventing Posttraumatic Stress Disorder*, Princeton: Princeton University Press, 1995.

Zimmerman, D. H. & Wieder, D. (1977) The Diary-Interview Method *Urban Life*, (5)4 479 - 498.

APPENDICES

Appendix 1

(Diary pages have been condensed)

Weekly Diary

Week number:

Diarist number:

If you have any questions regarding your diary, please phone Ian Convery on
01524 592756

How to complete your diary

Thank you for agreeing to join this important study. Here are some points to bear in mind when filling in your diary.

Please remember that this is your diary. We are interested in finding out as much as possible about the way the foot and mouth outbreak has affected your life, so please tell us as much as you can about yourself, no matter how unimportant it seems. For example, if you felt poorly but decided not to do anything about it, or were worried about your job but kept it to yourself, we'd like to know. If you are not sure whether to tell us something or not then please include it, we'd rather have too much information than too little.

Please don't worry about spelling, grammar or handwriting, but just try to write as clearly as you can, using a pen.

Try to make a few notes in the event section as you go through the week. This will help you when you come to fill in the diary at the end of the week.

Please also feel free to include drawings, poems or other material with your diary entries if you would like.

This diary booklet contains the following:

- Some *initial questions* about how you have been feeling over the last week, your health, quality of life and relationships
- Some *things to consider* when filling in your diary
- An *event section* to help you when you come to complete you diary
- *Diary pages*

If you have any questions about the diary please phone Ian Convery on 01524 592756 or e-mail i.convery@lancaster.ac.uk

Some Initial Questions

We would like to ask you some questions about how you have been feeling over the last week, your health, quality of life and relationships. From the following questions please choose the option that best applies to you. You can make some additional comments in relation to these questions, or discuss them in more detail in your diary entries.

1. How confident do you feel about the future this week?

2. How has your relationship with family and friends been this week?

Very poor **Poor** **average** **Good** **Very good**

Comments:

3. How has your relationship with work colleagues been this week?

Very poor **Poor** **average** **Good** **Very good**

Comments:

4. How do you rate your overall health during this week?

Very poor **Poor** **average** **Good** **Very good**

Comments:

5. How do you rate your overall quality of life during this week?

Very poor **Poor** **average** **Good** **Very good**

Comments:

Some things to consider

Please tell us about any experiences or problems that have occurred during the last week, no matter how minor they seem. Tell us what helps you and what doesn't help you. As you complete your diary, think about the following:

- Anything which might have caused you problems or upset you
- How such events affected your daily routine
- How did they make you feel?
- Anything you did to make yourself feel better, e.g. resting in bed, going for a walk or talking to a friend.
- Anything you did which made things worse.
- Anyone you talked to about your problems or who gave you advice or help in any way. This might include family and friends, work colleagues, your local vet, or other health professionals such as GPs or nurses.

Event section

People have sometimes found it useful to write down what happened each day to help them complete their diary. For example:

Tuesday	Went into town, bumped into Chris, talked about...
----------------	--

Monday	
Tuesday	
Wednesday	
Thursday	
Friday	
Saturday	
Sunday	

Diary

This is where we'd like you to write your weekly diary. Please use as many pages as necessary to complete your diary entry for this week.
(Followed by blank pages)

Appendix Two

Panel Group Meetings

Phase 1

Group	Date
1	17.12.01
2	23.01.02
3	31.01.02
4	13.02.02
5	21.02.02
6	28.02.02

Phase 2

Group	Date
mixed	15.05.03
mixed	21.05.03
mixed	04.06.03
mixed	11.06.03
mixed	18.06.03
mixed	03.07.03

Panel Interviews

Respondent Code	Group	Date
54	1	17.01.02
53	1	21.01.02
52	1	08.01.02
51	1	22.01.02
50	1	22.01.02
49	1	21.01.02
48	1	17.01.02
47	1	17.01.02
46	1	09.01.02
45	2	30.01.02
44	2	26.02.02
43	2	06.02.02

42	2	29.01.02
41	2	07.02.02
40	2	07.02.02
39	2	05.02.02
38 Tape inaudible, PM very upset, did not carry out another interview	2	06.02.02
37	2	28.01.02
36	3	04.02.02
35	3	15.02.02
34	3	15.02.02
33	3	07.02.02
32	3	04.02.02
31	3	04.02.02
30	3	13.02.02
29	3	07.02.02
28	3	04.02.02
27	3	04.02.02
26	4	01.03.02
25 (Requested interview to be withdrawn)	4	21.02.02
24	4	21.02.02
23	4	21/02/02
22	4	27.02.02
21	4	26.02.02
20	4	26.02.02
19	4	23.02.02
18	5	07.03.02
17	5	12.03.02`
16	5	07.03.02
15	5	25.02.02
14	5	25.02.02
13	5	25.02.02
12 Withdrew at beginning – family crisis	5	
11 Withdrew at beginning – “not for me”	5	
10	5	08.03.02
09	5	26.02.02
08	6	06.03.02
07	6	14.03.02
06	6	04.03.02
05	6	05.03.02
04	6	14.03.02
03	6	08.03.02
02	6	14.03.02
01	6	08.03.02
55	6	27.02.02
56	6	11.03.02

Additional Interviews

Organisation	Date
Cumbria County Council	29.01.02
Rural Health Care Practitioner	01.02.02
North Cumbria Newspaper Reporter	04.02.02
Council for Agricultural Rural Life	07.02.02
Radio Cumbria Freelance Journalist	01.03.02
Farmer, South Cumbria	22.03.02
Radio Cumbria Journalist	08.04.02
Cumbria Alcohol and Drug Advisory Service	22.04.02
Business Link Cumbria	24.04.02
Cumbria Stress Information Network, Voluntary Action Cumbria	01.05.02
Women's Refuge Worker (Domestic Violence)	21.06.02
Slaughter team manager/slaughterman	15.07.02
'Penrith Spur' farmer (stock culled)	04.06.03
Cumbria Constabulary	20.11.03
Army, Chief of Staff	06.04.04

Appendix Three

Additional Data

Cumbria Alcohol and Drug Advisory Centre - (CADAS) - Contact made following local media report about this charity receiving about 40 requests for information and advice on drinking and gambling from farmers or family members, since the FMD crisis. CADAS had not identified farmers as a group with these sorts of problems before. Reported some increased use of alcohol during the time of waiting and worrying about getting FMD. Reported continued use post cull, clean up and enforced inactivity periods. Reports that for some, particularly younger farmers, compensation money led to culture of heavy pub drinking and in some cases gambling.¹

CADAS manager reported worries about post-FMD domestic violence:

Towards the end, when they were more or less given the clearance on Cumbria, that's when we started getting the odd call through. Farming long hours, isolation, decreasing returns, culture of 'stoicism' – stressful occupation – all can trigger abuse. Domestic violence often alcohol relate'.²

Council for Agriculture and Rural Life - (CARL) Made contact because some panel members spoke of getting practical help from the voluntary sector. This group provided emotional, financial and practical support, mobilised by local people:

The contingency plan, and I have a copy of the Ministry's contingency plan, the contingency plan actually wasn't effective and it was left to the voluntary sector to get up and running and I couldn't find places to point people. So if somebody rang up and said look I've got a major problem here with fodder or movement or I'm worried about the neighbours, whatever it is, you had to set to and try as best you could to at least do something about that because you couldn't pass them on to anybody else.

Service was run by volunteers working very long hours and having to 'work outside the boxes' in order to meet needs. Public sector funding was offered quite late on and not without problems:

It was only later on that the Countryside Agency matched but you see that was because it was based on a faulty premise. I tried to get this over to Nick Brown's office. What they said when they came along with their matched funding eventually was that we were matched funded through the Countryside Agency as charitable giving. The starting point should have been what is needed, not what happens to be given by charity because you might be matching a very inadequate amount and therefore you're still falling short, or you might have been matching an amount that was quite adequate. There was no attempt to engage, no attempt to try and understand what was really needed.³

Business Link - Cumbria - Contact made through Director, member of project steering group. Recorded group discussion with 6 members of the FMD Business Recovery Team, the front-line workers who maintained the telephones during the crisis. They reported being exposed to continuous barrage of telephone queries from small businesses who were largely confused, anxious, distressed or angry; and a small minority who were verbally abusive and personally insulting. They felt that they had had little external recognition or acknowledgement for what

¹ Interview with Director, April 2002

² Interview with Manager, June 2002

³ Interview with Chairperson, July 2002.

they did. Some were seconded on temporary basis (6 weeks or 3 month contracts) and reported feeling overwhelmed. Reported that lack of clear information about government support for rural businesses meant 'rumour and counter rumour' would provoke many fruitless calls, time consuming and stressful for both parties.

The calls did start coming in pretty thick and fast. . . .everybody wanted to unload their anger at everything. . . you know they were not quick calls and you couldn't get them off the phone quick enough to be able to administer the job that you were supposed to be doing and that got very frustrating because the work mounted up. . . and they kept saying: "well I put my application in where is it? I want it now", sort, of thing, and you kept saying well you know we'll get through it as quickly as possible. . .

And like a load of the grant applications that have come back are from friends as well and so you know it's your own friends and relations or whatever and then you've got people ringing up saying you don't care and you don't understand.⁴

Local Media journalists, Radio Cumbria and Cumbria Newspapers. Both emphasised how local media are part of their community, reflecting local knowledge, understanding, but also sense of 'responsibility':

I think the local media, local radio, I think probably the papers as well, the thing that has been enormously important is that it's in touch with the local people that are being directly affected and I think that the local media, all of the different people, programmes, radio stations, came in to their own in being in touch and in giving people the voice, but also when people didn't feel they were getting answers to questions was to try and ask those questions, even if they weren't getting answers and I think we could have done better at that certainly. I don't think our questioning was half hard enough with some people but I think that we at least had a go. And I think that it made local people realise that there was a role for local media, you know, that it was there for them. Somebody said to me at the time, they said we only ever always listen to Radio Cumbria when it snows, 'but it's snowing all the time at the moment'!⁵

⁴ Group interview April 2002

⁵ Interview, Radio Cumbria journalist, March 2002

Cumbria Constabulary Officers attended the project's interim findings conference (October 2003) and expressed an interest in the study. A group interview was carried out with 3 officers who had been involved with the FMD epidemic, on many levels: community relations, law enforcement and health and safety issues that arose from the handling of the crisis, e.g. dealing with road blocks, mapping 'safe' routes for animal disposal and haulage to disposal sites. They reported that from the beginning, there was a sense of being overwhelmed, 'playing a catch up game.' The enormity of the task was not realised in those early weeks. North Cumbria Police had a 'liaison desk' at MAFF/DEFRA site at Rosehill, Carlisle, but meetings with other agencies were ad hoc until the army took over. The liaison desk was run by one officer who was inundated, 'the phone never stopped', with enquiries, the vast majority relating to the law in relation to animal movement. Information about this and related legislation e.g. need to block roads was not to hand; it was 'learning on the job'. They reported confusion over efficacy of disease control plans that were put in place (e.g. disinfectant mats etc).

Lack of communication between agencies caused undue distress, long delays in some cases and duplication in others. Everyday rural policing was disrupted – e.g. difficulty of visiting 'infected' farms; officers sometimes not aware of farm FMD status. There were some firearm incidents, mainly police called by concerned neighbours who feared suicidal tendencies. No major incident and those farmers involved willingly co-operated. Concerns were expressed about recruitment practices that disasters like these can create. This was particularly so for animal slaughter and post slaughter, clean up teams. Officers reported concerns that occasionally unnecessary distress was caused to farming households. Incidents ranged from gross incompetence (slaughter team failing to kill 'cleanly') to poor communication skills, to indifference to farming household's loss and suffering (workers, leaving 'litter' etc.) One officer was also a farmer, who stressed that there are 'mental health' issues, particularly for farming women: '*Talk of FMD still triggers an emotional response*'.⁶

Army, Chief of Staff (of a regional Brigade Headquarters) X is responsible for all military units within his region; this includes 3 Regular Battalions and 6 Territorial Battalions. During the FMD epidemic this Brigade covered military operations within Lancashire and Cumbria. X was the 'Regular' Training Officer of a Territorial Army (TA) Infantry Battalion, which was under the operational Command of Brigadier Birtwistle. He became the operations officer for this unit's support to MAFF/Defra. Although the unit operated from within Lancashire, X's description of military operations is generic. Discussion centred on initial delays; backlogs; minimising the effects of culling; and the importance of flexibility in planning.

So diagnosis of an outbreak in a specific area would lead to rings being drawn, locations identified on a large map. However the production of maps relied on one woman with a 'lumi colour'; obviously she could only do so many in a day so immediately, this caused, a day, 2 day delay, waiting for maps to be delivered. This would trigger someone [from Defra] going down to the [diagnosed] farmer to assess the situation. The farmer may already have been informed by phone and from his/her perspective nothing happened for days [the delay between diagnosis and plotting the farm on the map]. Then the valuer part clicks in, farmer chooses a valuer who might not be available for 3 more days. The stock are then valued, then slaughtered, then carcasses 'lifted', so whole process could take a matter of weeks...The over riding intent for us in terms of trauma was to avoid the farmer seeing the animals lying there and nothing happening so by the time the farmer came back, the animals should have gone.

⁶ Interview with three officers from Cumbria Constabulary, November 2003

Military Liaison Officers were appointed to co-ordinate 'on farm' culls. They were from both urban and rural backgrounds although many from Cumbria, came from farming backgrounds, which helped forge positive relations with farmers. Whilst troops are robust, they were tired, and operating in strange circumstances. Also some of the TAs had at that point, very little operational experience. There were concerns about psychological health but:

A sense of humour gets us through, of course not on the farms but within our own space. It's the way soldiers work with things. Also the evening briefings, I was able to judge how tired they were. I mean one occasion I had to brief them about lancing the animals [to release gases]. Normally a soldier would laugh about this but I was greeted with a wall of blank faces, so I know they were getting to the stage where they thought this is getting too much, dirty, unpleasant. There was support if they needed it; also through the command infrastructure there is a natural support system within that. I was concerned about one, we rested him, it was getting to him.

A multi-agency approach is needed, co-coordinated to make the best use of local knowledge, expertise and resources to achieve an element of synergy. Logistical planning e.g. how long particular tasks take, equipment needed, feasibility of carrying out particular tasks in particular settings, etc. Plans need to be in place and regularly revisited, before and during deployment of on the ground operations. Military contingency planning can become a 'red herring'; as very difficult to plan for every conceivable thing that might require the military's support. Flexibility is needed and organisations need to understand what is appropriate as per existing Military Aid to Government departments' guidelines (MAGD). It has been suggested that one lesson learned from the 2001 FMD epidemic is that the military should simply be tasked earlier in future. But effective contingency plans would avoid the need to call in the military in the first place.

DEFRA should have been able to manage for themselves, unless of course, resources allocated routinely were not enough. But we [the Army] didn't bring extra resources; we used the resources already there. We just brought them together. Also as a neutral organisation perhaps, we are more able to suggest ways forward without causing offence.⁷

⁷ Interview with Army Chief of Staff, April 2004.

Appendix 4

Project Newsletter

We produced ten issues of 'The Diarist' between March 2002 and December 2003. It provided space to share news, events, information about useful organisations and project developments. Respondents were invited to make their own contributions or comments on items they thought relevant to the research. An example is reproduced below. Some respondents referred to 'The Diarist' in their diary entries:

I received the Newsletter sent out to the Standing Panel. It was a relief to finally get some information regarding the burial site. It was good to have an explanation on how things work on the site in terms that we can understand.

(Community resident, diary, April 2002)

Key newsletter issues:

March 2002	First Action Group meeting; Radio 4 'Costing the Earth'; Cumbria Rural Women's Complimentary Therapy sessions.
April 2002	Waste management issues at Great Orton (EA); Cumbria Inquiry; Cumbria Rural Women's Network.
May 2002	Counselling service; Cumbria Inquiry; Milburn School project; PM reports (EU FMD inquiry - meeting; Waste management meeting).
July 2002	Cumbria Inquiry; EU inquiry Report; National Audit Office Report; Rising from the Ashes Conference; EQ-5D
Sept 2002	Cumbria Inquiry; EU Report.
Dec 2002	Cultural documents of FMD; Cumbria rural CAB; Rural Regeneration.
March 2003	Archiving; Project closure PM group meetings, Eden Arts school project
May 2003	Watchtree memorial; PM group meetings
Sept 2003	Flagging VoE conference; Arts Exhibition space; Archiving Update
Dec 2003	VoE Conference reports; OSC; Archiving.

The Diarist

May 2002
The Newsletter of the Standing Panel
on Foot and Mouth Disease

Project Six Months Milestone

This is a good moment for us to say **THANK YOU** to all of you for the time and commitment you have put into the project. We are often asked, 'How's it going?' It's hard to sum up in a sentence or two, but I think we all agree that it's going well. Your diaries are giving us a very clear picture of your lives and concerns. As we expected they vary a good deal, in content, in length and how you choose to use them. But the information you have already given us is showing how worthwhile this long-term method of research can be. It's now six months since the first group meeting was held in Penrith. During that time Cathy and Josephine have joined Maggie and Ian on the research team, we've conducted all the individual interviews and you have contributed more than 800 diaries. Based on what you've told us so far, we've submitted evidence to the various inquiries taking place at the moment. Some of you have also been attending inquiry meetings, and we include 2 reports from respondents in this newsletter.

Cumbria Public Inquiry

We have so far covered every day of this inquiry, the four formal sessions at Kendal and the informal evening meetings, which took place-13th -16th May at halls around the county. We have submitted written evidence based on our findings so far and have been asked to present this evidence and answer questions at the formal hearing in Carlisle on the afternoon of 31st May. We'll report back in the next newsletter.

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. We have just heard that the school has won a major art prize for their work. All the year-six class will go to the Tate-Modern art gallery in London where the school will be awarded £2000 to spend on the children. Specially made copies of the children's drawings will now tour art galleries around the country, and the sculptures will be displayed at the Tate Modern. It's good to hear of something so creative and positive coming from last year's hardship. If you are in that area it's well worth the detour to go and see the sheep sculptures on the green.



Action Research...in Action!

We are delighted to report that we have been successful in securing funds for 2 projects, both initiated in response to your requests, information and concerns.

Counselling

After discussions with Voluntary Action Cumbria, the North Cumbria Rural Nurses and the NHS Department of Psychology and Counselling, we made a successful bid to fund 60 free sessions with trained counsellors. These will be available to any individuals who have been affected by FMD and who would like to talk things over with a detached, sympathetic and professional counsellor **in strict confidence**. If you or anyone you know would like to know more about these sessions then please get in touch with us or the North Cumbria Rural Nurses. You can also contact this service direct on 01228 603100, please mention **RURAL ACCESS PROJECT** when you call. This is a stand-alone service; people do not have to go through their GP to access it.

More Waste Management Issues...

