Exploring the needs, concerns and behaviours of people with existing respiratory conditions in relation to the H1N1 'swine influenza' pandemic: a multicentre survey and qualitative study

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Abstract

Exploring the needs, concerns and behaviours of people with existing respiratory conditions in relation to the H1N1 'swine influenza' pandemic: a multicentre survey and qualitative study

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Background: People with respiratory conditions are a 'high-risk' group for H1N1 pandemic swine influenza ('swine flu'), hence they and their families may have information needs, worries and concerns regarding the condition. Health-related behaviours, including vaccination, are recommended during the pandemic; understanding uptake of these is important.
Objectives: To explore and compare information needs, worries and concerns, and health-related behaviours regarding swine flu in people with respiratory conditions and their family members.
Methods: Mixed-methods study – cross-sectional survey (253 patients, 101 family members); one-to-one interviews (13 patients, seven family members) and focus groups (*n* = three groups, 30 participants). Data collected October 2009–January 2010 from hospital chest clinics (*n* = 7) and patient support groups (*n* = 10) in North West England.
Results: Most patients (P) and family members (FM) wanted more information (*n* = 158, 62.5% P; *n* = 55, 54.4% FM), but few felt completely uninformed (*n* = 15, 5.9% P; *n* = 3, 3.0% FM). Most had already received information about swine flu (*n* = 187, 73.9% P; *n* = 78, 77.2% FM), mainly via a leaflet delivered to their home (*n* = 125, 49.4% P; *n* = 55, 54.5% FM). Information received was considered helpful (*n* = 154, 60.9% P; *n* = 77, 72.6% FM), but many wanted more condition-specific information (*n* = 141, 55.7% P; *n* = 60, 59.4% FM). More patients were worried (*n* = 147, 58.3%) than not worried (*n* = 99, 39.3%) about swine flu. FM were less often concerned about personal risk (*n* = 47, 46.6% worried) than about risk to patients (*n* = 76, 77.6%). Two-thirds (*n* = 161, 63.6% P; 65, 65.6% FM) incorrectly believed patients had increased risk of developing swine flu, but most (*n* = 204, 81.0% P; 89, 89.9% FM) correctly identified patients' greater risk of developing complications. Commonly adopted preventative measures were more frequent hand-washing (107, 42.8% P; 38, 37.6% FM) and greater use of sanitising hand gel (*n* = 100, 40.5% P; 37, 36.6% FM). In total, 212 patients (83.8%) and 69 family members (68.3%) were very/fairly likely to take up swine flu vaccination. Qualitative data mirrored survey findings.
Conclusions: Participants were generally well-informed about swine flu, but more targeted information would have been welcomed. Participants were not highly anxious about swine flu, but did recognise risks for patients. Behaviour change was modest, but in line with recommendations. Vaccination intent was high.
Study registration: The study has been registered as REC/IRAS (Ref 09/H1015/76) and NIHR CSP (Ref 32483).

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List of abbreviations

A&E	accident and emergency department
ABPA	allergic bronchopulmonary aspergillosis
BLF	British Lung Foundation
BME	black and minority ethnic
COPD	chronic obstructive pulmonary disease
GP	general practitioner
HPA	Health Protection Agency
HTA	Health Technology Assessment
ILD	interstitial lung disease
NIHR	National Institute for Health Research
NPFS	National Pandemic Flu Service
UNICEF	United Nations Children's Fund
WHO	World Health Organization

All abbreviations that have been used in this report are listed here unless the abbreviation is well known (e.g. NHS), or it has been used only once, or it is a non-standard abbreviation used only in figures/tables/appendices, in which case the abbreviation is defined in the figure legend or in the notes at the end of the table.

Executive summary

Background

The H1N1 swine influenza (swine flu) pandemic resulted in mass information campaigns, largely aimed at the general public. Little is known about whether these met the needs of people with respiratory conditions and their families. People with respiratory conditions were identified as being at risk of potentially life-threatening complications of 'swine flu', hence they and their families may have had worries and concerns regarding the condition. A number of health behaviours, including vaccination, were recommended during the pandemic; given their 'high-risk' status, it is important to identify whether these were adopted by people with respiratory problems and their family members.

