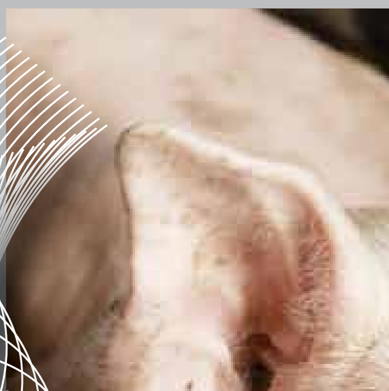
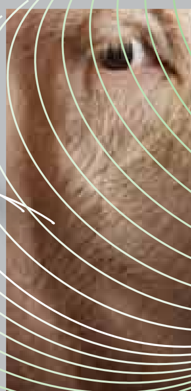
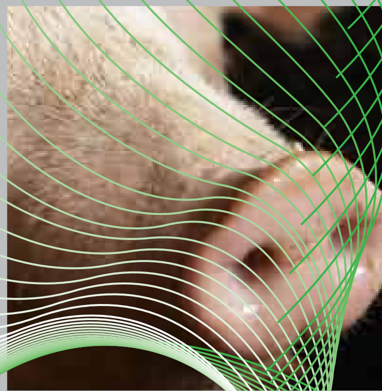
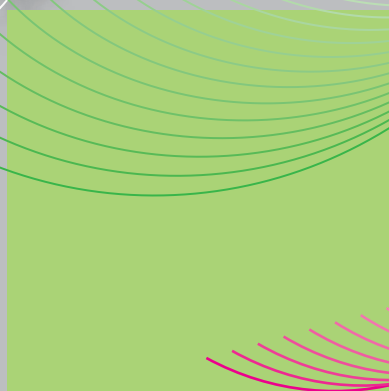
Chapter 6:
The Views of Parents



Chapter 6: The Views of Parents

6.1 Synopsis of Interviews

Introduction

We felt it was important to obtain the views of the parents of children who had been affected by the outbreak. A letter from Professor Griffin was sent to all the families affected by the outbreak plus a further eight members of the public who had contacted the Health Protection Agency (HPA) about issues relating to the outbreak or its management, to seek their views.

The letter was sent by the Surrey and Sussex Health Protection Unit (SySxHPU) to preserve the confidentiality of the families and was accompanied by a cover letter from the HPU Director and a set of questions about the outbreak drafted by the Investigation. The letter invited the families to a meeting with Professor Griffin at one of three venues (Rochester-Chatham, Crawley and Croydon), selected for the families' convenience. If the families did not wish to attend a face-to-face meeting, they were given the opportunity to respond to the questions by post, anonymously if they wished, or by email.

A postal address was set up for the Investigation together with an email address (responses@griffininvestigation.org.uk).

6.1.1 Summary of Meetings with Affected Families

Eighteen families affected by the outbreak met Professor Griffin, an additional member of the Investigation Committee and the Committee Secretariat at Rochester-Chatham (six families), Croydon (eight) and Crawley (four). Another family, whose child had *E. coli* O157 following a visit to Godstone Farm earlier in the year, and one parent whose child had not been infected with *E. coli* O157, but who had contacted the HPA, also met the Team (see Table 6.1).

Notes taken during the face-to-face meetings were emailed to the families to check for factual accuracy. These were collated and are included as **Appendix 8** of this Report. Verbal consent from the families was obtained during the face-to-face meetings. The main points that arose are summarised in Table 6.2.

A further nine families provided responses by post (six of these families had children infected with *E. coli* O157, one respondent was the grandfather of one of the families who attended a meeting and two had visited the Farm during the period of the outbreak). For completeness, we have included these responses in **Appendix 8**, but details are not included in the summary tables 6.1 and 6.2 as far less information was available from the written responses compared with the information from the face-to-face interviews.