Last month a respondent who lives next to a Lakeland Waste Management site where carcasses were buried last year attended a meeting and sends this report to the Diarist:

A liaison meeting was held on April 12th between Lakeland Waste Management and the residents of Newbiggin. Several issues were raised, primarily the smell and the height of the cells. In 1993, when Wimpy had the site, planning permission had been granted for the cells to be higher than ground level. But when asked how much higher the cells are going to be, the answer was that they are still within the Planning Permission but they could not tell us the exact height. There was even a Planning Officer there but he could not answer the question. So that begs the question – how do they know if they *are* still within the permitted height? Planning permission is also being sought for a Gas Generation compound including a gas flare, generator, offices and surrounding fence. The flare is already on the site. The Environment Agency told them which type of flare was required and they had 6 months to apply for planning permission, but the application was not presented. The Development Director said they had run out of time, so they had put the flare in place anyway. Since this is what the environment rules state, it's unlikely that Planning permission would be refused.

But 6 months is more than ample time to apply for permission – it makes you think that they regard it as unnecessary. As to the smell issue, they say that checks are carried out every day on and around the site – but not, I think at 6 o'clock in the morning or late evening when it seems to be at its worst. Monday mornings can be particularly bad, but not the Monday morning after the meeting. That says a lot don't you think? The area manager gave out his phone number at the site so we could ring him direct at the time of the smell and he could investigate immediately. I bet he wishes he hadn't! Over all the people from LWM, the Planning Authority and the Environment Agency did answer most of the questions put to them. But I still get the feeling that they will push the boundaries of the planning permission as far as they can. After all, it is a big money concern. I feel the name of the game is 'Don't tell them too much and try to keep them quiet.' I left with the feeling that I knew very little more than when I went. For them it was a good PR exercise but I still think that they tell you what they want you to know, and I for one don't have much faith in them

Your News -

We know that most of you have been settling back into the normal routines of your work and life. If you have any views, news or photos you would like to share with us we would value your contributions.

Appendix 5 EuroQol

This section of the report examines the use of the EuroQol EQ-5D quality of life (QOL) questionnaire during the project⁸. It presents results from the FMD EQ-5D study, including a comparison study with an earlier (and larger, $n=799$) EQ-5D study carried out in Cumbria in 2000 (commissioned by the former North Cumbria Health Authority Public Health Unit). As discussed in Section 2, the action research philosophy of the project allowed the team to respond to steering group and respondent comments at various points. For a number of reasons, it was decided to discontinue using the EQ-5D and concentrate instead on developing an 'internally valid' tool for comparing and contrasting quantitative and qualitative data within the project. This led on to the development of the Ethnoplots (see Section 4).

As Kind *et al* indicate (1998:736), the EQ-5D questionnaire defines health in terms of five dimensions: mobility, self-care, usual activities (work, study, housework, family or leisure), pain or discomfort, and anxiety or depression. Each dimension is then subdivided into three categories which indicate whether the respondent has no problem, some problem or extreme problem. By combining different levels from each dimension, it is possible for EQ-5D to define a total of 243 health states. Total scores across these dimensions produces a numeric score for health status on which full health has a value of 1 and death has a value of 0 (EuroQol Group, 1998). The questionnaire also records respondents' rating of their own overall health status using a thermometer like scale, marked 0-100.

The EQ-5D was administered to all project respondents in July 2002. Each was given a questionnaire (as part of the monthly diary collection visit) together with a freepost envelope for return to the project office. In order to increase the size of the EQ5D sample itself, respondents were also asked to recruit 'another person' (this could be another family member, friend or work colleague) to complete a questionnaire⁹. In total, 67 questionnaires were returned, a response rate of 62%.

Two phases of analysis were planned: exploratory comparison with the national EQ-5D survey (based on work by Kind *et al.*, 1998), and more formal statistical comparison with a EQ-5D study completed in 1999 by North Cumbria Health Authority (NCHA) in Carlisle. In relation to the NCHA dataset, both the Centre for Health Economics at University of York (who played a significant role in developing EQ-5D) and the EuroQol Group in the Netherlands were consulted regarding the appropriateness of comparing a small purposive sample (Lancaster study $n=67$) with a much larger random sample (NCHA, $n=799$).

Firstly, however, in relation to the national EQ-5D survey, Kind *et al.* (1998) identified that the rates of reported problems increased significantly with age for all dimensions with the exception of anxiety/depression. No similar patterns were identified for the Lancaster data¹⁰, indeed the level of scatter (Table 1) precluded formal statistical analysis.

In relation to the visual analogue scale, Kind *et al.* (1998) found that in general the mean value decreased with age, and decreased significantly for respondents aged over 50 years. Once again,

⁸ In the original bid document, we proposed undertaking 'some simple quantitative analysis based on the structured data from the individual diaries and from administration of the EuroQol 5D tool to each member of the panel at three points during the project.'

⁹ Additional approval from LREC was obtained on 10/07/02 to broaden the purposive sample to include a family member or close friend within the respondent's community.

¹⁰ One respondent recorded a score of -0.7 (a combination score of mobility 2; self-care 2, usual activities 3, pain/discomfort 3 and anxiety/depression 3), which would, according to the EuroQol user guide (1998), indicate that they were 'worse than dead' (see Dolan, 2000 for further discussion of the 'worse than dead scenario' including possible compensatory mechanisms).

no such pattern was identified for the Lancaster data (Table 2). The mean state of health recorded on the visual analogue scale was 78.3, compared with 82.5 for the national EQ-5D survey (Kind *et al.* 1998).

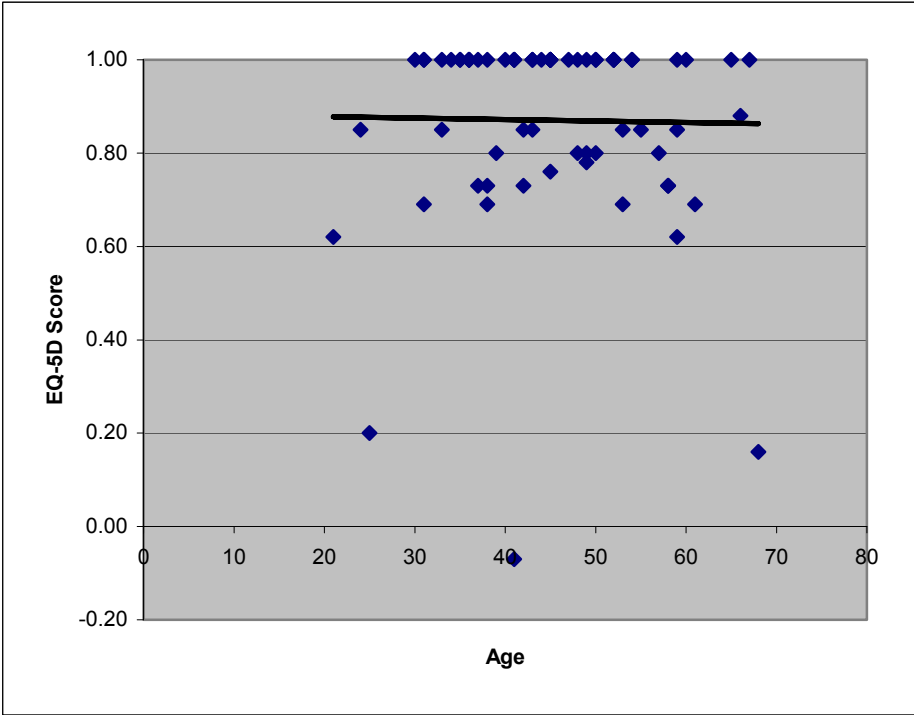


Fig 9 EQ-5D combined score and age data

(trend line shown for illustrative purposes only)

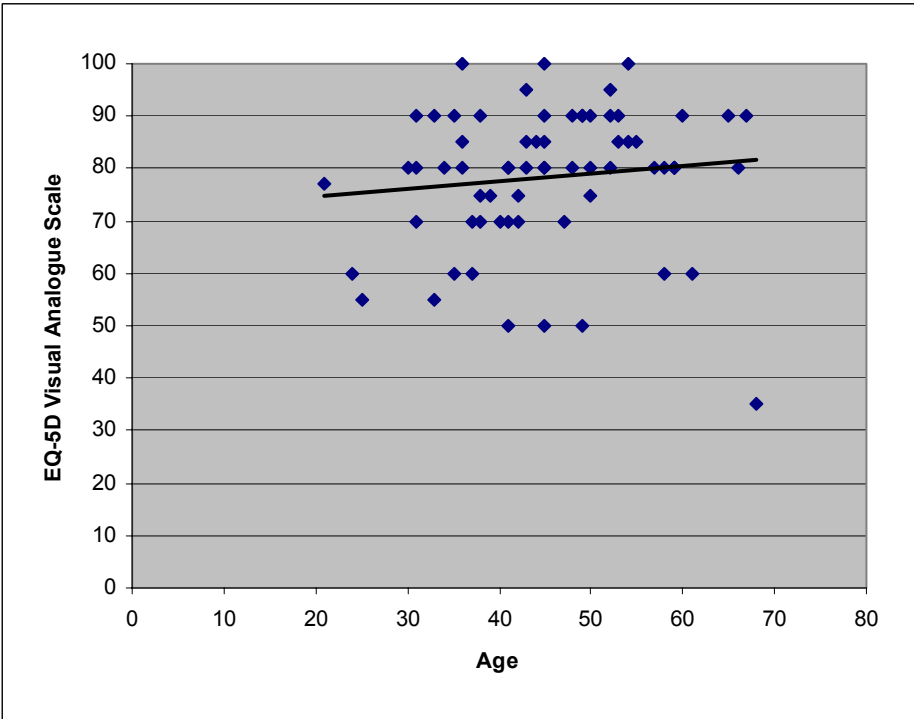


Fig 10 EQ5D visual analogue scale and age data

(trend line shown for illustrative purposes only)

Comparisons between Lancaster study and North Cumbrian study

In 2000, NCHA commissioned CN Research to undertake ‘research into the general public’s perception of health care in their area’ (CN Research, 2000). Around two hundred members of the Cumbrian Citizens Panel were randomly selected and interviewed in four areas of North Cumbria ($n=799$). At an early stage in designing the FMD study, a decision was made to conduct a comparison study between the existing NCHA EQ-5D data and EQ-5D data collected by the Lancaster study. This was to provide a ‘baseline’ to compare pre and post FMD QOL indicators within North Cumbria.

However, this decision proved to be problematic for a number of reasons. Firstly, when an electronic version of the NCHA data was finally obtained, it was apparent that p.4 of the EQ-5D questionnaire had not been recorded. This section of the questionnaire contains questions concerning respondent age, sex, smoking behaviour, education, economic position and location. The absence of this information meant that as it was not possible to be certain that any differences suggested by data analysis were not linked in some way to these confounding variables. For example, Dolan (2000:20) states that ‘when valuations for all EQ-5D health states are calculated, older respondents have estimated values that are lower than those of younger respondents’. Kind *et al.* (1998) also indicate differences in the perception of health according to respondent’s age, social class, housing tenure, economic position and smoking behaviour. In addition, ‘women aged over 70 tended to report higher rates of problems than did men of the same age.’

Findings of the comparison study are thus conjectural. Nevertheless, limited statistical analysis was carried out on these data and the results are discussed below. As these data were unmatched (and also given the issue of potentially confounding variables outlined earlier), statistical analysis was restricted to the non-parametric Mann Whitney-*U* test.

Table 3 presents the EQ-5D combined score data for Lancaster study and the NCHA study. No statistically significant relationship was identified. Table 4 indicates results of the comparisons between the Lancaster data and the NCHA data in relation to perceptions of their overall health. This was based on the EQ-5D visual analogue scale (0 denoting the worst imaginable health state and 100 the best imaginable health state). A slight statistical significance was identified ($P=0.10$), with the Lancaster group recording a higher score on the visual analogue scale (mean score for Lancaster 78.3, NCHA 74.8).

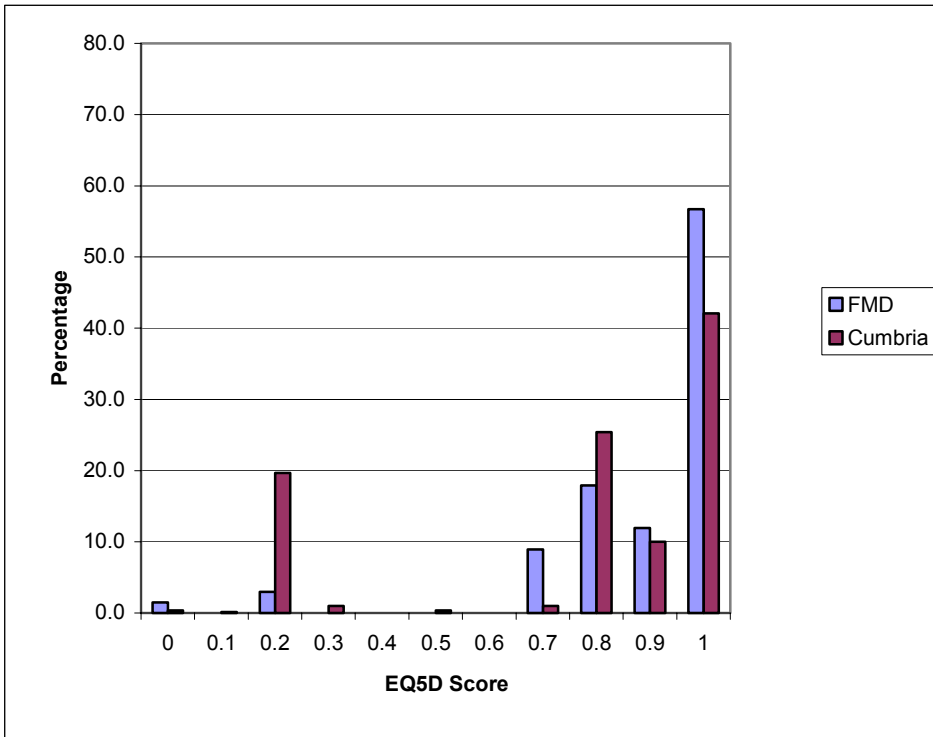


Fig 11
EQ5D Combined score data for Lancaster study and NCHA

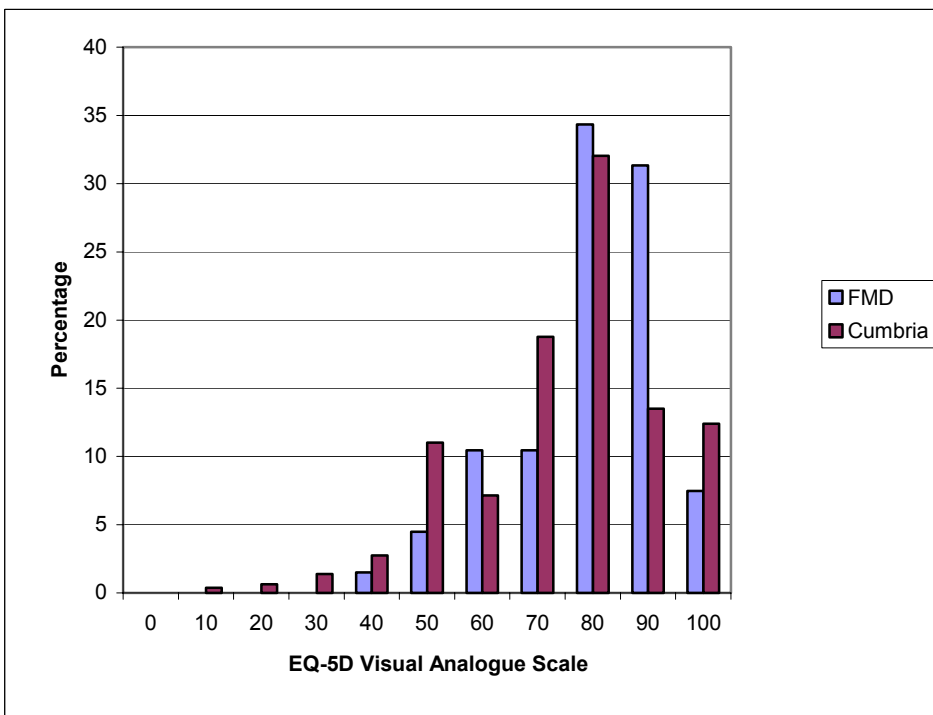


Fig 12
Comparison of EQ5D combined score data for Lancaster study and NCHA

Reflections on using EQ-5D

The absence of sections of the NCHA EQ-5D data, together with a very negative response from respondents towards the EQ-5D (as indicated below), led to further discussions with the project steering group (over a number of meetings¹¹) in which it was decided to cancel the second administration of EQ-5D and focus instead on developing a data analysis technique that would combine the structured and unstructured sections of the diary, thus providing 'internal project validity'. (the Ethnoplots).

Below are extracts from researcher fieldnotes. Most were entries between August and September 2002 and capture conversations researchers had with respondents as they delivered or collected EuroQol forms.

K filled in EQ form during my visit and I left a form for R. She was confused by the 'health state' scale (thermometer):

It's confusing this black box. Do you draw the line from that or directly in the scale?
(Field notes, 13th August 2002)

J and M had filled in the EQ forms. M handed them to me saying:

... it's the sort of questions you'd ask the elderly isn't it?
(Field notes, 14th August 2002)

A filled in EQ form during my visit and took one for a friend. He said:

Are you recruiting for an old people's home?
(Field notes, 14th August 2002)

I handed D the form. He scanned it and laughed out right. When I quizzed him he said,

The questions, they're very vague aren't they!
(Field notes 13th August 2002)

P filled in EQ form and asked if he could have one for his friend. He found some of the terms confusing:

My definition of anxiety is probably very different to someone else's
(Field notes 19th August 2002)

Handed B 2 EQ forms and we sat and discussed the questions as she requested. B felt that the 'health state' scale is rather arbitrary, suggesting that one person 'full of cold' might score 'very low' but equally, another who had just suffered a bereavement, might have the same score. She wanted to know how we were going to make sense of such individual interpretations.

(Field notes 27th August 2002)

¹¹ For example, '...members of the research team reported problems respondents had in fully understanding the question being asked on the EQ-5D questionnaire' (minutes of Advisory Group meeting, November 2002).

Appendix 6 Development of Ethnoplots

The Development of 'Ethnoplots'

Way of representing **structured & unstructured** parts of the diary

The first few pages of the diary contain five questions about the respondents **self reported health, quality of life, etc.**

We wanted to compare these questions with diary narratives

Represent **longitudinal nature of dataset** (18 months of diaries – 72 diaries per respondent)

Some Initial Questions
We would like to ask you some questions about how you have been feeling over the last week, your health, quality of life and relationships. From the following questions please choose the option that best applies to you. You can make some additional comments in relation to these questions, or discuss them in more detail in your diary entries.