Objectives

1. To explore, in samples of people with existing respiratory conditions and their family members:
   i. information needs (priority topics of information, preferred sources of information, perceived usefulness of available information, gaps in knowledge/misconceptions) regarding the current swine flu pandemic
   ii. concerns (perceptions of susceptibility, risk of complications, risk of death) regarding the current swine flu pandemic
   iii. health-related behaviours (adoption of recommended preventative measures, avoidance behaviours, anticipated use of health services) with respect to the current swine flu pandemic.
2. To compare information needs, concerns and health-related behaviours of patients and family members.
3. To explore associations between the above factors and condition-related/demographic variables.

Methods

A mixed-methods study involving a cross-sectional questionnaire survey, focusing on current/recent needs, concerns and behaviours, conducted by post and telephone; one-to-one interviews and focus groups were conducted. Inclusion criteria were: adult (18 years or over) with clinician-diagnosed long-term respiratory condition of any severity or family member of such a patient; able to provide informed consent to participate; and able to complete an English-language questionnaire or participate in an interview or focus group conducted in English. Patient and family member questionnaires were developed specifically for the study, with content guided by review of the literature, expertise in the project team and guidance from a User Reference Group, made up of patients with a respiratory problem and their family members. A topic guide, which drew upon questionnaire content, was developed for the interviews and focus groups.

Data were collected from hospital chest clinics ($n = 7$) and patient support groups ($n = 10$) in North West England. Survey data were entered into SPSS v15.0 and first analysed descriptively; logistic regression was planned but rejected owing to results of bivariable analyses of key outcomes. Interviews and focus groups were audio recorded and transcribed verbatim. 'Framework analysis' was used to identify main themes and permit comparisons within and across transcripts.

Results

Sample

Patient questionnaires were completed between 12 October 2009 and 5 February 2010, and family member questionnaires between 17 October 2009 and 2 February 2010. The three focus groups were conducted on 18 November 2009, 19 November 2009 and 19 December 2009, and interviews were conducted between November 2009 and

January 2010. The study sample consisted of 354 survey participants (253 patients and 101 family members); 20 interviewees (13 patients and seven family members); and 30 focus group participants, across three focus groups, most of whom were patients.

Information needs

Most ($n = 158$, 62.5% patients; $n = 55$, 54.4% family members) wanted more information, but few felt completely uninformed ($n = 15$, 5.9% patients; $n = 3$, 3.0% family members). Most had already received information about swine flu($n = 187$, 73.9% patients; $n = 78$, 77.2% family members), mainly via a leaflet delivered to their home ($n = 125$, 49.4% patients; $n = 55$, 54.5% family members) or through mass media sources (e.g. television $n = 116$, 45.8% patients; $n = 44$, 43.6% family members). The health professional from whom patients and family members most commonly received information was their general practitioner (GP) ($n = 75$, 29.6% patients; $n = 21$, 20.8% family members). Doubts were commonly expressed about the credibility of mass media as an information source. Most thought the information received was helpful ($n = 154$, 60.9% patients; $n = 77$, 72.6% family members), but many also wanted more specific information for people with chest problems ($n = 141$, 55.7% patients; $n = 60$, 59.4% family members), especially regarding how swine flu would affect chest problems. Data from focus groups and interviews mirrored survey findings. The data extracts below typify views regarding information provision:

> We got some information through the post, but I'm not sure where that came from, I do recall it had man sort of sneezing on it … and there is an internet site which I think is specific for swine flu and we checked on that one, and that seemed to be enough for us, we didn't really need any more than that. But I've been to the local GP for repeat prescriptions for my wife and there are notices all over the place which really replicate the information that we've got.

> It might be helpful if one could tie specific complaints into the swine flu scene … I have … bronchiectasis … I'm just wondering if I did get swine flu whether that would make the symptoms worse, whether it would complicate matters. I find I haven't got any information on that.