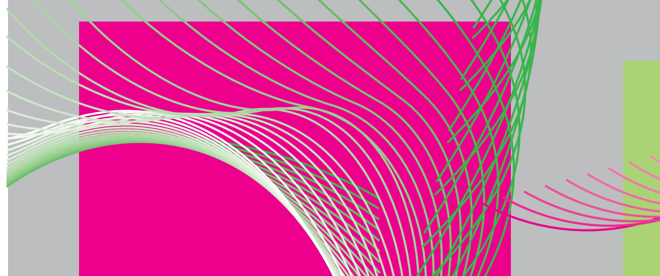


Table 6.1: Summary of meetings

Families contacted:	All families affected by the August outbreak 8 who had contacted the HPA 1 case of *E. coli* O157 earlier in 2009
Total number of families who met the Investigation Team:	20 18 from the August outbreak 1 earlier case 1 who had contacted the HPA (not affected by *E. coli* O157)
Total number of families who provided written responses:	9

Table 6.2: Main points arising from meetings with 19 affected families

Dates visited:		
- Week of Mon 24.08.2009 to Sun 30.08.09 (includes Bank Holiday Sat and Sun)	9	(47%)
- Week of Mon 31.08.09 to Sun 06.09.09 (includes Bank Holiday Mon)	7	(37%)
- Number who had visited the Farm before	16	(84%)
Differences noted about this visit:		
- Farm exceptionally busy	5	(26%)
- Child had animal contact for first time	3	(16%)
- Observed children picking up feed from floor	5	(26%)
Handwashing arrangements: - Noted cold water	11	(58%)
- Noted difficulty using taps	6	(32%)
Severity of illness: - Child(ren) admitted to hospital	13	(68%)
- Child(ren) admitted to specialist renal care with acute renal failure	8	(42%)
Prior knowledge of *E. coli*		
- General awareness of *E. coli* O157 or *E. coli*	16	(84%)
- Aware of *E. coli* associated with uncooked food	8	(42%)
- Believed *E. coli* was a risk for pregnant women	3	(16%)
Knowledge that *E. coli* is present in animal faeces	ZERO	

6.1.2 Principal Comments

It is noted that the observations and comments are those of the families alone. These are the views of the parents interviewed at the face-to-face meetings but may not be typical of the views of the families as a whole.

Familiarity with Godstone Farm

The majority of the families (16) were regular visitors to Godstone and said that their children enjoyed visits there. Only three families had not visited before.

When asked if there had been anything different about their visit, some (five) noted that the Farm was exceptionally busy. There had been a queue to get in and/or they had to wait to use the washing facilities. They noticed straw and paper towels strewn over the floor.

Two parents noted their child had fed the animals for the first time and one child had gone into the rabbit pen for the first time.

Five parents observed children picking up feed from the floor to feed the animals.

Handwashing

All the parents said they were aware of the need to wash their children's hands. A number said they were very careful and had used hand gels. It is unclear whether gels had been used instead of handwashing and none seemed to be aware that handwashing with soap is crucial and that gels alone are not effective.

Several commented that the taps were difficult to use, particularly for the younger children, and at most of the sinks there was only cold water. Eleven families commented that there was little supervision by farm staff and considered that there should have been more staff supervision at handwashing and animal contact areas.

Signage

Most families had noticed signs about handwashing at the Farm but some felt there should have been more. Many of those who had visited after the first few cases were confirmed commented that they had not noticed specific signs about *E. coli* O157.

Awareness of *E. coli* O157

The majority (16) of parents had heard about *E. coli*. Eight thought that it was associated with eating poorly cooked food or thought it was a 'tummy bug'. Only three were aware of the association with animal contact but thought this was specifically a problem during pregnancy. None was aware of the association of *E. coli* O157 infection with animal faeces or animal contact in children, or indeed the very serious nature of this infection.

Clinical Management

A common theme emerging was a lack of urgency at primary care level in dealing with children (many under five years of age) who presented with bloody diarrhoea and stomach cramps.

Several of the parents made repeated visits to their GP surgery or out-of-hours service before stool samples were taken. Several of the parents decided to present to their local A&E Departments and the children were then admitted as their clinical condition deteriorated rapidly. All the parents whose children were referred to the specialist Paediatric Nephrology services at the Evelina or Great Ormond Street Hospitals were extremely complimentary and appreciative of the excellent service they received there.