1. How confident do you feel about the future this week?

2. How has your relationship with family and friends been this week?

Very poor Poor average Good Very good
Comments:

3. How has your relationship with work colleagues been this week?

Very poor Poor average Good Very good
Comments:

4. How do you rate your overall health during this week?

Very poor Poor average Good Very good
Comments:

5. How do you rate your overall quality of life during this week?

Very poor Poor average Good Very good
Comments:

For example, here is a completed diary from May 2003

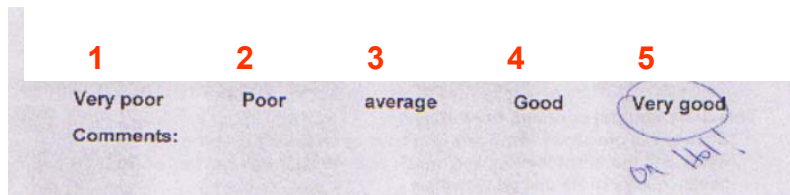
Relationships with work colleagues have been very good as I've been on holiday...

3. How has your relationship with work colleagues been this week?

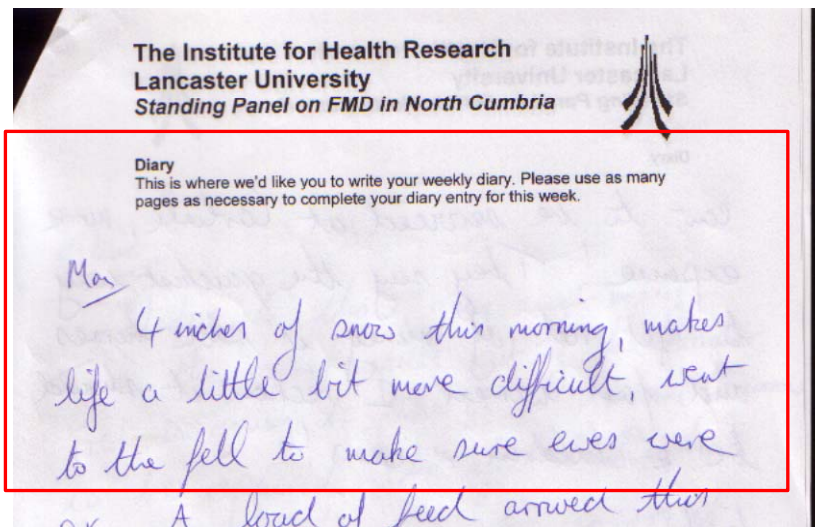
Very poor Poor average Good Very good
Comments:

on holiday

Numbers are assigned to these responses...



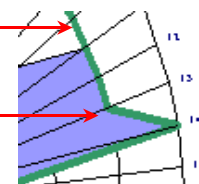
Unstructured section of diary...



Respondents responses to questions of:

self-reported health

quality of life (QOL)



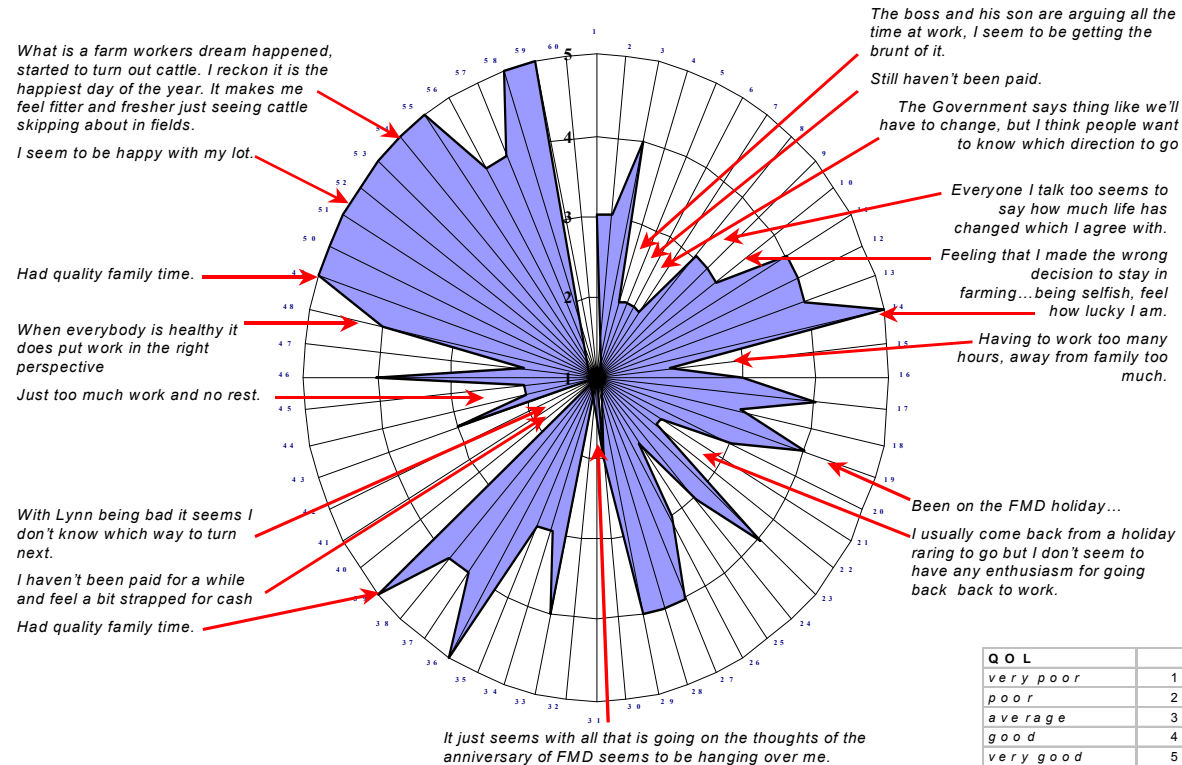
Unstructured diary entries are plotted alongside structured entries from the same week

With Marjorie being bad it seems I don't know which way to turn next.

The numbers around the outside of the plot represent completed diaries and have been plotted chronologically Dec 2001 – May 2003

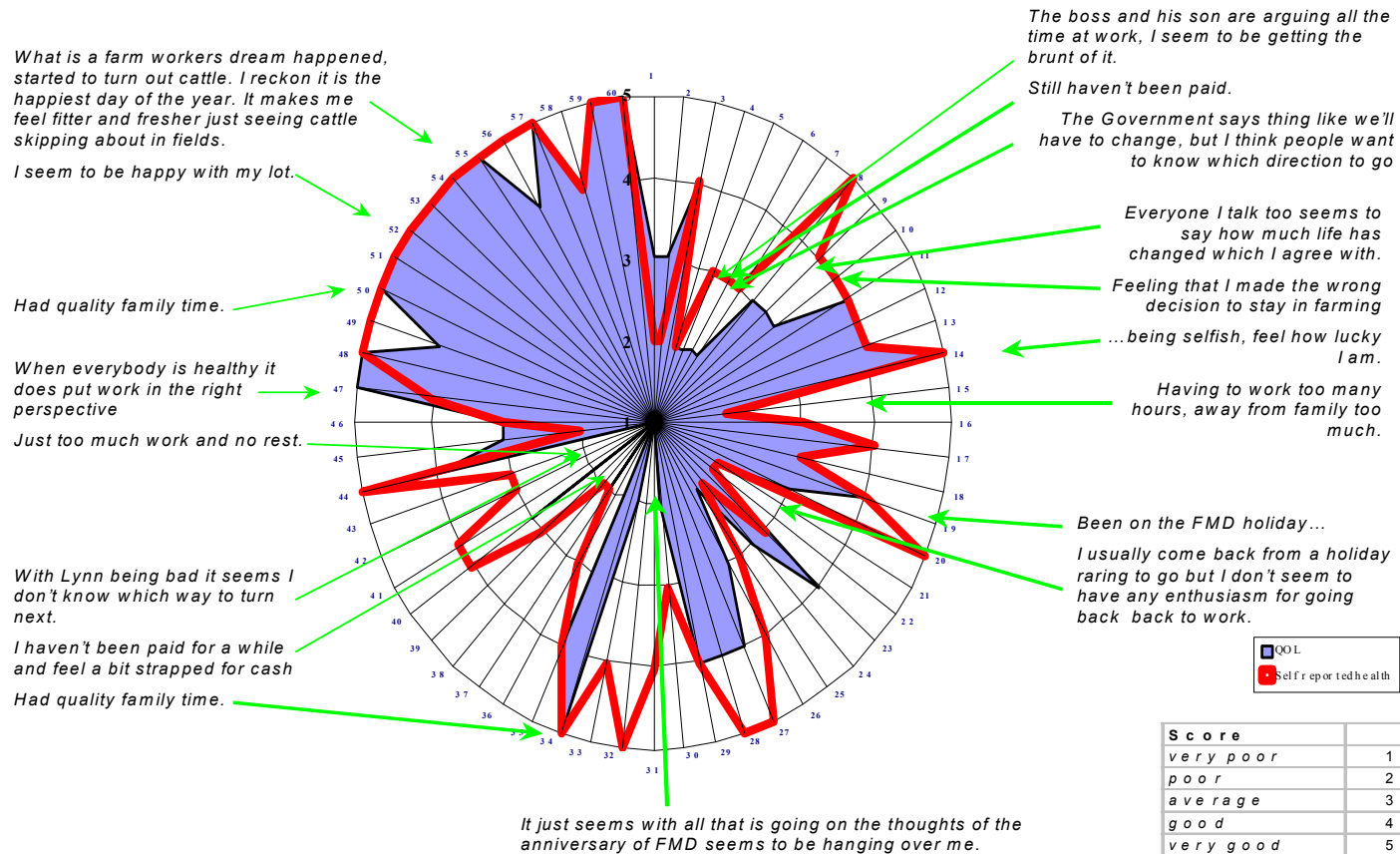


Farming group



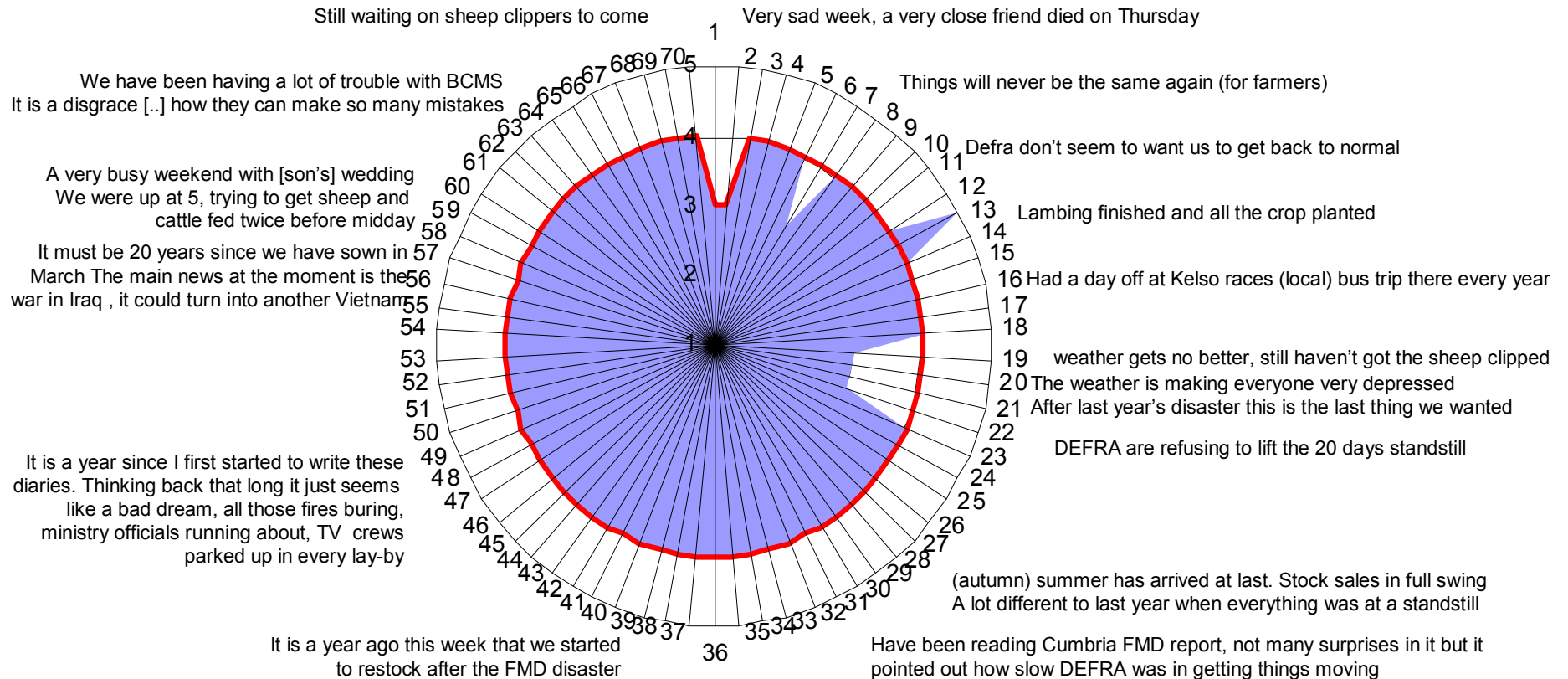
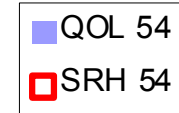
'Ethnoplots' Respondent responses to a **quality of life** question in the structured section of the diary are plotted alongside unstructured diary entries from the same week (the numbers around the outside of the plot represent completed diaries, and have been plotted chronologically from December 2001 to May 2003).

Farming group

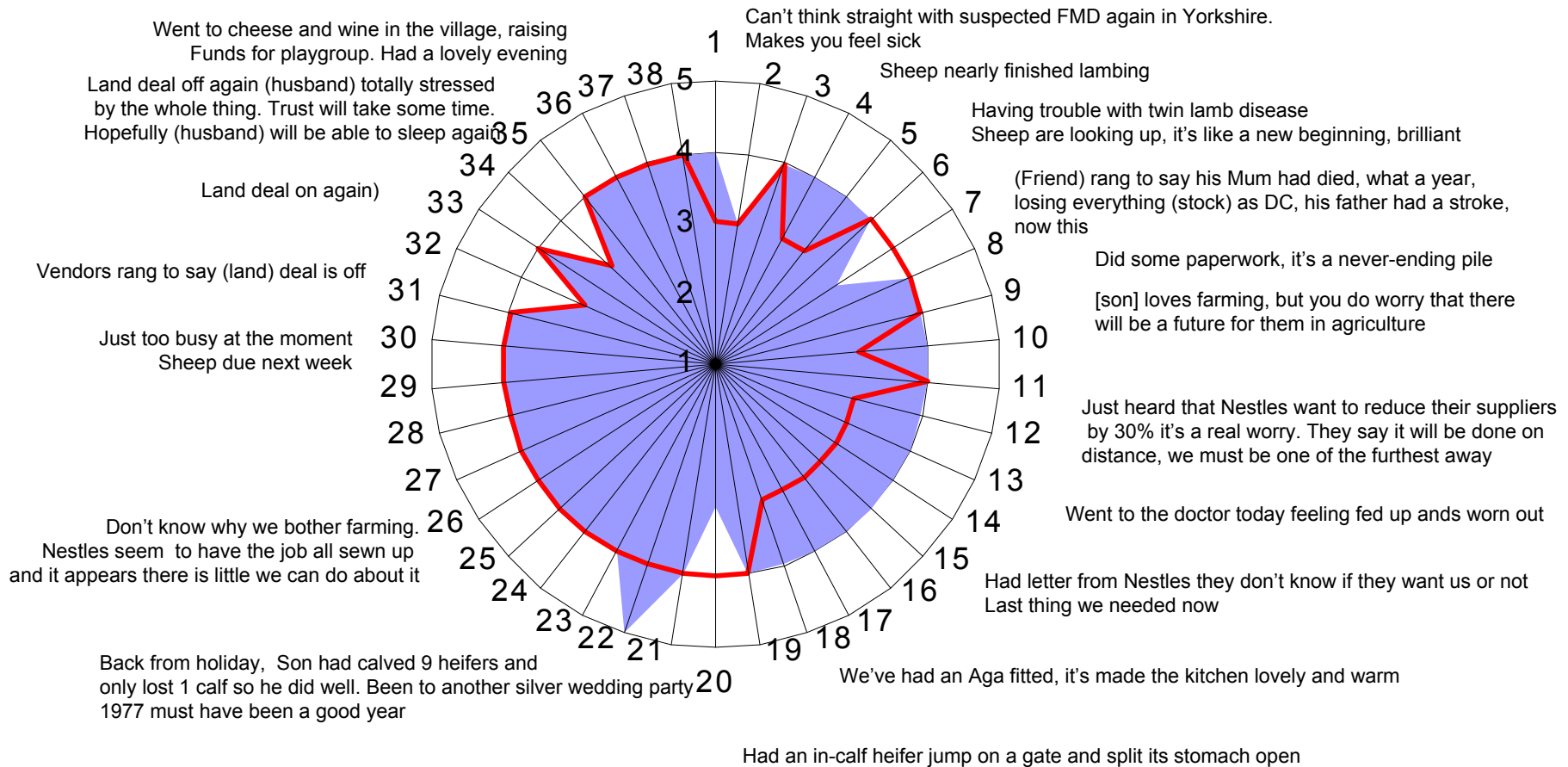
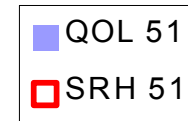


'Ethnoplots' - responses to a **quality of life & self reported health** question in the structured section of the project diary plotted alongside free-text diary entries from the same week (the numbers around the outside of the plot represent completed diaries, plotted chronologically from December 2001 to May 2003).