Concerns

More patients were worried ($n = 147$, 58.3%) than not worried (99, 39.3%) about swine flu, although few were extremely anxious. Family members were less often concerned about personal risk ($n = 47$, 46.6% worried) than about risk to patients ($n = 76$, 77.6%). Two-thirds ($n = 161$, 63.6% patients; $n = 65$, 65.6% family members) incorrectly believed patients had increased risk of developing swine flu, but most ($n = 204$, 81.0% patients; $n = 89$, 89.9% family members) correctly identified patients' greater risk of developing complications. Overall, 133 patients (52.7%), but only 28 family members (27.7%), were worried they might die from swine flu, while 65 (66.3%) family members had such concerns for their relative with chest problems. Eighty-eight patients (34.8%) and 31 family members (30.7%) agreed that 'too much fuss is being made about swine flu', particularly by the mass media. Qualitative data mirrored survey findings and the data extracts below were typical:

> No, I mean obviously it crossed my mind and I thought, you can't just isolate yourself, you can't make the front door a barrier because there's germs out there, you've just got to get on with it, just got to get on with your life.

> I only knew what I knew from the news and the papers, like thousands were going to die and all this … [at] the time you believe what you're hearing because you don't know any different and it's quite frightening.

Behaviours

The preventative measures most commonly adopted were increased frequency of hand-washing ($n = 107$, 42.8% patients; $n = 38$, 37.6% family members) and greater use of sanitising hand gel ($n = 100$, 40.5% patients; $n = 37$, 36.6% family members). Most ($n = 171$, 68.4% patients; $n = 70$, 69.3% family members) thought swine flu vaccination would be helpful. 212 patients (83.8%) and 69 family members (68.3%) were very/fairly likely to take up swine flu vaccination, with 84 family members (83.2%) believing that patients should do so. The most common help-seeking behaviour of patients if swine flu was suspected would have been phoning their GP ($n = 81$, 32.0%), but for family members it was staying at home and self-treating ($n = 31$, 30.7%). Media reports influenced likely behaviour, particularly with respect to uptake of swine flu vaccination and use

of antiviral medication. Again, qualitative data echoed survey findings, as these data extracts illustrate:

> No, it's not altered me at all, no. I've just carried on normally… yes, I've started washing my hands regular, I have done that … But as far as being in crowds, no, that hasn't bothered me.

> Well straight, I'd phone the doctor straight away and probably be advised by them. If for any reason I suppose I couldn't get through to the doctor I'd probably phone the helpline, the NHS [Direct] helpline … and see what advice they gave me.

> I think a lot of it, you know, when you read it in the press … I think reports in the press when they say, only 25% of national health workers, the nurses, what have you, have agreed to have it. That then makes me think they know something I don't or – so to me it's very negative the way it's been put into the press, very negative.

Out of all of the bivariable associations between participant characteristics and key outcomes (perceived knowledge about swine flu, concern about the 'fuss' raised over swine flu and intention to have the swine flu vaccination) investigated for patients, only three were statistically significant at the 5% level. Participants educated to degree level or above were more likely to feel that they knew as much as they needed to know or knew quite a lot (66.7%) than those educated to a lower level (50.0%) and with no formal qualifications (34.4%, $\chi^2_{TREND} = 9.25$, df = 1, $p = 0.002$). Participants living alone were more likely to agree that 'Too much fuss is being made about the risk of swine flu' than those living with a partner (45.9% versus 31.5%, $\chi^2 = 4.16$, df = 1, $p = 0.041$). Fewer black and minority ethnic (BME) groups indicated that they were 'very likely' to have the swine flu vaccination (47.6% versus 71.7%, $\chi^2 = 5.23$, df = 1, $p = 0.022$).

In comparable analyses for family members, four different combinations of characteristic and outcome were statistically significant at 5%. Those considering that they knew as much as they needed to or knew quite a lot about swine flu tended to be younger [mean age 55.4 years, standard deviation (SD) 62.7] than those who did not (mean 62.7 years, SD 12.8, $t = 2.43$, df = 87, $p = 0.017$). Participants educated to degree level or above were again more likely to indicate that knew as much as they needed to/knew quite a lot about swine flu (85.7%) than those educated to a lower level (59.7%) and those with no formal qualifications (31.8%, $\chi^2_{TREND} = 12.65$, df = 1, $p < 0.001$). This was also true for feeling that they knew as much as they needed to (66.7% versus 34.2% versus 13.6%, $\chi^2_{TREND} = 12.74$, df = 1, $p < 0.001$). The respiratory diagnosis of the patient was not significantly associated with the family member's intention to have the swine flu vaccination when the miscellaneous 'other' category of diagnoses was included ($\chi^2 = 5.22$, df = 2, $p = 0.074$). However, when patients with diagnoses of asthma and chronic obstructive pulmonary disease (COPD) only were compared, more family members of asthma patients said that they were very likely to have the vaccination (73.7%) than family members of COPD patients (36.8%, $\chi^2 = 5.22$, df = 1, $p = 0.022$).