Table 6.3 sets out the clinical details of the children and their management as described by the parents during the face-to-face meetings.

Communication and Advice

Communication and advice received by the parents did not appear to be consistent. Some families had been contacted by the HPU and some by the local authority Environmental Health Department (LA EHD).

Some parents mentioned they had been given a leaflet about *E. coli*. One parent mentioned that the environmental health officer (EHO) who interviewed her had commented that they were more used to investigating restaurants. One of the parents had been told by their GP that their child (who still had positive stool samples for *E. coli* O157) could attend school. Another family commented about the lack of awareness of staff in their local A&E Department about the outbreak, even though there were already numbers of cases in the local area at the time their child was admitted.

The parent of a child who had *E. coli* O157 associated with Godstone in March 2009 was concerned that there was little awareness by the HPA of this case before the outbreak in August.

One family (not directly infected with *E. coli* O157) expressed concern that the primary school attended by two children who were known to be infected, had no idea of the Public Health Regulations and the implications for the school, particularly in terms of preventing secondary spread, and had additionally received no help or instruction from the LA.

6.1.3 Future Action

Many of the families said their experiences had been so traumatic they would not visit an Open Farm with their children again. However, many recognised the value of an animal contact experience for children in general and thought that much more information should be made available so that parents could make an informed decision on animal contact.

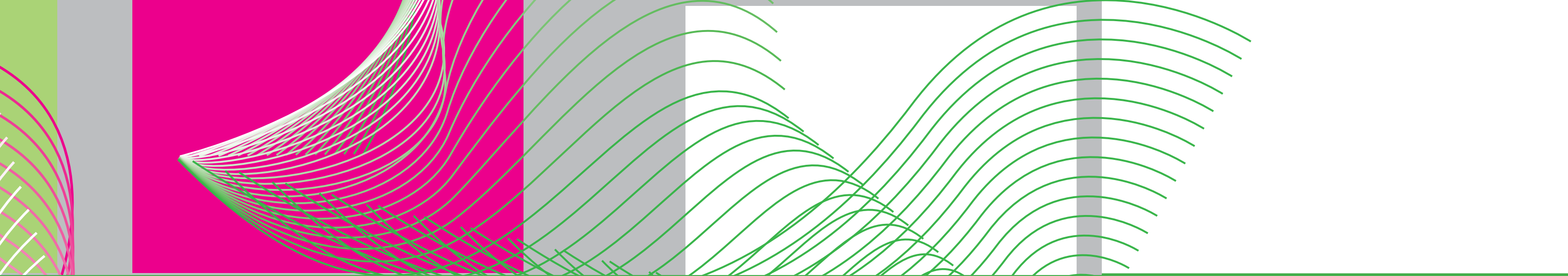
A large number of the families felt there should be increased staff supervision in animal contact and handwashing areas. Better training of staff was also mentioned, as well as more controls during periods of high visitor numbers.

Some of the families felt there should be better signage specifically about *E. coli* O157 although they did acknowledge that the Farm had a number of general handwashing signs.

The families whose children were infected with *E. coli* O157 are now much more aware about the transmission of *E. coli* O157 from animal faeces and feel that the general public visiting Open Farms do not have this awareness.

Many families had clearly given thought to how the Farm could have prevented or reduced faecal contamination. For example, one parent said that the children should not be able to walk into the animal pens. There should be improved cleaning regimes with hay and animal feed pellets regularly removed from the public areas and railings regularly cleaned. There should be more information to visitors about the potential for faecal contamination of boots, shoes and buggies and the possible consequences.

One parent suggested that farm staff should walk through disinfectant after working in an animal pen and before walking through a public area. Another parent felt Open Farms should improve their risk assessments.



Several families wondered whether the mix of animal petting and recreational activities was suitable. Godstone Farm has several large children's play areas (including an outdoor activity area, toboggan run, sandpits and an indoor plastic soft play area with ball pond).