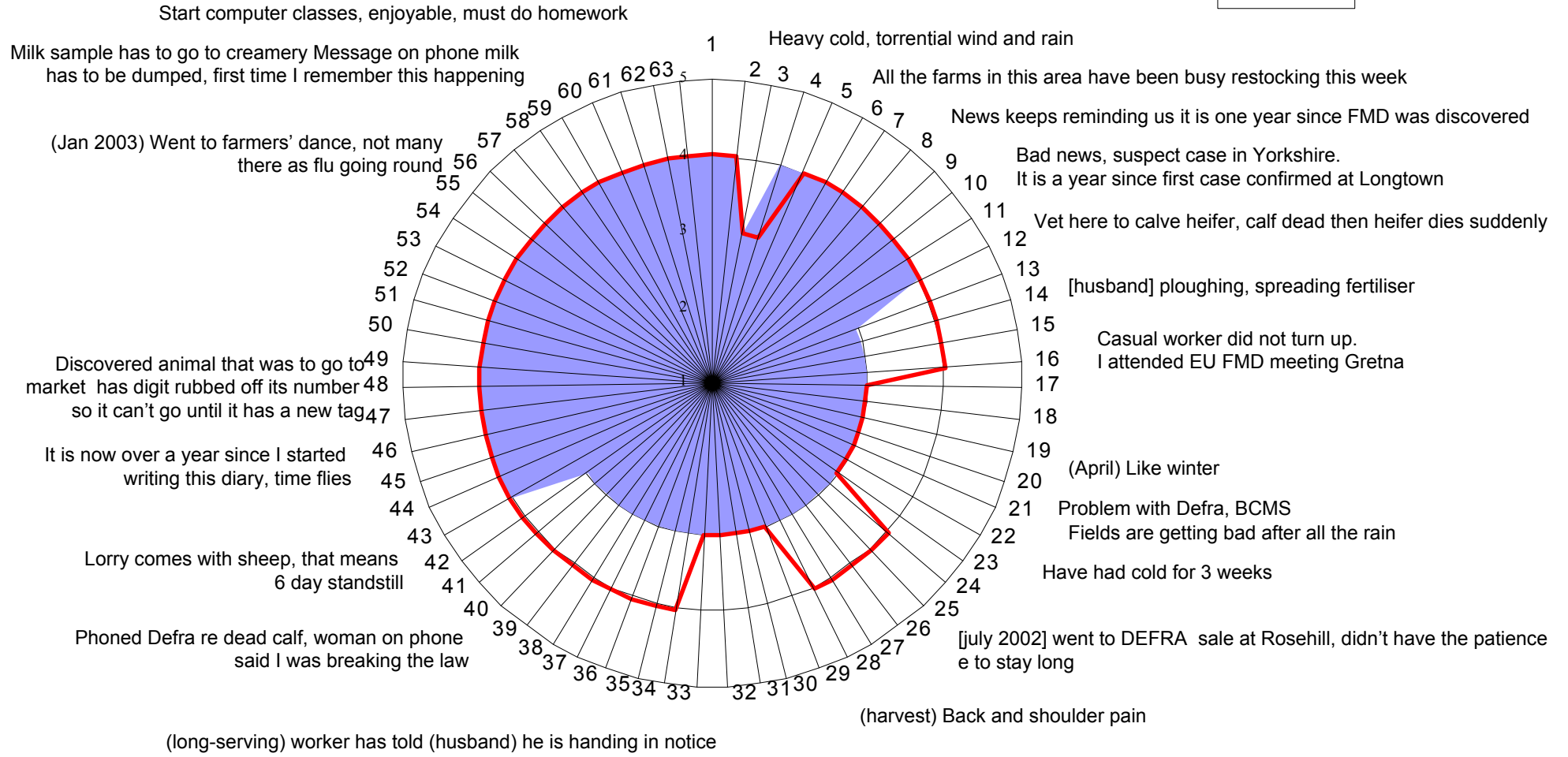
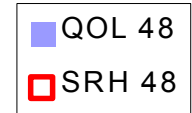
Farming group



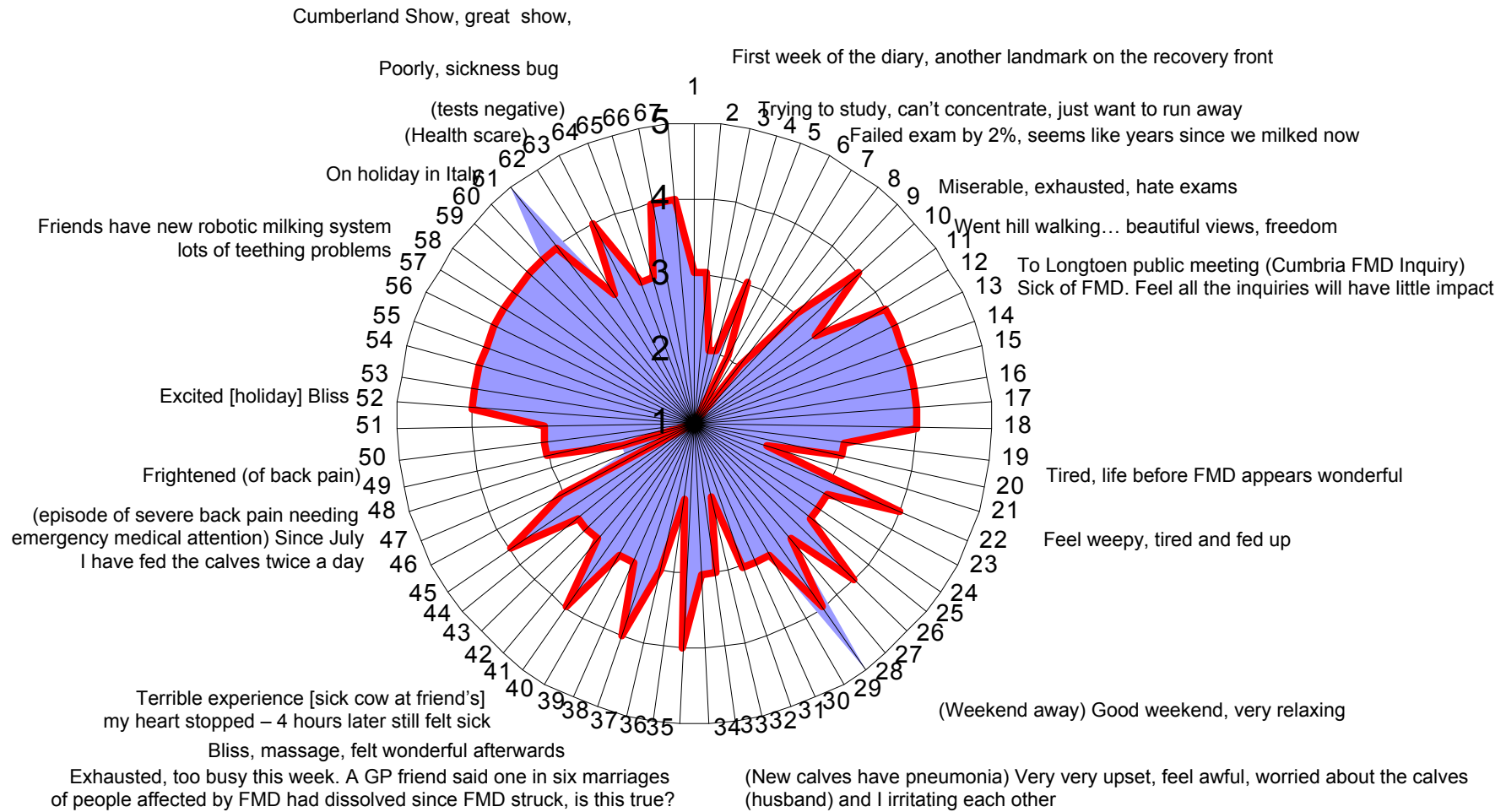
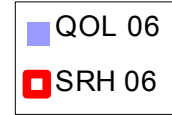
Farming group



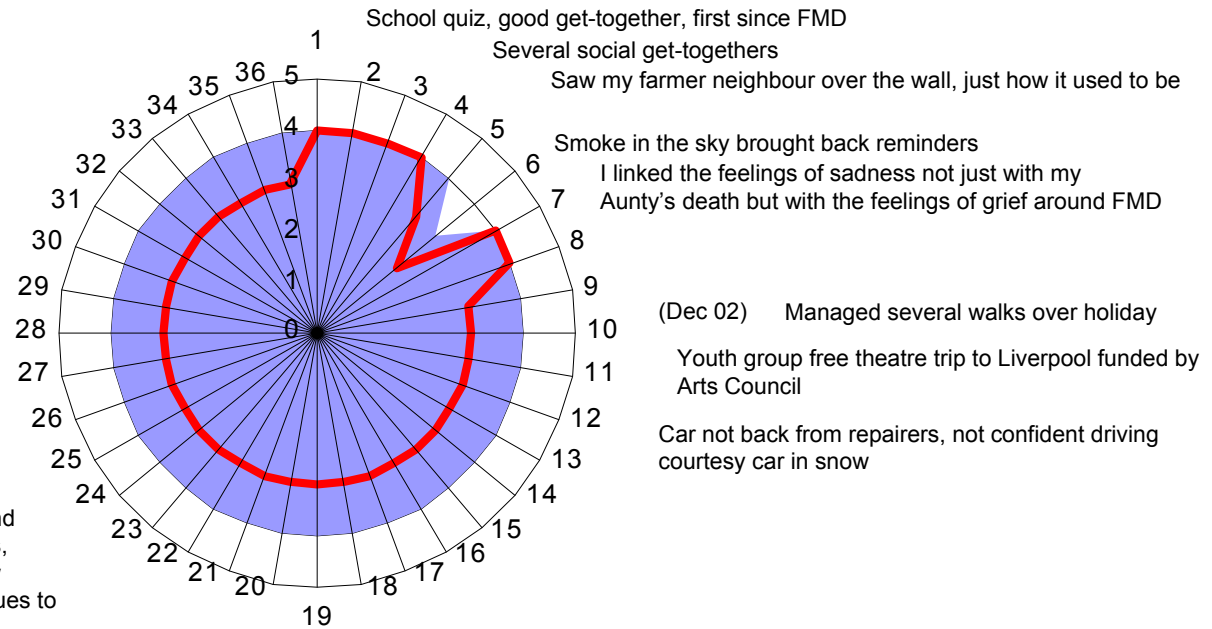
Farming group



Health and veterinary group

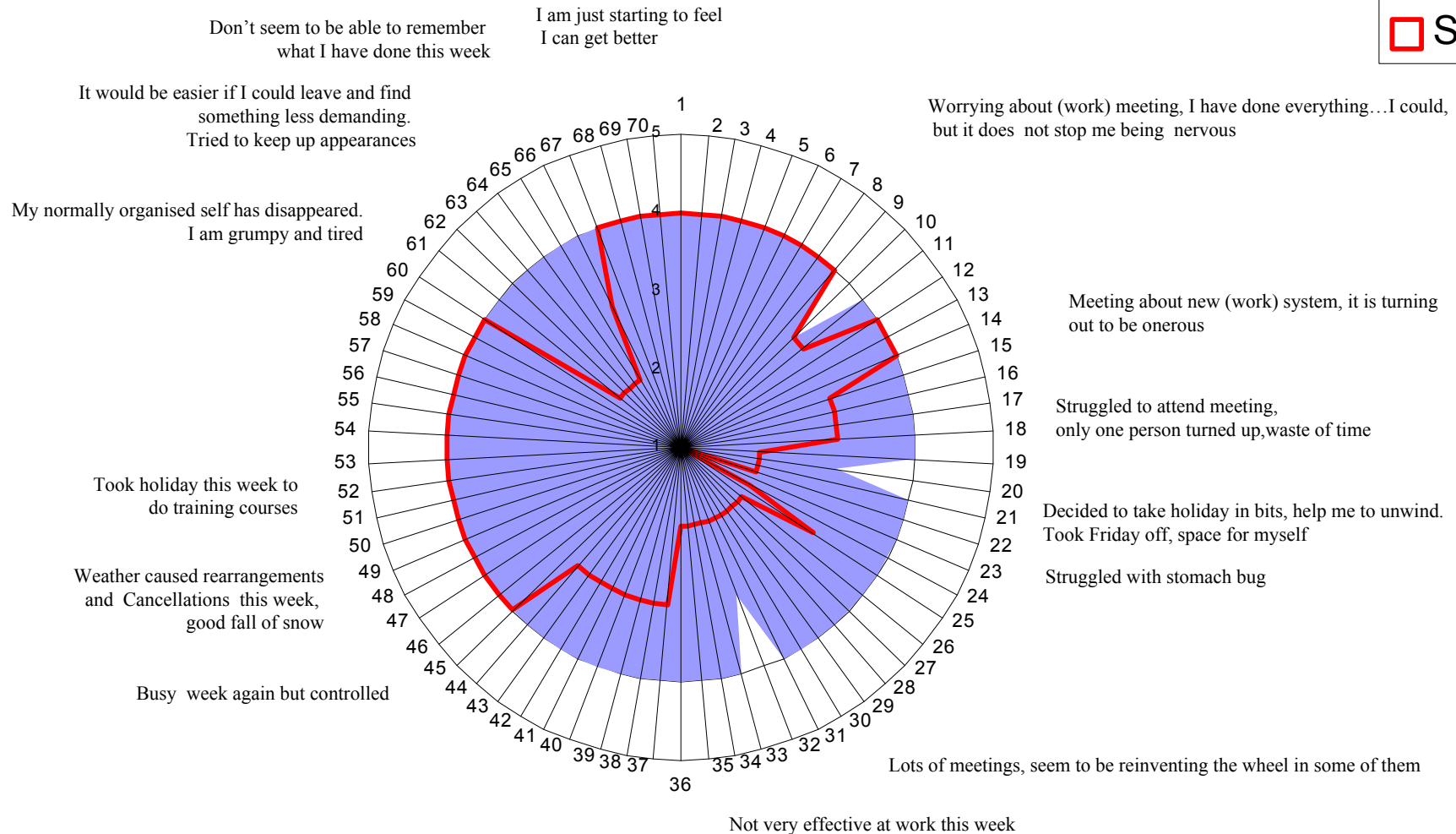
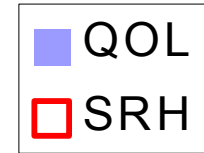


Health and veterinary group

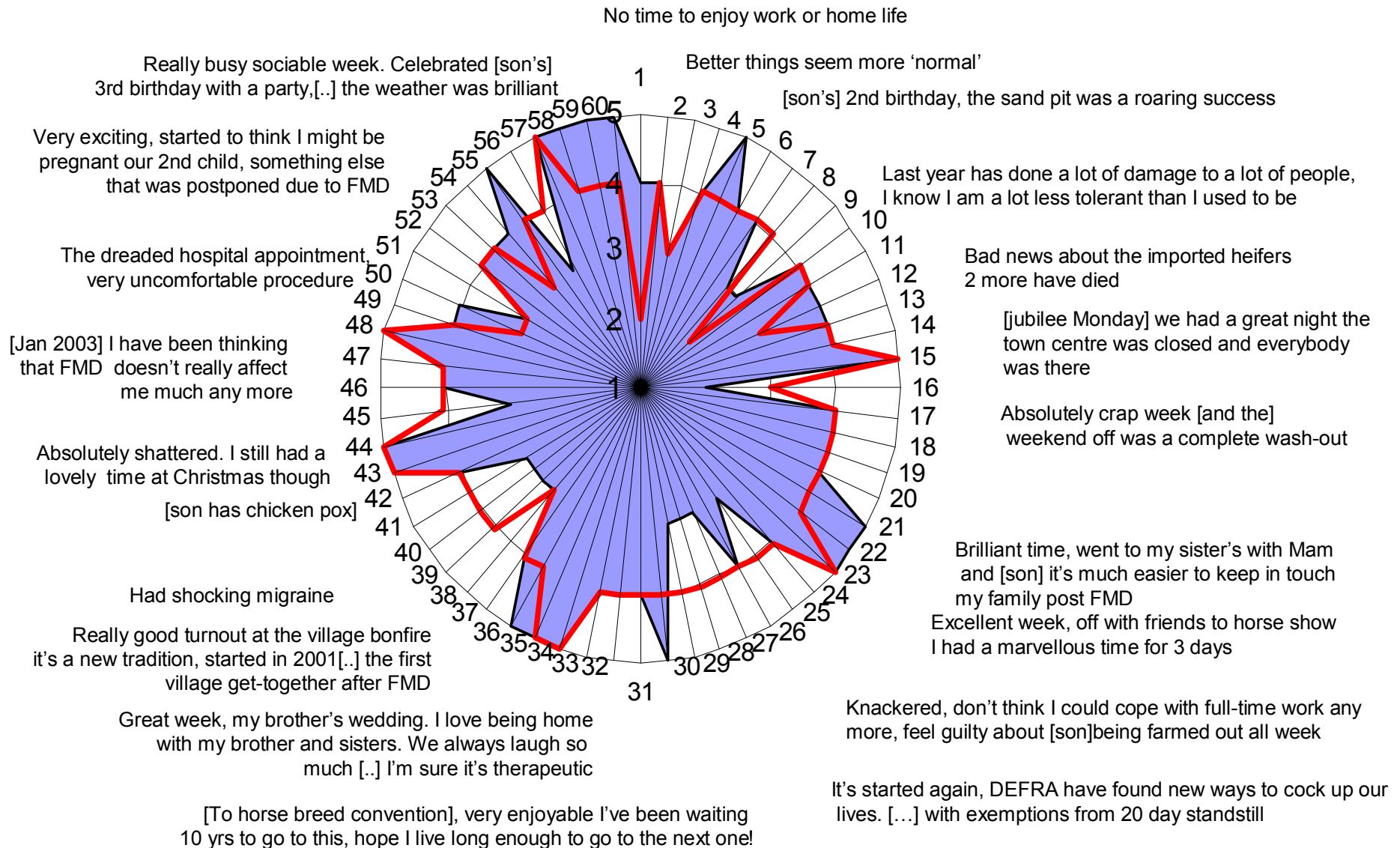
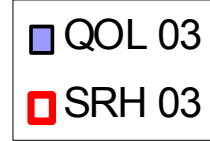


During the rest of the year, respondent details her busy work schedule, the problems of rural practice, and her family's increasing independence, which enables her and her husband to take time off together. Apart from her tiredness, and frustration with building work, she makes few specific references to her own health. She continues to play an active and supportive role in community events and activities