Conclusions

Our data suggest that people with chest problems and their family members were generally well informed regarding swine flu, but that some gaps in information-giving and knowledge remained. Better targeting of information towards the specific needs of people with respiratory conditions and their families was suggested. Information to help patients and family members discriminate between seasonal influenza, swine flu and symptoms of their respiratory problem was particularly highlighted; developing such information would be challenging, as symptoms overlap. Patients and family members suggested development of information to aid in understanding the likely impact of swine flu on respiratory problems; this need may extend to many long-term conditions.

Most patients and family members were not highly anxious about swine flu. There was some confusion regarding susceptibility to swine flu, suggesting a need for improved communication of the message regarding this issue. Participants clearly recognised patients as being at greater risk than the general population of swine flu complications. Despite this, survey response rates, particularly amongst family members, suggest that the topic of swine flu may have had limited saliency by the time of data collection.

Behaviour change was modest but in line with recommendations from authoritative sources, and

there appeared to be good levels of penetration of some key messages regarding prevention and help-seeking. Vaccination intent was very high in this sample, which may have been due, in part, to effective communication of risk, but may also have been influenced by sample composition. Some concerns about vaccination, especially with regard to safety and interaction with underlying respiratory problems and associated medications, were apparent. This suggests that there is more to be done to ensure appropriate communication of risk. It is also somewhat paradoxical, given the high levels of vaccination intent.

The influence of the mass media on perceptions of, and responses to, the pandemic was apparent, especially within the qualitative data. In particular, questioning in the mass media of the effectiveness of antiviral medications may have affected views on and willingness to take these. Our data highlight a contradiction with respect to the role of the mass media as a communication medium within a pandemic, in that they were widely used but of questionable credibility. Likewise, the data highlight tensions between the use of mass media as a means of raising awareness versus its potential to reduce interest in a pandemic through perceived oversaturation, 'hyping' or misrepresentation of issues.

Recommendations for future research

- Work to identify effective means of delivering targeted information to high-risk groups during a pandemic would be of particular value.
- Follow-up work to establish whether vaccination intentions were followed through (and, if not, why this was the case) would be of value. It would also be interesting to establish why these patients and family members were so highly motivated and whether this could provide lessons for future vaccination programmes.
- Further research to improve understanding of risk perception (from the effects of swine flu and from vaccination) and its influence on decision-making in high-risk groups is needed and could make a valuable contribution to the efficacy of future vaccination programmes.
- Future work is needed to establish whether issues identified by our participants regarding the role of the mass media would also be raised by people with respiratory conditions more widely or by other high-risk groups.
- Given the extensive reporting of the pandemic by the mass media and, indeed, the use by health-related agencies of the mass media to communicate pandemic-related messages, work is urgently needed to explore further the influence of mass media reports on pandemic-related knowledge and behaviour in high-risk groups, and to better understand how mass media can most effectively be used to communicate risk data, especially to high-risk groups, in a pandemic.
- Issues of saliency suggest lessons for timing of future comparable research within a pandemic.
- Our experiences highlight the need to recognise, and develop strategies to overcome, the challenges of including 'hard-to-reach' groups (including family members, BME groups and young adults) when undertaking short projects in the context of an ongoing pandemic.

Study registration

The study has been registered as REC/IRAS (Ref 09/H1015/76) and NIHR CSP (Ref 32483).