Several families realised the potential for these areas becoming contaminated with faecal material on children's shoes or for the children to get faecal material on their hands when removing their shoes to play in the soft play area. In addition, several families remarked that their children actually preferred the play areas to the animal contact areas.

Many of the families could not understand why the Farm had not closed earlier. Furthermore they expected that it was the HPA which had responsible powers for closure and expressed surprise when they were later told that the HPA had no regulatory powers.

Table 6.3: Clinical details of individual children from interviewed families

Case No: *	Days from farm visit to onset of symptoms	Days from farm visit to stool sample	Days from farm visit to being seen by GP	Days from farm visit to A&E attendance or admission to hospital	Duration of hospital admission (days)	Presenting symptoms	Treatment
1)	3	6 (hospital)	6	6: Admitted	12	Bloody diarrhoea Abdominal pain Bloody urine	Intravenous fluid Anti-emetic Blood transfusion Naso-gastric feed No dialysis
2)	6	No stool sample	Not seen by GP	No hospital attendance	Not admitted	Bloody diarrhoea Abdominal pain	None required
3)	9	12	Not seen by GP	11: Parents took child to A&E 11: Admitted from A&E	2	Bloody diarrhoea Dehydration Nausea Vomiting	Rehydration with oral fluid
4)	3	4	3	4: Parents took child to A&E 4: Admitted from A&E	7	Bloody diarrhoea Abdominal pain Vomiting Prolapsed bowel	Intravenous rehydration
5)	6	Unknown	Not seen by GP	7: Parent took child to A&E 7: Admitted from A&E	6	Bloody diarrhoea Abdominal cramps	
6)	5	7	Not seen by GP	7: Parents took child to A&E. Not admitted	Not admitted	Bloody diarrhoea Vomiting Violent stomach cramps	Amoxycillin Rehydration with oral fluid
7)	3	8	5: Call to NHS Direct 5 :Emergency GP Service 8: GP visit	No hospital attendance	Not admitted	Bloody diarrhoea Vomiting Stomach cramps	Rehydration with oral fluid
8)	9	No stool sample	9	9: Advised to go to local hospital by GP 9: Admitted 11: Transferred to specialised renal unit	14	Dehydration Diarrhoea Limp and floppy Renal Failure Anaemia (HUS)	Intravenous rehydration Blood transfusion (2) Peritoneal Dialysis (8 days) Morphine

* Case numbers refer to this Table only and do not relate to case numbers referred to elsewhere in the Report

Case No: *	Days from farm visit to onset of symptoms	Days from farm visit to stool sample	Days from farm visit to being seen by GP	Days from farm visit to A&E attendance or admission to hospital	Duration of hospital admission (days)	Presenting symptoms	Treatment
9)	9	No stool sample	9	9: Advised to go to local hospital by GP 10: Transferred to specialised renal unit	41	Dehydration Diarrhoea Renal Failure Anaemia (HUS)	Intravenous rehydration Blood transfusion (2) Peritoneal Dialysis (33 days) Haemodialysis Naso-gastric feed
10)	14	14	14	No hospital attendance	Not admitted	Diarrhoea	None required
11)	No symptoms	14	14	No hospital attendance	Not admitted	Asymptomatic	None required
12)	4	7	7: Consulted GP 13: Called GP as child very unwell	13: Advised to go to local hospital by GP 13: Admitted	3	Bloody diarrhoea Abdominal pain Dehydrated Vomiting	Intravenous rehydration
13)	21	21	21: Consulted GP 21 (evening): Called Out of Hours Service	23: Admitted to local hospital from GP Out of Hours Service	2	Bloody diarrhoea Cramps	Oral rehydration
14)	10	No stool sample	11: Phoned GP and then saw Out of Hours Service 13: Consulted GP	No hospital attendance	Not admitted	Diarrhoea Cramps Nausea Bloody diarrhoea Vomiting	Oral rehydration Antispasmodic syrup
15)	No symptoms	24	Not seen by GP	No hospital attendance	Not admitted	Asymptomatic	None required