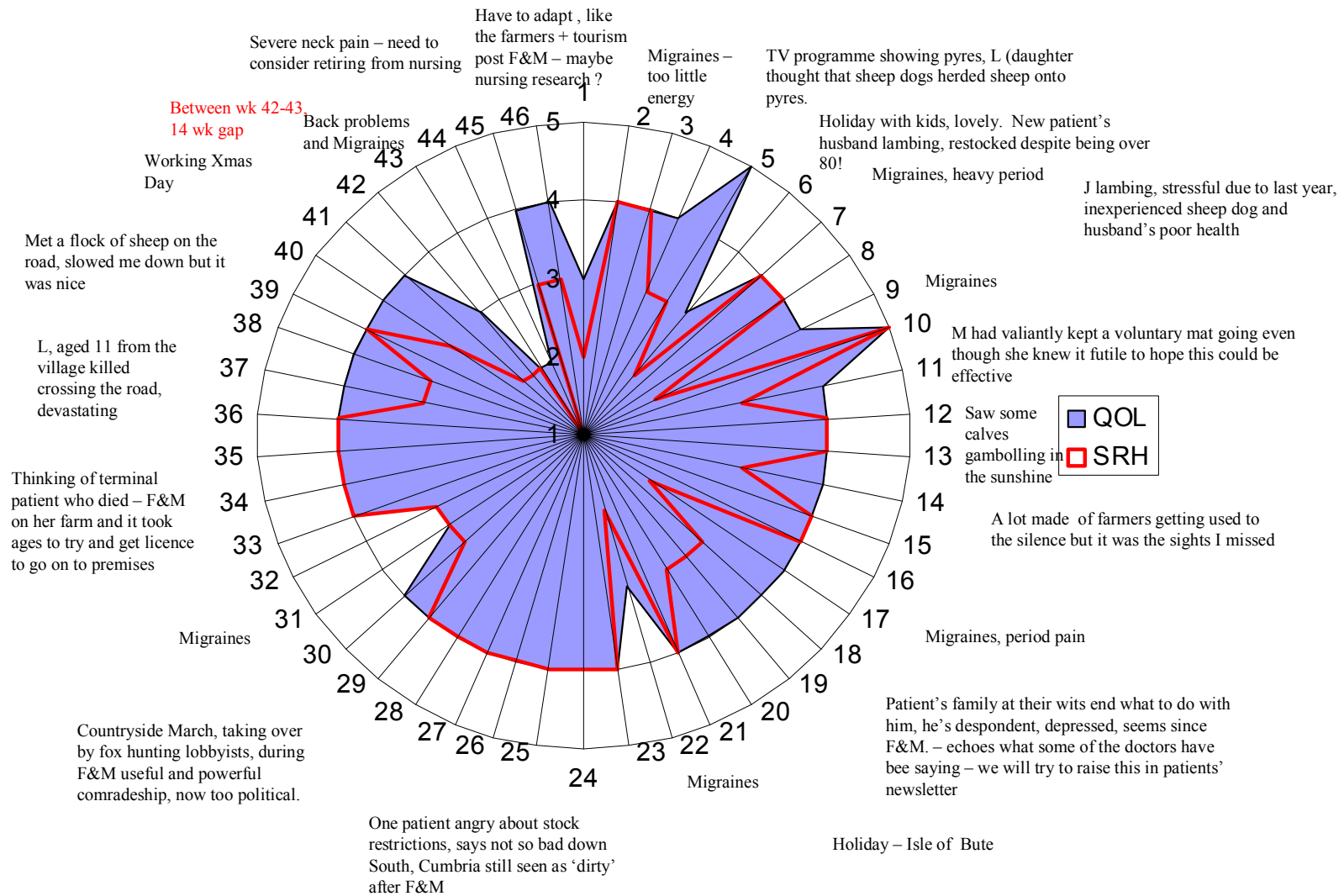
Health and veterinary group



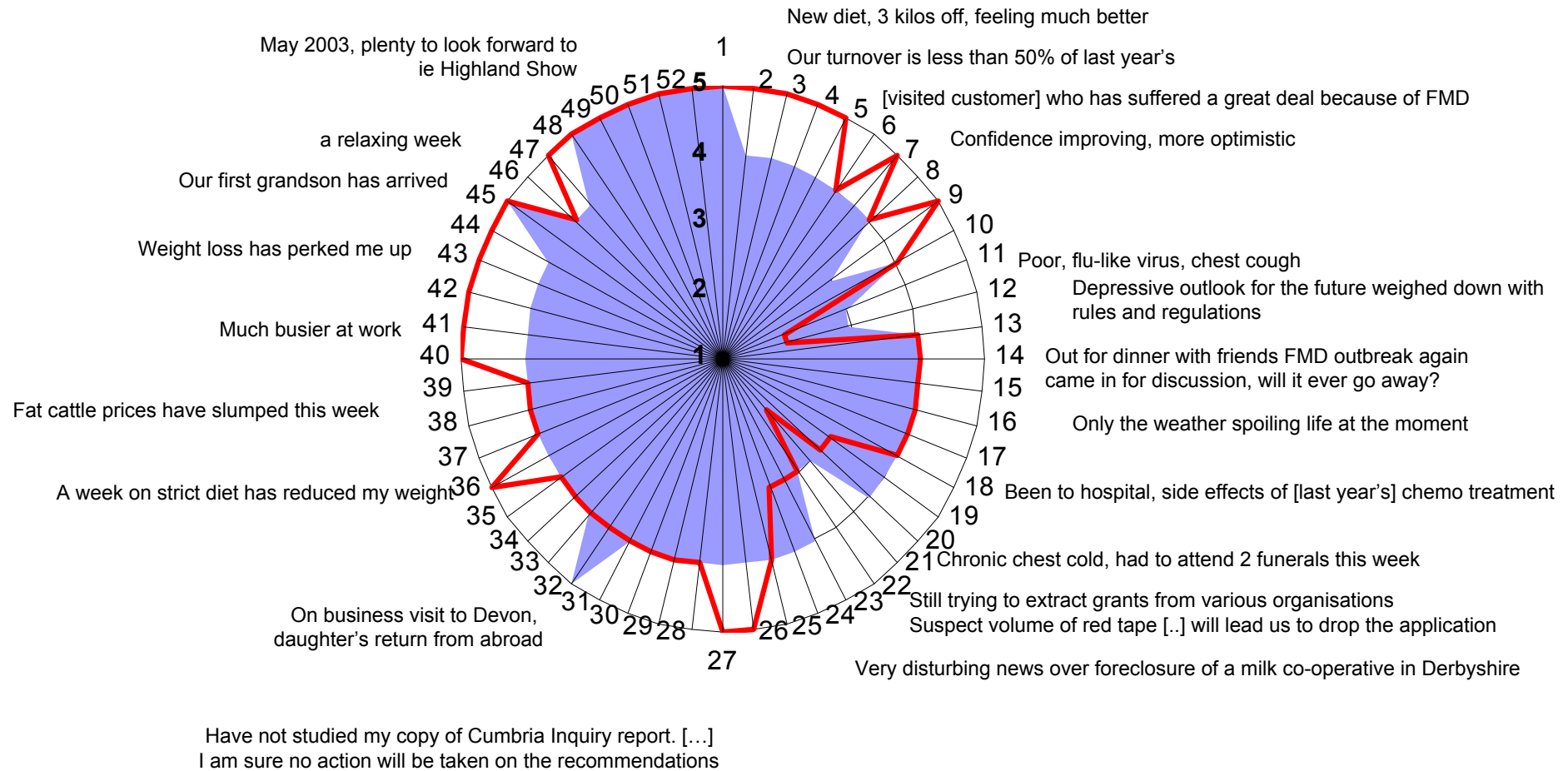
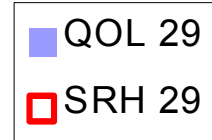
Health veterinary group



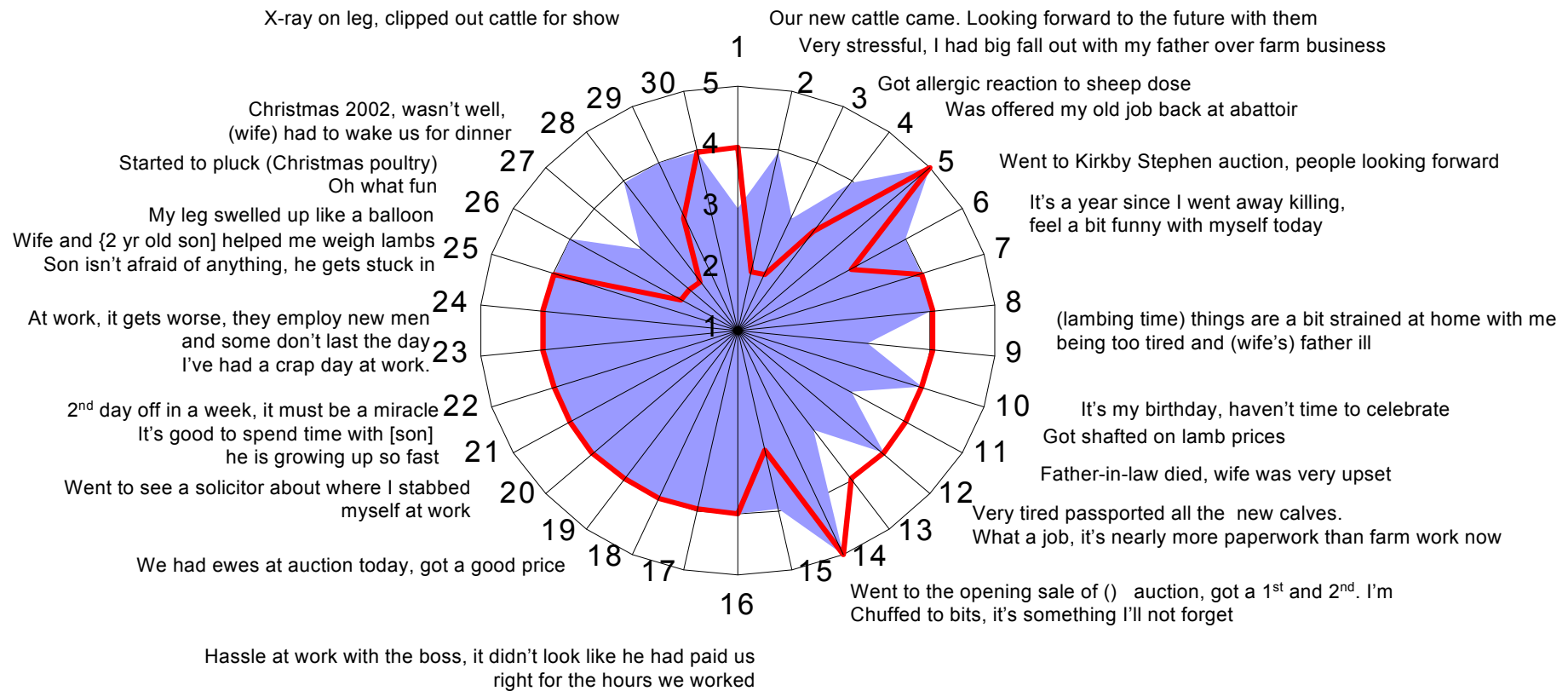
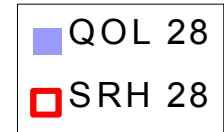
Health and veterinary group



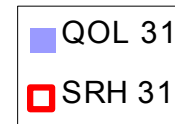
Agriculture-related group



Agriculture related group



Agriculture related group



3 inspectors from RPA, BCMS came.
 Put all cattle through crush to read ear tags
 I wish they would communicate with vet officers.
 The job could have been done the same day as TB testing

1 Got heavy cold

More like we are back to normal

Spent Monday morning reading TB results

7 (restocked), cows settling in nicely, first one calved

Booked a week's holiday off work as
 I will need 2 days off for TB testing

(employers hold) on-farm machinery sale, good crowd of buyers

Had a show and sale of charolais cattle
 I had put a lot of effort into getting cattle
 into the market and was glad to see
 an excellent show of them

11 (cull) anniversary weekend, a couple of sleepless nights
 as memories came back

Better now previous week is over

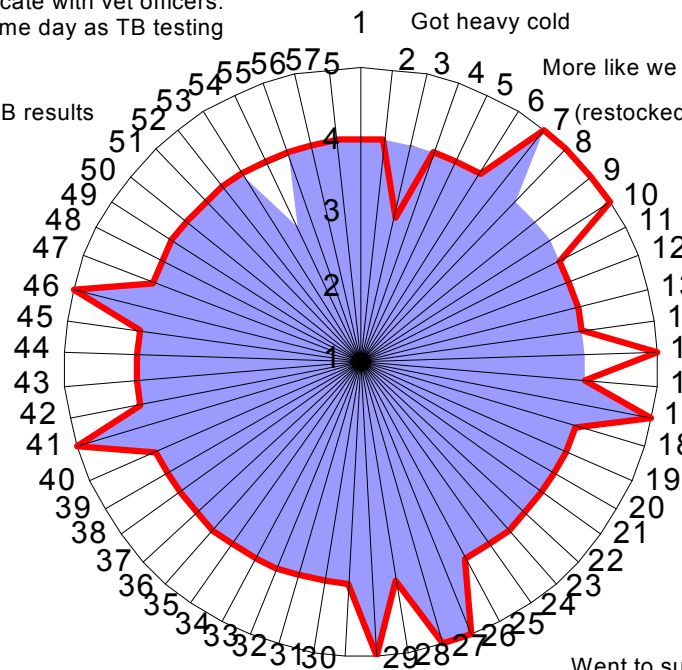
First sale of breeding ewes (at auction)
 Decided hay was fit to bale

17 Attended a wedding, what a lovely day

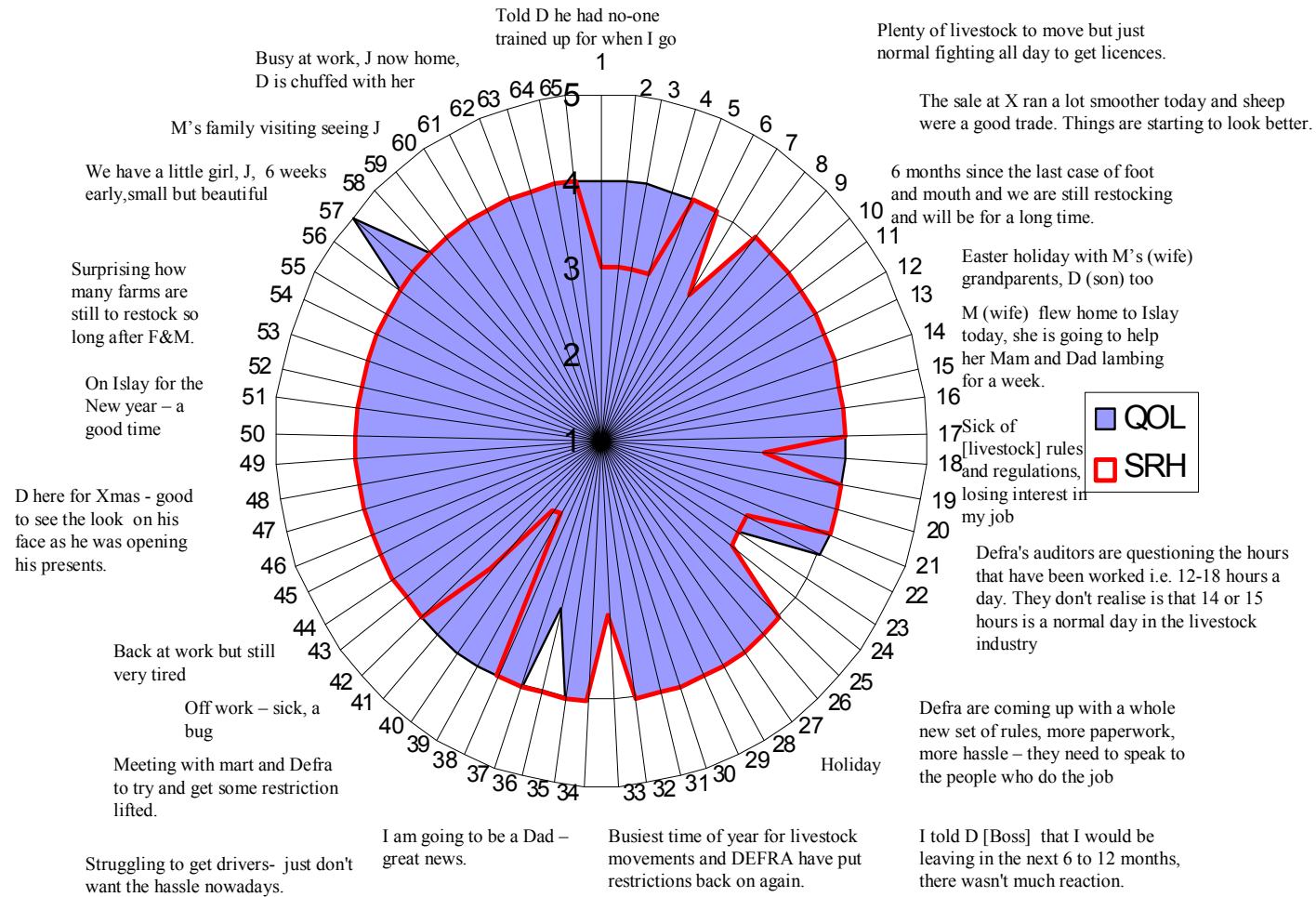
23 Went to support village activities for Jubilee