Chapter 1
Introduction

Respiratory conditions are highly prevalent in the UK and are the most common reason for general practice consultations and emergency medical admissions to hospital.[1–2] People with respiratory conditions are at high risk for 'seasonal' influenza, and annual vaccination is recommended. However, uptake in 2008–9 was only 45.3%, which, although close to the national average for 'at-risk' groups (47.1%), is below that seen in some other long-term conditions (e.g. coronary heart disease 54.6%, diabetes 67.5%, diabetes on medication 70.6%, stroke/transient ischaemic attack 57.3%).[3] Although vaccination against seasonal influenza is recommended for main carers of individuals with long-term conditions, uptake amongst these in 2008–9 was low (39% of those eligible).[3] People with respiratory conditions have been identified as being at greater risk for developing complications of 'swine flu' – both by authoritative sources[4–8] and in mass media reports that are likely to be read by patients and their family members.[9,10]

During 2009, from the first emergence of H1N1 swine flu cases in Mexico in April 2009, up to the declaration by the World Health Organization (WHO) of a pandemic in June 2009 and beyond, a plethora of information about swine flu appeared, especially on the internet. However, its quality has been variable, and sometimes questionable, with some websites even offering, for sale, dubious 'prevention guides' or 'miracle cures'.[11–14] Some have argued that wide availability of information has resulted in 'an informed public',[15] and an Ipsos MORI poll conducted in May 2009, ahead of the declaration of a pandemic, suggested that individuals felt generally well informed about swine flu.[16,17] However, the same poll also found that over 50% of the 1000 members of the general population polled did not think that swine flu information they had received applied to them.[16,17] At the start of the pandemic there was little specific information available to patients with chest problems and their families from authoritative sources. Although this did change slightly during 2009, the amount of respiratory condition-specific information on swine flu has remained low, and little is known about whether available information met the needs of patients and their families.

The need to balance raising awareness of the pandemic and associated risks against creating undue anxiety, particularly in at-risk groups, was identified.[18–22] Successful 'public communication of risk and uncertainty' was suggested as having a 'critical role' in this.[20] Likewise, the challenges of overcoming complacency or scepticism, either about government-provided information or about the 'real' threat from swine flu, have been highlighted.[17] The WHO and the United Nations Children's Fund (UNICEF) identified the need for 'assessment of knowledge, awareness and perceptions' in at-risk populations in relation to the pandemic.[23]

Government agencies in the UK and elsewhere have provided the public with recommendations regarding preventative measures (e.g. hand-washing, use of tissues) and other behaviours (e.g. self-management, help-seeking),[5,24] some of which have a strong evidence base.[25] The level of 'penetration' (e.g. reaching target groups, uptake of advice) of these recommendations in at-risk groups, such as those with chest problems, is not currently well known.

Previous behaviour-focused public health initiatives regarding respiratory viruses, which used a range of media and approaches, have met with mixed success.[26–29] A survey conducted shortly before the pandemic was declared[16,17] found that 62% of those studied were not undertaking recommended preventative measures. The same study also found low levels of 'avoidance behaviours' (e.g. limiting contact with others). This study, however, involved the general population; whether behaviours have differed in at-risk populations is unclear.

Pressure on services was being reported even before the declaration of the pandemic in June 2009,[18,30] and the launch of the National Pandemic Flu Service (NPFS) towards the end of July 2009[31] was, in part, in response to this; the importance of individuals using services appropriately is therefore apparent. The need for appropriate self-management and advance planning by those with long-term conditions and their families during the pandemic was highlighted.[7,32,33] Equally, however,

given the higher risk of complications in patients with chest problems who develop swine flu, the importance of patients and family members being able to recognise and appropriately respond to symptoms, and seek help when needed, was identified.[4,23,31–33]

In light of these considerations, a study that explored information needs, concerns and behaviours of patients with chest problems and their family members was proposed.

Chapter 2
Methods

Research objectives

1. To explore in samples of people with existing respiratory conditions and their family members:
   i. information needs (priority topics of information, preferred sources of information, perceived usefulness of available information, gaps in knowledge/misconceptions) regarding the current swine flu pandemic.
   ii. concerns (perceptions regarding susceptibility, risk of complications, risk of death) regarding the current swine flu pandemic.
   iii. health-related behaviours (adoption of recommended preventative measures, avoidance behaviours, anticipated use of health services) with respect to the current swine flu pandemic.
2. To compare information needs, concerns and health-related behaviours of patients and family members.
3. To explore associations between the above factors and condition-related/demographic variables.