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Case No: *	Days from farm visit to onset of symptoms	Days from farm visit to stool sample	Days from farm visit to being seen by GP	Days from farm visit to A&E attendance or admission to hospital	Duration of hospital admission (days)	Presenting symptoms	Treatment
16)	4	7: on 2nd visit to GP	4: Consulted GP and also "a few days later"	10: Attended local A&E as child unwell 10: Transferred immediately from A&E to specialised renal unit	11	Diarrhoea Vomiting Blood in urine Abdominal pain Anaemia (HUS) Renal failure	Oral rehydration Blood transfusion Peritoneal dialysis (3 days) Morphine
17)	Not stated	No stool sample	Not seen by GP	No hospital attendance	Not admitted	Diarrhoea for 1 day	None required
18)	7	10	9: Phoned NHS Direct 9: Advised to go to local A&E 10: Consulted GP	9: Seen in local A&E. Not admitted 11: Seen in local A&E. Not admitted 12: Seen in local A&E. Admitted 13: Transferred to specialised renal unit	42	Bloody diarrhoea Abdominal cramps Dehydrated Floppy Anaemia (HUS) Renal failure	Intravenous rehydration Peritoneal dialysis (4 weeks)
19)	2	6	6	6: Admitted to local hospital 10: Transferred to specialised renal unit	13	Bloody diarrhoea Abdominal cramps Vomiting Renal failure	Peritoneal dialysis (10 days)
20)	4	6	6: Phoned Out of Hours Service. Advised to go to Walk-In Clinic at local hospital	6: Attended local hospital; not admitted 7: Seen at Walk-In Clinic. Not admitted 15 Admitted to local hospital 15: Transferred to specialised renal unit	21	Bloody diarrhoea Vomiting Swollen feet and hands Kidney failure Anaemia (HUS)	Oral rehydration Peritoneal dialysis (7 days) Blood transfusion (x 3)

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Case No: *	Days from farm visit to onset of symptoms	Days from farm visit to stool sample	Days from farm visit to being seen by GP	Days from farm visit to A&E attendance or admission to hospital	Duration of hospital admission (days)	Presenting symptoms	Treatment
21)	9	10	10: Phoned NHS Direct Advised to see GP 10: Consulted GP Advised to go to local hospital 11: Called Out of Hours GP Service	10: Seen at local hospital. Not admitted 13: Admitted to local hospital 14: Transferred to specialised renal unit	12	Bloody diarrhoea Vomiting Renal failure Anaemia (HUS) Low platelets (HUS)	Peritoneal dialysis (10 days) Blood transfusion Naso-gastric feed
22)	3	5	9: Saw GP and referred to local A&E	9: Admitted to local hospital 10: Transferred to specialised renal unit	11	Bloody diarrhoea Acute renal failure (not passing urine)	Peritoneal dialysis (12-14 days) Blood transfusion (x 2)
23)	5	16	16	No hospital attendance	Not admitted	Bloody diarrhoea Abdominal cramps	None required
24)	14	20	Not seen by GP	18: Out of Hours Clinic at local hospital Not admitted	Not admitted	Bloody diarrhoea Abdominal cramps	None required
25)	6	7	7	8: Attended local A&E. Not admitted 10: Attended local A&E. Not admitted 11: Attended local A&E. Not admitted 12: Attended local A&E. Admitted 13: Transferred to specialised renal unit	3	Bloody diarrhoea Vomiting Dehydration Renal failure Anaemia (HUS)	Antibiotic (amoxicillin) Intravenous rehydration (Dialysis not needed)
26)	6	8	6: Phoned Out of Hours GP for advice (not seen) 8: Phoned GP, not seen, advised to send stool sample 11: Consulted GP	15: Attended local A&E. Not admitted	Not admitted	Bloody diarrhoea Abdominal cramps	None

* Case numbers refer to this Table only and do not relate to case numbers referred to elsewhere in the Report
Source: Information provided by parents at the face-to-face meetings

Note that the ages of the children have been removed for confidentiality reasons. However the age range of the 26 children referred to in the table is between one and 14