Return of vet to check TB results

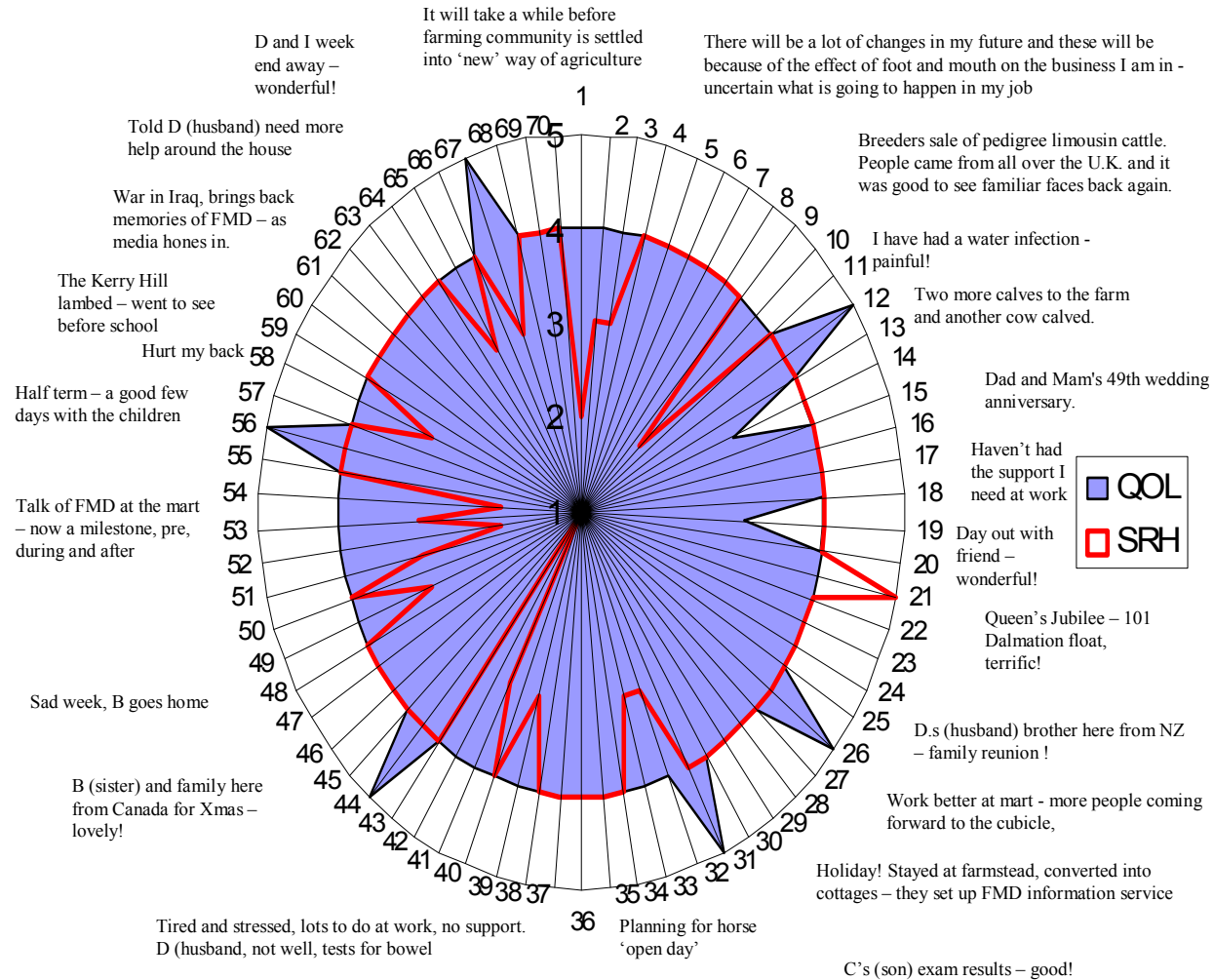
Sick of weather



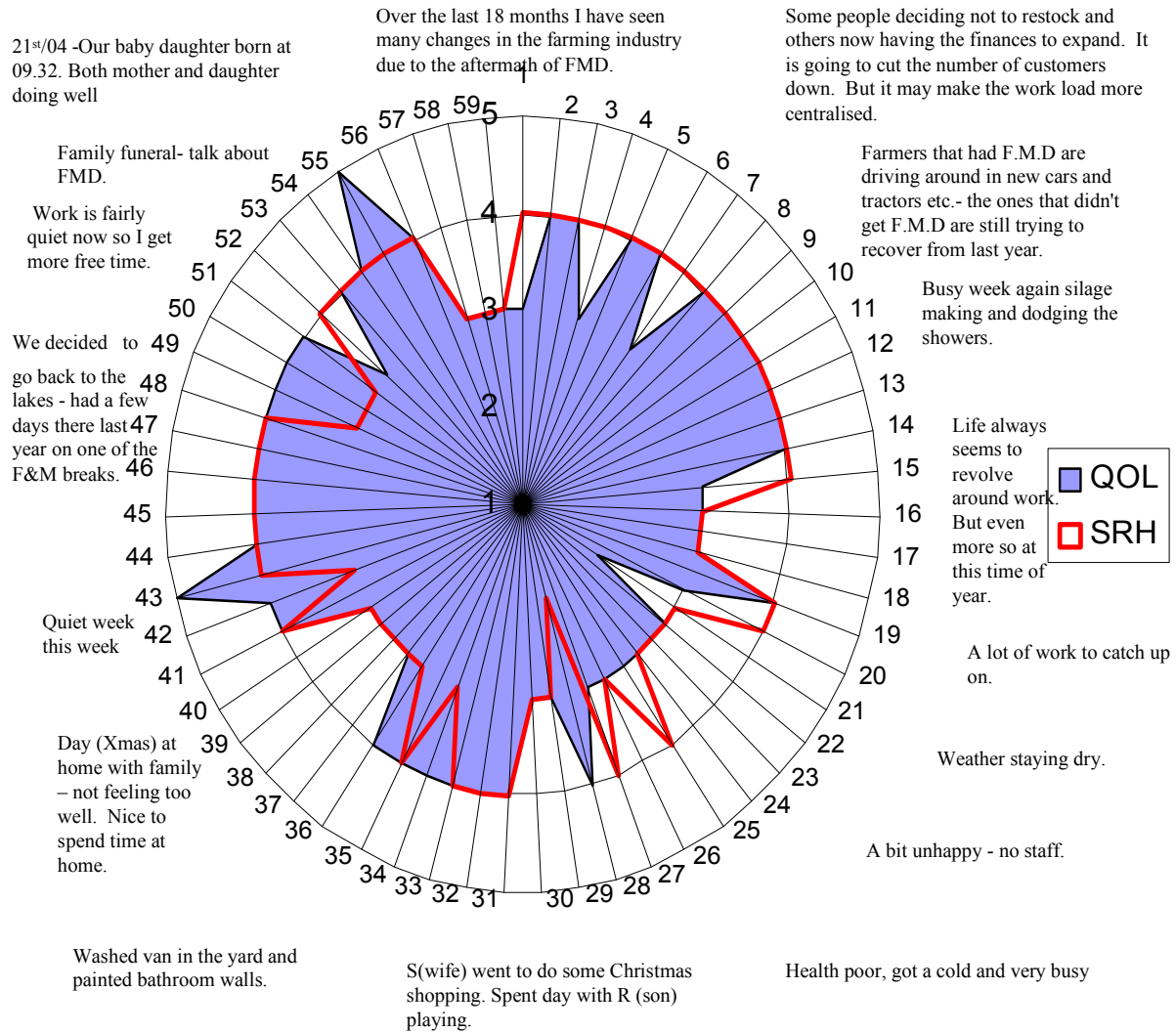
Agriculture-related group



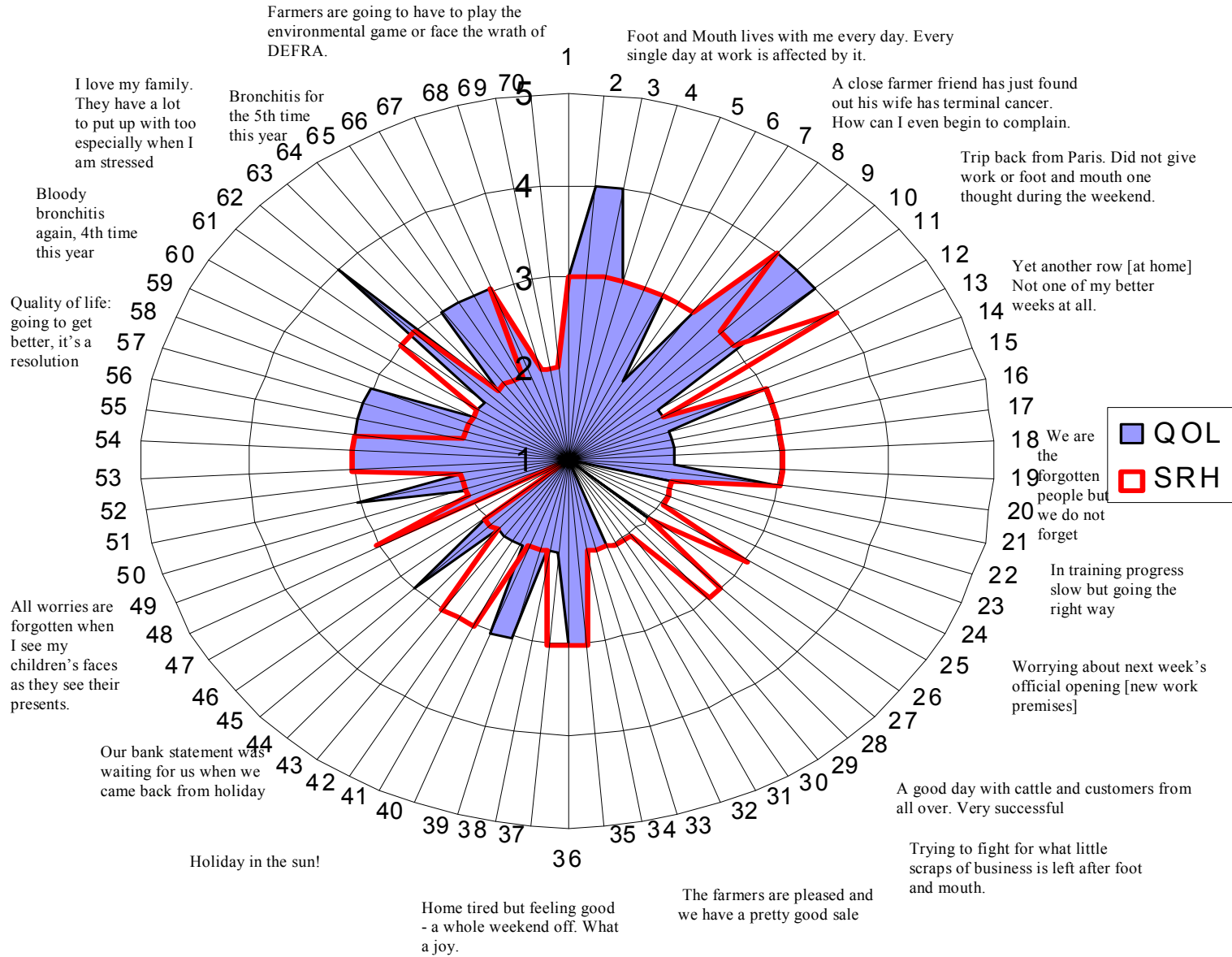
Agriculture-related group



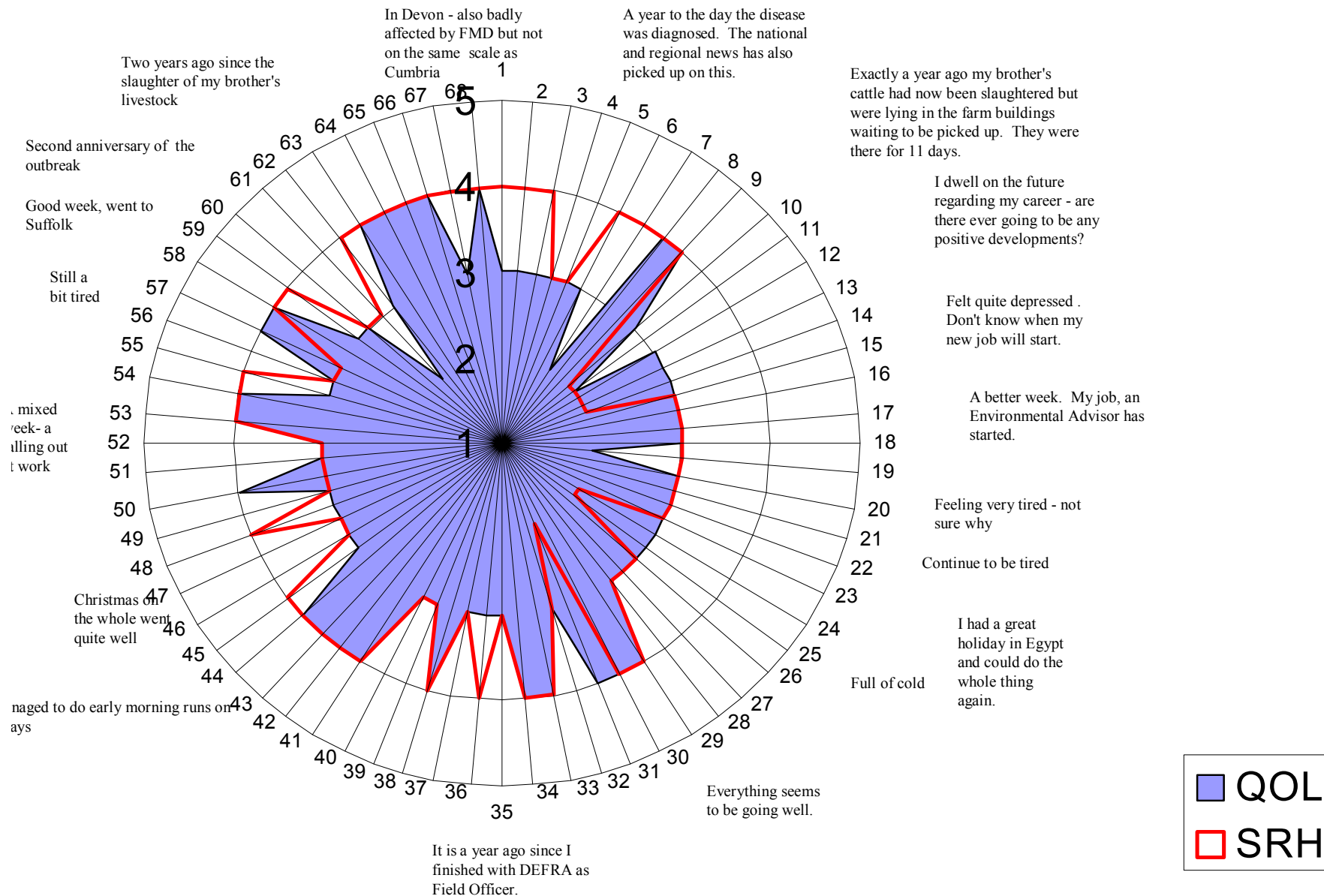
Agriculture-related group



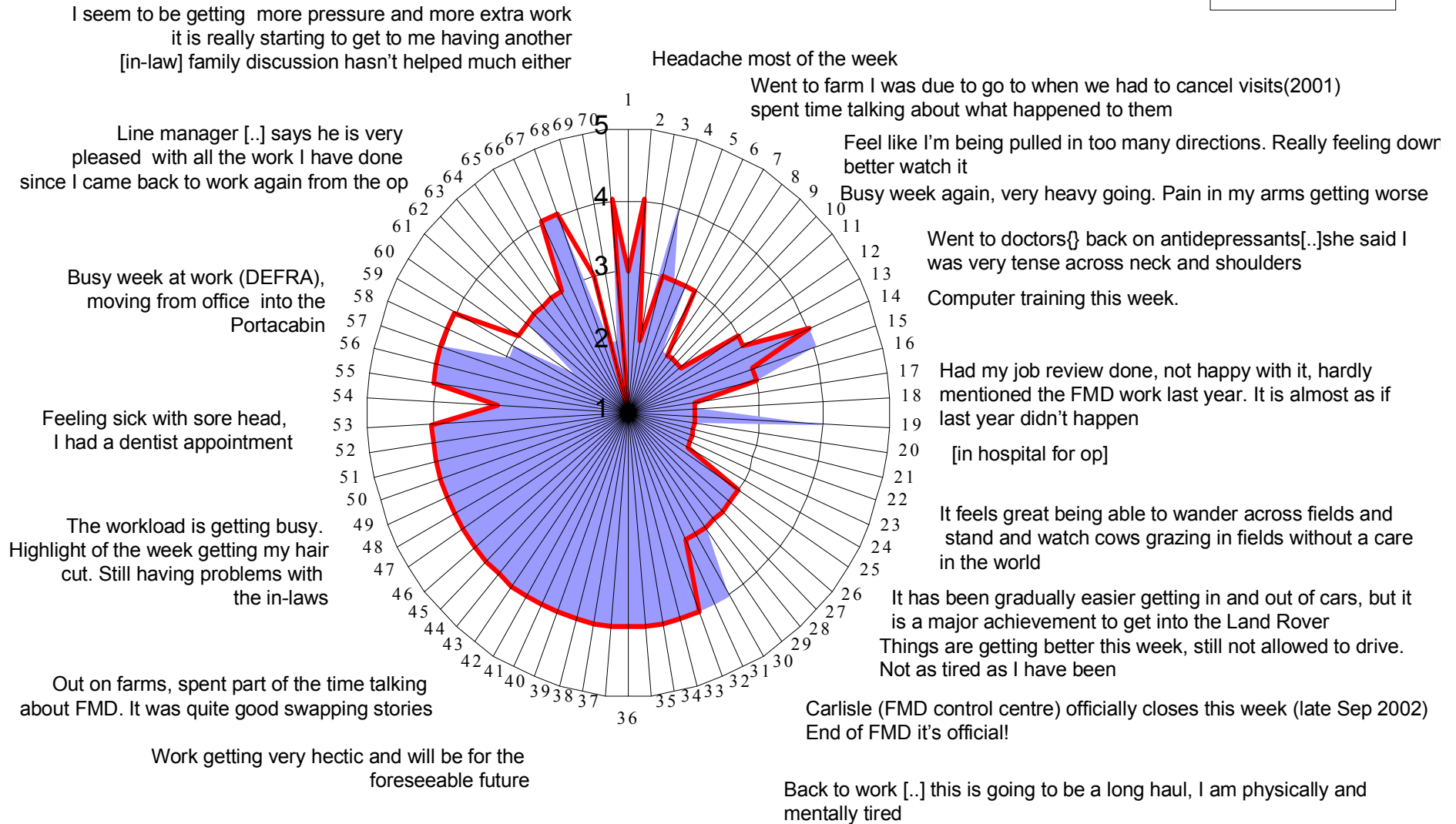
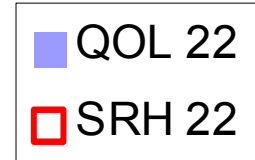
Agriculture-related group



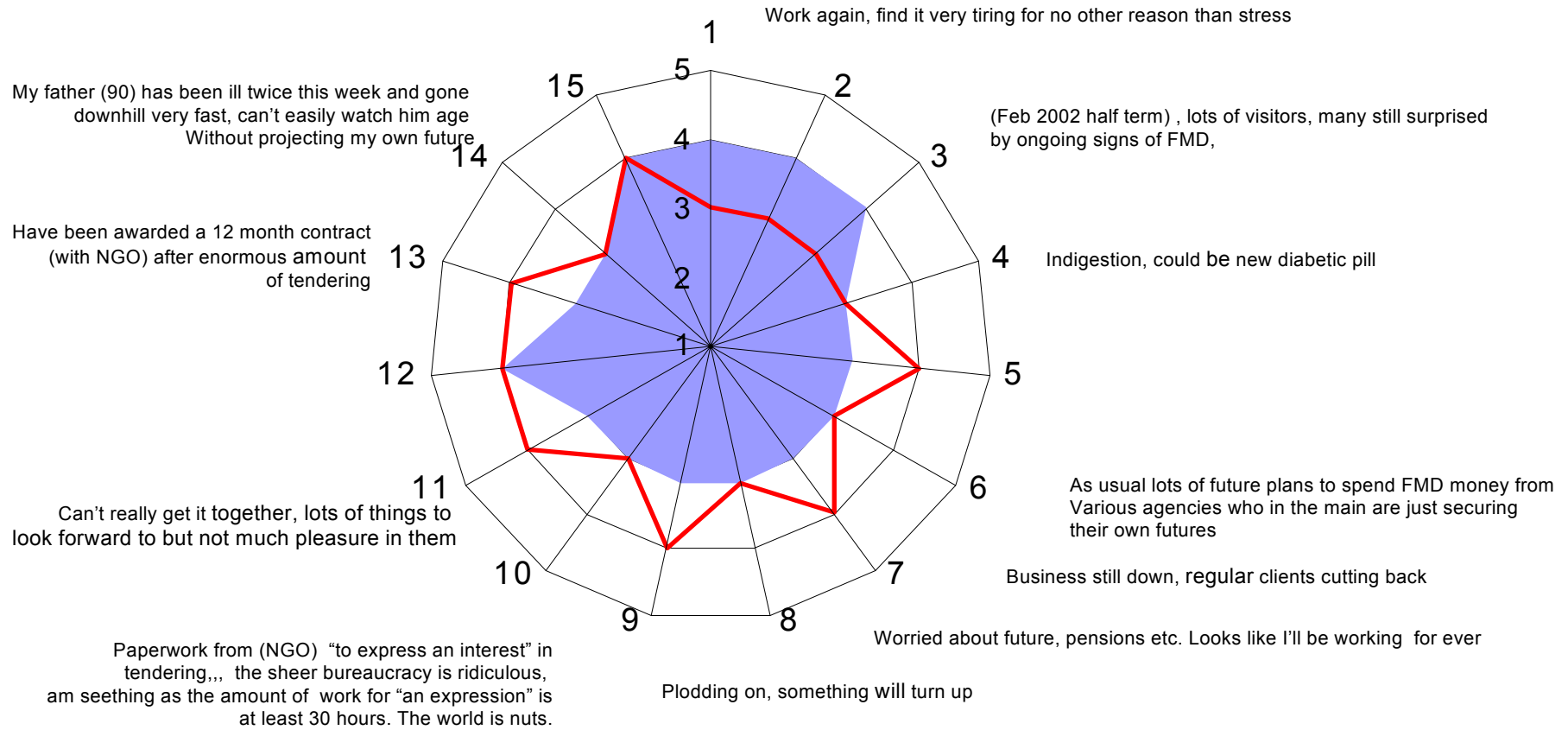
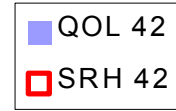
Front line group