Study design

Primary research, adopting a mixed-methods, exploratory design, involving quantitative (postal and telephone surveys) and qualitative (focus groups and one-to-one interviews) elements.

Setting

The study was conducted in North West England. This region has a population of 6.7 million, covering a large geographic area from Cumbria in the north to Merseyside and Cheshire in the south.[34] It has two large cities: Manchester and Liverpool. In 2007, 16.2% of the population were aged 65 years or older, and 89% identified themselves as 'white British'.[35] The region's strategic health authority, NHS North West, has responsibility for 24 primary care trusts, 38 hospital trusts (23 acute trusts, seven specialist trusts and eight mental health trusts; 27 trusts had achieved foundation trust status as at June 2010) and the North West Ambulance Service.[36] The region as a whole has consistently higher unemployment and poorer health outcomes (including life expectancy and respiratory disease rates) than are typical for the UK, although there is marked intraregional variation.[37]

Target population

Adults (18+ years) with a clinician-diagnosed chest problem (long-term, non-cancerous conditions, all severity levels) and close family members (18+ years) of such individuals. Both patient–family member dyads and singletons from either group were recruited.

Our definition of family members included spouses/partners; children (only if aged 18+); parents of adult (18+ years) patients; siblings; and other close relatives, such as aunts, uncles, nephews, nieces and cousins. Family members either self-nominated or were given a questionnaire pack by their family member with chest problems.

Inclusion/exclusion criteria

The same inclusion and exclusion criteria were used for survey, focus group and interview elements.

Patients

Inclusion

- Adult (18 years or over).
- Clinician-diagnosed long-term respiratory condition [(including asthma, chronic obstructive pulmonary disease (COPD), interstitial lung disease (ILD), allergic bronchopulmonary aspergillosis (ABPA), cystic fibrosis, bronchiectasis, chronic cough, tuberculosis] of any severity.
- Able to provide informed consent to participate.
- Able to complete an English-language questionnaire or participate in a focus group conducted in English.

Exclusion

- Under the age of 18 years.
- Acute respiratory illness.
- Cancer diagnosis as main respiratory problem (as the focus was on long-term conditions).
- Unable to give informed consent.
- Unable to complete English-language questionnaire or participate in focus group conducted in English.

Family members

Inclusion

- Adult (18 years or over).
- Family member of patient with clinician-diagnosed long-term, non-cancerous respiratory condition.
- Able to provide informed consent to participate.
- Able to complete an English-language questionnaire or participate in a focus group conducted in English.

Exclusion

- Under the age of 18 years.
- Unable to give informed consent.
- Unable to complete English-language questionnaire or participate in focus group conducted in English.

Each of the study components (survey, focus groups and one-to-one interviews) will now be described in more detail.

Survey

Design

Cross-sectional questionnaire survey,[38] involving postal and telephone elements.

Sites

Survey participants were recruited through distribution of questionnaires at seven hospital chest clinics (four district general hospitals, two university teaching hospitals and one specialist centre/tertiary referral centre), from British Lung Foundation (BLF) 'Breathe Easy' patient/carer support groups ($n = 7$ across the North West region) and via a newspaper advertisement (this approach, rather than recruiting through general practices, was adopted because of the extra demand on primary care services due to the pandemic and previous experience of the challenges of conducting research in primary care). The hospital sites all ran several chest clinics each week, with the specialist centre running the most clinics. The sites all had diverse patient populations, including asthma, COPD and ILD, and, at the specialist centre, other conditions, such as ABPA.

Sample

In each group, a sample of $n = 171$ would allow estimation of 95% confidence intervals for percentages with a margin of error of ± 7.5%. The aim was therefore to recruit a minimum $n = 200$ patients and $n = 200$ family members to allow for exclusion of incomplete data sets.