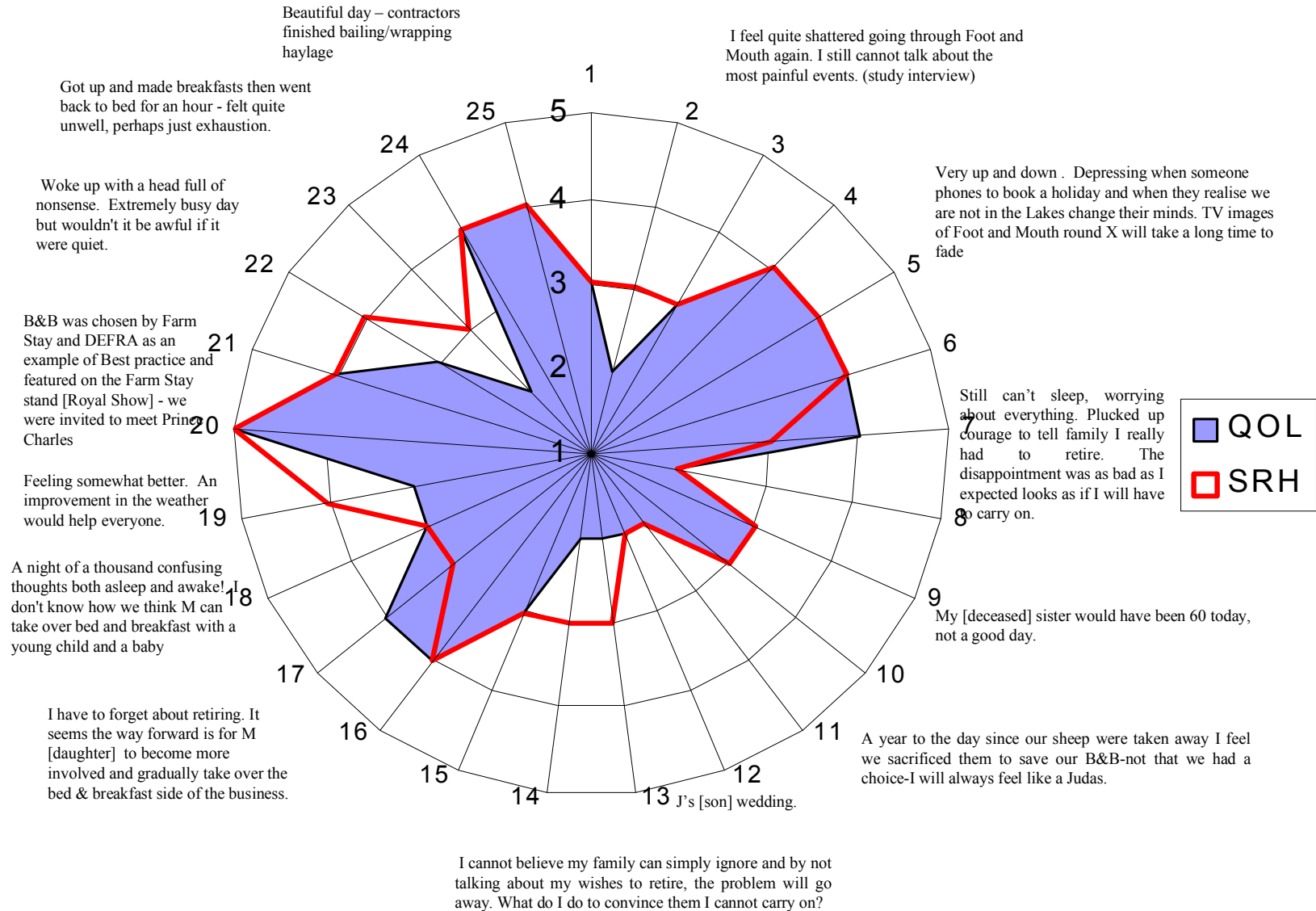
Front-line group



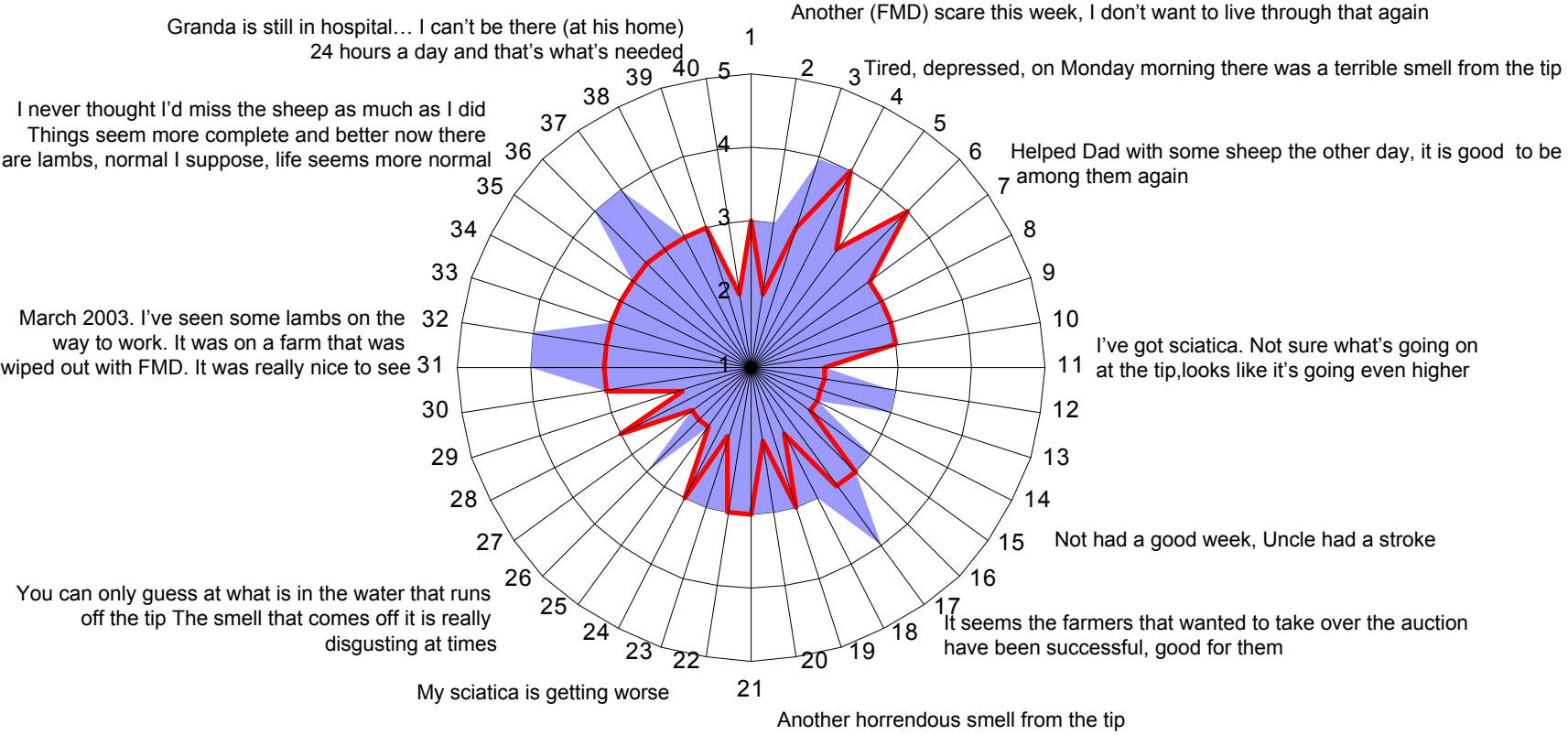
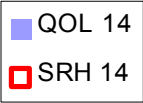
Small business



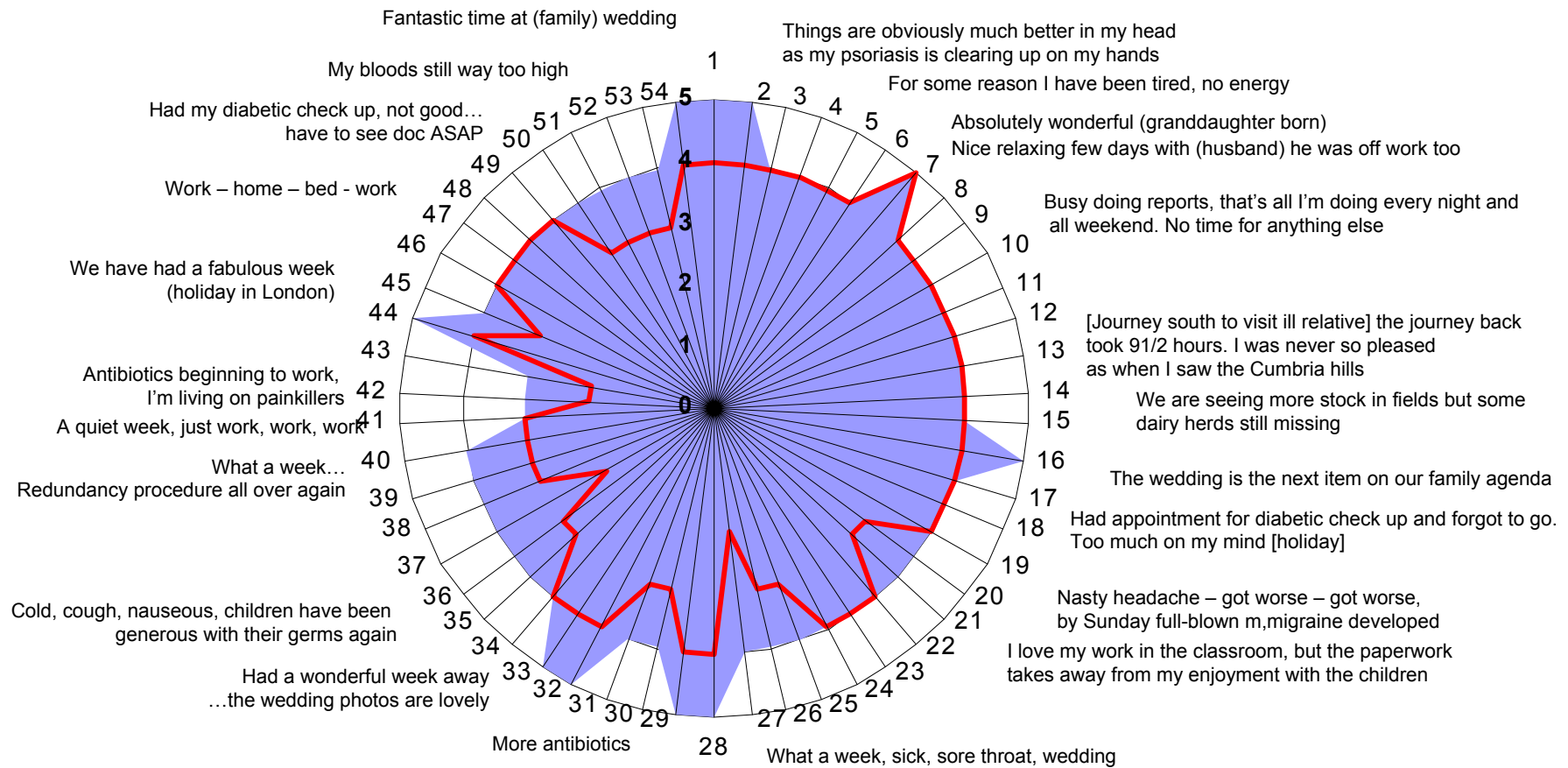
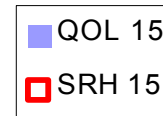
Small business



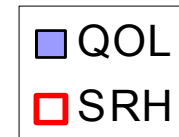
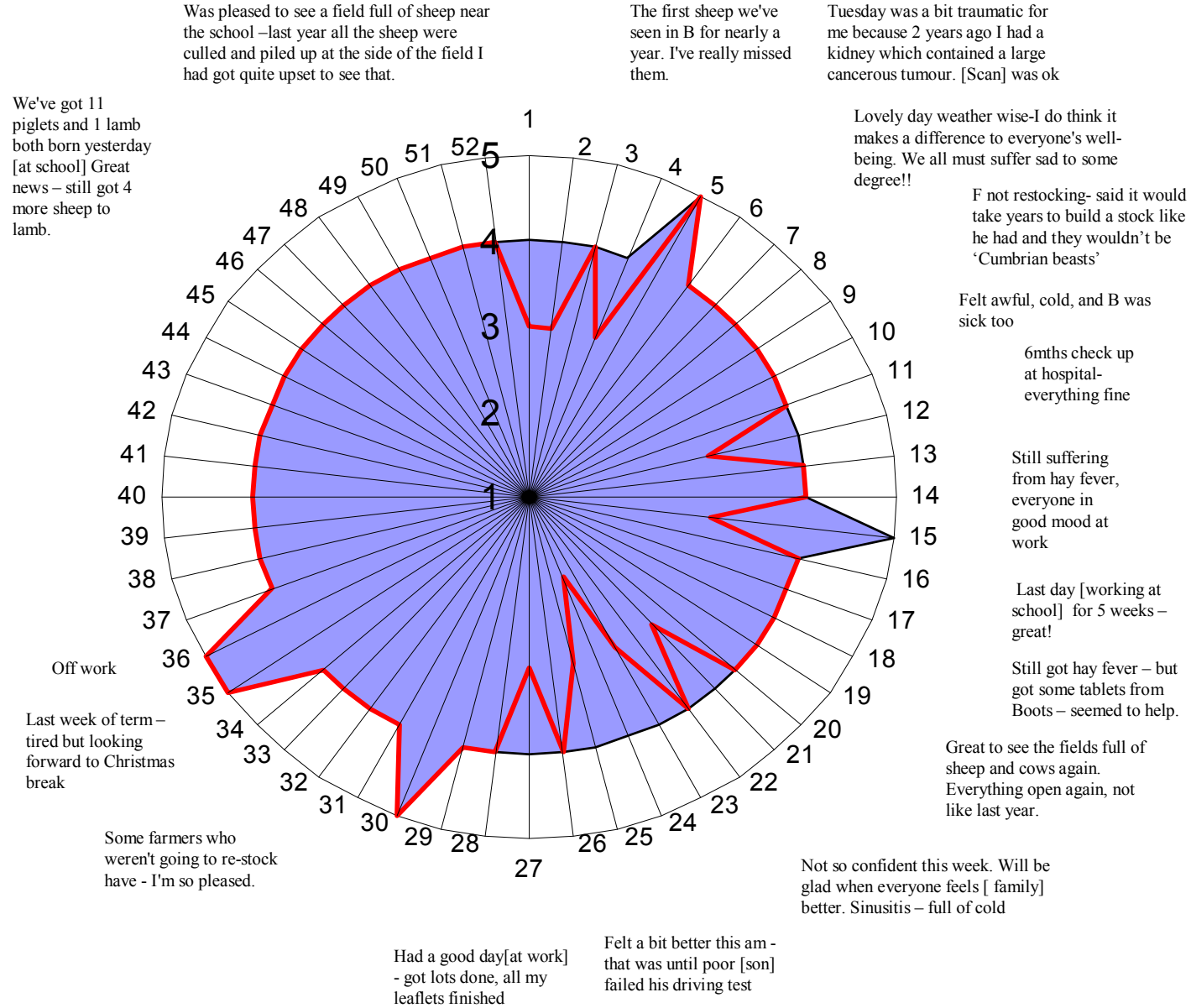
Community group



Community group

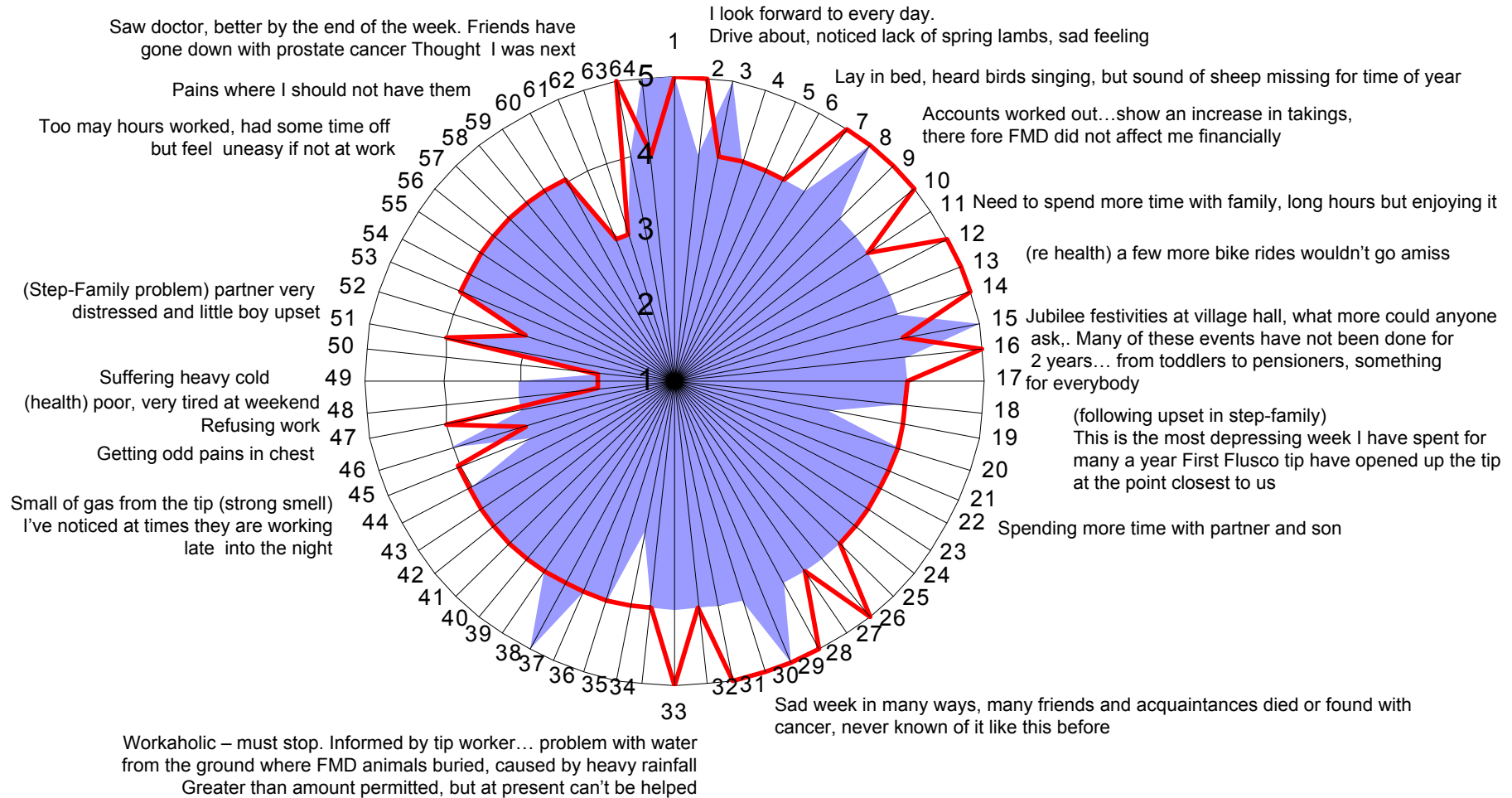
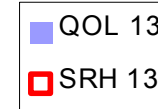


Community group

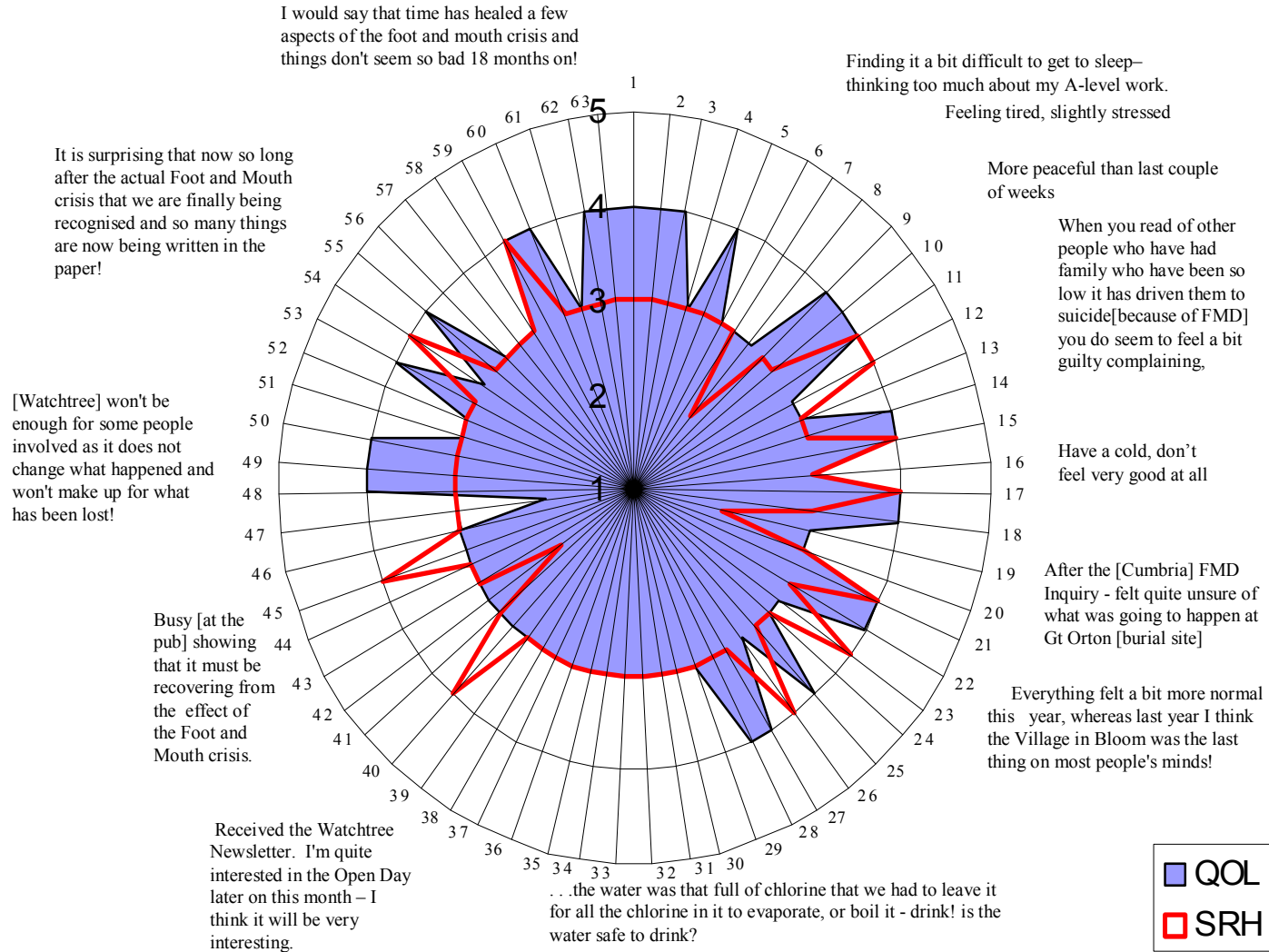


Community group

(last diary) I saw people depressed by FMD, how can I tell them not to worry there is more to life? Like an illness one recovers, but we don't forget



Community group



Appendix 7

Action Research

Part of the action research cycle involves regular feedback to service responders, both in the statutory and non-statutory sectors. **Informal meetings** were held with clinical psychologists; public health practitioners; GPs; the Cumbria Community Foundation; Voluntary Action Cumbria, Cumbria Waste Management Trust, site managers of disposal sites. A small additional grant of £3,896 was obtained from the Cumbria Recovery Fund to enable us to hold social group meetings for those panel members who wished to 'opt in' to such events. Many had suffered considerably over the previous year when social contact was severely curtailed. Some panel members live near landfill sites and throughout the project, have **charted events at some of these carcass disposal sites** post FMD. The research team made contact with a local Environmental Officer based at Great Orton burial site and with the site manager. A visit to Great Orton was made in February 2003. In May 2003 we also attended a memorial service dedicated to the animals buried there and to mark the beginnings of a designated nature reserve 'Watchtree'. The site produces regular newsletters, the content of which we have at times shared with panel members.

In addition an **Action Group** was held on 20 March 2002 to discuss ways of developing service (statutory and non-statutory) responses to the findings which emerge from the study. Once approved, copies of the report will be disseminated within this group.

The project was also instrumental in obtaining a small additional grant from the Recovery Fund for a temporary increase in **access to counselling** in FMD affected areas, extra sessions were purchased from the NHS Clinical Psychology department based in Carlisle.

The aim of the **project newsletter** was 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 were relevant to the research. The newsletter called 'The Diarist' ran to 10 issues. See Appendix 4.

Archiving proposals - The diaries represent a detailed record of recollections of the UK 2001 FMD epidemic in Cumbria and subsequent 18 months of everyday work and home life. They offer rich insight into Cumbrian rural life at the beginning of the 21st century, an immediacy of contact with everyday experiences of living with and through the 2001 FMD epidemic and constitute unique, prime and everyday historical evidence. We have consulted with panel members, local and national archivists about creating a publicly accessible resource based on the material collected in this project. Funding is currently being sought to continue this work.

Feeding into policy process – at the time of publication, two further meetings are planned with Cumbria County Council Cabinet (agenda item on implementing its FMD Inquiry recommendations) and Carlisle City Council's Health Overview & Scrutiny Committee.

Panel Members Evaluation: at the close of the project we asked respondents about how they would value participation on the study. Eight questions were distributed on a paper schedule at the project's final group meetings.

1. What for you has been the importance of recording your thoughts and experiences over this time?

It has made me observe and think about how incidents can affect other people in society, not just yourself directly. Example the present war in Iraq, what will be the aftermath worldwide and for the Iraqi people.

Although not involved to any great extent in F&M, but it has been an occasion each week to reflect on the past week and events and taking stock of my life and people around me.

Personally I haven't felt a great urge to record things but I think it's very important that someone (i.e. all of you) has looked into the human side of the outbreak and its effects, so I'm very willing to help

It has been very useful to clarify my thoughts and think things through. When you are busy you don't always stop to think things through as much as you should.

It has been a tool by which I feel I have been able to mark/measure our (me and my family) progress/recovery from FMD

I suppose the diaries have brought in a certain discipline as the recording of information has enabled one to identify relevant incidents

It gave you the opportunity to really think about what you went through. Those farmers who did not get the disease did not know what others went through.

Hopefully this recorded information will ensure that human interests i.e. health and business are considered and safeguarded, in the events of future epidemics)

It has been a chance to reflect on what happened, to look to the future and to recognise the frustration and anger)

I think it was good to record my thoughts and experiences as they happened, as over time you do forget details of events or how strongly you may have felt about something. It is also all recorded and will be good to look back on, I've enjoyed having a look back myself, interesting!

To let other people know that the experience we have all shared has had a long term effect on our lives and our futures

Just one of the ways of probably letting the public know the stress and strain those connected with farming during and since F&M

Being able to pass on my thoughts and experiences to others

So other people know what we went through and what we had to put up with from DEFRA

I wish we could turn back time and I would have liked to record a diary at the time of F&M. I am unsure what use it is writing after the event.

The thought that my diary may help in a small way to help other people now after the outbreak or to help in any future outbreaks

At the beginning it helped to clarify what I had done that year

I've never kept a diary before –just thinking about the previous week made me realise how much we forget almost immediately...

It has helped me to see the effect F&M had on me even if I was peripheral to the outbreak. It also helped me to take time for myself to reflect back on the week which was helpful on most levels.

To help in any way possible to improve the management of support if there was another similar type outbreak. I think that it has encouraged me to continue to ask questions of customers and friends how they are getting on during and after the outbreak.

2. Has the process of diary keeping helped clarify things about your experience of 2001 and its aftermath?

Yes, it definitely has! At first I wasn't quite sure how I would write my diaries, but it has definitely been useful and has made me more aware of what was going on around me. It has been interesting.

Yes, I didn't realise how much it had affected me and it helped me realise how badly affected those on the front line (ie farmers) may have felt and still be having difficulty.

Yes and No! I tend to quickly forget about the past and only look forward, always looking on the positive side. (EVERY CLOUD HAS A SILVER LINING)

2001 did not traumatise me to any extent, it was for me an unfortunate interlude, which affected many people in this area.

Committing thoughts and information to paper has always helped me to remember particular situations and experiences.

It made you realise what you took for granted – farmers are ~~(crossed out)~~ were used to doing what they wanted to do in the day. During 2001 and after you had to do what DEFRA and its regulations allowed.

Yes, this process has been useful in a number of ways and has helped considerably in coming to terms with the effects of the epidemic and its affect both on personal and business level.

It has helped me stop and look at the future, and what I want to be doing in the future, or maybe helped provoke my mid-life crisis.

It has focussed my mind. I would have forgotten more about F&M sooner but for the diaries.

It would have been interesting to have had all the experiences noted that we all went through during foot and mouth.

Not sure that it has.

Yes it makes one think back when it would have been easier to bury one's head in the sand and forget all about (sic)

Yes I've learned a lot about the farming industry. Talking to farmers and smallholders has helped them express their anxieties in full to a non-agriculturalist

Yes, It confirmed the large amount of knowledge of farming that I had rapidly acquired in 2001, and before and after. This has continued to benefit my ministry although retired.

It just made me think. If we knew then what we know now we wouldn't have let DEFRA take our animals

Mostly people have tried to move on and it is very rarely mentioned

Yes it has. It has also made me think more about the things that other people went through, that were more directly affected by FMD than I was

Yes it has.

I think that I really feel that most of the killing was unnecessary – a rape of our farms and farmers lives nothing can ever put that right – it will be with those affected forever.

Yes, but I feel the group meetings were more reminiscent of the emotional impact of the outbreak

It's made me think even more how fortunate we, as a retail business in Cumbria have been.

3. Have you enjoyed writing the diary or has it felt like a chore? What has kept you going with diary-keeping over the past year/18 months?

I have enjoyed writing the diaries, some have been happier than others, but I have got quite used to writing them, and sitting down and reflecting on the previous weeks.

On the whole it's not been a chore, but as I said above I think it's an important thing to do which has helped when I've not really felt like writing it)

Yes, it has made me start keeping a personal diary with a view to leaving it for the family history. My life is run from a diary re appointments, but this is a little extra. It has been no chore. Pleasure!

Definitely not a chore, it has in fact encouraged me to start keeping details of my life and look back into my past.

Once in "the system" it is surprising how recording the diaries has become a venture which has been relatively easy to continue

I have always kept a diary for the last 20 years. This was easier to do – I tended to write about the week in general rather than an individual day account

I wouldn't go as far, to say I have enjoyed writing the diary, but it has certainly been a welcome form of therapy. (this respondent found it hard to find time/concentration to write, and continued with the project using recorded conversations with researcher)

Mostly it has been a chore or a discipline, but I am pleased that I have done it.!

I have deep respect for the agricultural community and would not want to feel I was letting them down

At first it was ok, but over the last 6 months it has become a chore

Sometimes I have quite enjoyed doing diary other times it has been a pain in the arse!

95% of the time I've enjoyed writing diaries. Sometimes it does seem a bit of a chore particularly when there hasn't been very much to write about. Not being able to keep a diary because of this made me feel I was cheating.

It was never a chore or enjoyment. It was something I felt I should do.

On the whole I have enjoyed keeping the diary but from time to time it became a little bit that way, mainly because we were very busy at work and I was struggling to find time to do it.

Although I enjoyed writing the diary it was often a chore making the time to do so. But I never regretted getting involved with the project. The importance of the ongoing effects of FMD were paramount to my keeping the diary for 18 months and also as an acknowledgement

Mostly I have enjoyed writing my diary – when work was becoming a pressure then occasionally my diary became just one more thing to do!

I said I'd do it! And until I had 28 reports to write I kept going !

4. There has been a small payment for members' participation – has this helped? In what way?

This has come to help over the past few months! This is not the reason I wrote the diaries, as it was a worthwhile project anyway, but with only being able to earn a little, this has been a good way of doing that.

I did not like to receive money for this, but as indicated in my diaries I put it to good use

Yes. I have bought a piece of furniture with it to mark the project. Felt very guilty however as a friend gave his to charity!

I have "stacked" the payments away, to be used on a special occasion as yet unidentified. I suppose that, once having committed myself to the diary payment was not absolutely necessary.

Yes it has. It was nice to receive the cash. I tended to use it for a treat – e.g. buying some flowers, magazine etc – something for me.

Very much indeed! There have been many times when I have been, quite honestly on the thin line and grateful for small mercies.

Made me feel guilty for not completing on time!

Only in terms of embarrassment

Yes, but not totally

Does not come into it but yes it has been very nice and quite a welcome bit of pocket money for my labours but it would still have been done if there had been no payment but it has helped keep me going

Payment in any form is always a help. The payment may be small but receiving it after five or six weeks makes up for it being very small.

I have given all my payments to charities. So you have helped a children's ward in Malawi and other charities. I am grateful for this.

Money always helps, but it didn't make me write any different.

Yes but I wish I'd saved it all up and bought something special at the end of the project. Instead it all got spent on various other things along the way.

Yes it has helped

Yes it has helped to a small extent. It was money I put aside as treat money for my children and myself. I felt they'd been affected during the outbreak so it was nice to have an indirect benefit to flitter on flippancies. Also knowing Ian would appear with some money made me feel I had to carry on – protestant work ethic I suppose.

5. Have you shared the diary with your family or has it been private?

It has to be an open document.

I have shared the fact that I write these diaries with my family, but usually write them and keep them to myself. My mother has been very helpful in collecting newspapers and articles for me.

My ordinary diary is a family one but this one I kept to myself.

I have kept my diary private.

An "open" document but not as yet read by anyone else.

No it has been private. I felt I was more true to myself if I wrote it alone.

6. Did you keep a diary before taking part in the research, has it encouraged you to continue?

No I did not keep a diary before this research, but I have enjoyed it! I like collecting bits and pieces to remind me of things, so perhaps a diary in the future may be a good idea!

Only a busy appointment diary, but started to keep a very general diary about important events in family life.

No, I did not before, but I am now keeping a more detailed diary of my life and people around me.

I issue a monthly sales letter at work and do record significant items for inclusion during the preceding month and I also have to keep information/quotations/appointments etc in a diary

I don't think I'll continue to write a diary but I will endeavor to remember more

This process may yet inspire me to keep a diary

No but I would like to see myself carrying on in some form. It was very good in many ways especially clarifying what was important to do and concentrate on.

7. How did you feel about:

a) Being interviewed for the project? b) Being visited by your researcher?

A bit upset at the time but fine afterwards.

Good to talk to someone who understands even now 2 yrs on.

No problem at all in fact I enjoyed the interview and visits.

Not alone!

Helped!

I was a bit nervous at first, but then fine! I do not mind this at all! I have got used to it and it is part of my month, together with writing the diaries. It is also good to keep you updated with project.

Yes, OK

Felt closer to the project by being visited

Quite enjoyed it.

A welcome face when he remembered to turn (sic) but really Ian has been a pleasant person and very understanding

No problem being interviewed, quite enjoyed it

Look forward to the researcher's visits

Being interviewed for the project was ok but I felt I didn't have much to write about. When the researcher came I always felt I hadn't written anything very interesting (H)

Yeah ok fine, no problem

Ok apart from I'm never in when Ian comes.

Not a problem

Quite enjoyed the visits, as it gave us a chance to talk about the diaries as time went on.

I enjoyed my interview and I have thoroughly enjoyed J's visits.

I enjoyed being interviewed it was very evocative in revisiting F&M and like all humans having someone's attention was a positive experience!

I enjoyed Ian's visits and they helped motivate me to keep up to date with my diary.

OK

Have enjoyed the visits by Ian and found it interesting to hear about and compare experiences and effects of the FMD outbreak.

8. Please write here anything you would like to add

I am still finding people with unresolved problems post 'foot and mouth'. The problems may have been there already and have been exacerbated by F&M. It has certainly left its mark.

I feel after the meetings I have got a better understanding of other people who were involved with F&M. I feel I am a bit of an odd-ball, as I was not affected by F&M to any great extent. By nature I don't worry a lot, but I find it frustrating finding others close to me getting into problems, but if they won't help themselves what can I do?

I had a short break in January as my mother was taken ill and into hospital and then died. Because we had been through FMD and the death of this farm and its 200 cattle I was able to cope better than my sister who escaped the FMD

THANKYOU! (respondent's signature)

I have written a bit in the diaries about "the process"

It has been a struggle to think of anything F&M related towards the end

I do feel the social night we had at Dalston was a huge success and I feel we should have another and even another further down the line perhaps after the project has finished just to keep us all in touch with the friends we have met and made through this project.

I've enjoyed the experience very much and would like to take part in other projects

After April 2001 I retired due to eyesight problems and age (65) I now realise and often have noted how exhausted I was 2001/2. I now look and see much better

Thanks for the opportunities.

When we got F&M I felt I was on the outside and David was on the inside feeling all the pain and heartache and it should have been him writing his feeling and experience

I hope this has helped with understanding what people went through and hopefully if it ever happens again people will be more understanding about the pressure that everyone has been under.

It was great to hear other people's experiences especially others who aren't connected with farming and agriculture. No one talks about F&M openly now, but it's still important in how people are being affected.

I think I would have been able to contribute a little more than I have if the survey had started earlier but I know that it was not possible.