Methods

Study packs (including patient/family member information sheets, consent forms, questionnaires and pre-paid return envelopes) were distributed by clinic staff (typically receptionists or clinic assistants) to consecutive patients attending chest clinics at the seven study sites between October and December 2009 (commencement of data collection was not simultaneous, for operational reasons, at some sites, hence data collection periods ranged from 6 to 12 weeks). Patients self-completed the questionnaire either in clinic (returning it to a drop-off point or clinic staff) or at home, returning it by post. Patient packs contained a family member pack and instructions for the patient regarding distribution of this; family questionnaires were therefore typically returned by post.

For BLF 'Breathe Easy' groups, packs were distributed to members by the group Chair, either at monthly meetings or by post (with a covering letter from the Chair) between November 2009 and January 2010; all questionnaires were self-completed at home and returned by post.

The newspaper advertisement ran once, in the *Manchester Evening News*, a daily newspaper that has wide circulation across the North West of England. It is free within Greater Manchester and distributed at rail stations, etc. It has a readership of approximately 0.5 million, more than one-half of whom are 15–44 years old. It is commonly used to run health-research-related stories and to place study advertisements. It was the publication recommended by the University of Manchester's media team as the best mapping on to the population of choice and being most likely to yield a good response. The advertisement ran on a Thursday (12 November 2009), which

is a particularly good day, as it is when jobs are advertised, hence readership is at its highest. Our advertisement was prominently placed, on p. 2 of the newspaper, and was followed the next day by a short article in the paper regarding the study. It included a study-related telephone number and, after an eligibility check, those who responded were either mailed a study pack for self-completion and return by post or the survey was undertaken over the telephone, according to the participant's preference. A copy of the advertisement is provided in Appendix 1; its wording was guided by our User Reference Group (members of the Central Manchester British Lung Foundation 'Breathe Easy' Group, who have worked with us for several years, advising on such aspects as priority topics for research; study design, especially acceptability and respondent burden; development of patient information sheets and lay summaries of findings), and was also to some extent dictated by requirements of the Research Ethics Committee that reviewed the study.

Instrument

Data were collected by means of patient and family member-specific questionnaires (see Appendices 2 and 3), developed de novo for the study. De novo development was necessary, as no appropriate tool already existed. Questionnaire development was guided by review of the literature[24–29,39–42] (including relevant theory, such as the Health Belief Model[42,43]), pooling of expertise in the project team, and guidance from a User Reference Group (all people with chest problems and/or their family members); where appropriate, items from the Ipsos MORI poll[16,17] were included/adapted. Topics that were addressed included: level of knowledge about swine flu; key information topics; sources of information; perceived usefulness of available information; concerns about swine flu; performance of recommended preventative measures; other behaviours (avoidance, health promotion, use of current medication); and anticipated use of health services. Questions regarding demographic and condition-related data were also included, with choice of items guided by previous work.[16,17,24–29]

The questionnaires were piloted with the User Reference Group, and independently reviewed by a researcher with related experience and two respiratory health-care professionals, and were then revised in response to feedback from these. Piloting established face validity. Psychometric testing was not undertaken owing to the exploratory nature of this study and the rapid turnaround required.

Data analysis

Data were entered into SPSS v15.0 and analysed descriptively. Patient and family member responses were first compared descriptively. We originally intended to fit logistic regression models to assess the association between characteristics of participants and key outcome variables. The latter were selected to represent the three areas of interest in the study (knowledge/information needs; concerns and behaviours):

- perceived level of knowledge about swine flu (recoded for simplicity in two ways as 'As much as I need or want to know' – yes/no, and 'As much as I need or want to know/Quite a lot but I'd like to know more' – yes/no)
- concerns about swine flu (strongly agree or tend to agree with 'Too much fuss is being made about the risk of swine flu' – yes/no)
- intentions about swine flu vaccination (very likely to have swine flu vaccination – yes/no).

The associations between these and characteristics of the participants were assessed first in bivariable analysis using Pearson's chi-squared test for gender, married/living with a partner, ethnicity and respiratory diagnosis, the chi-squared test for trend for highest level of education, and the unpaired *t*-test for age. For patients, only one association turned out to be statistically significant for each of the three outcomes, and it was considered that there was sufficient association present to warrant a more in-depth multivariable analysis using logistic regression. For family members, two associations were statistically significant for perceived knowledge about swine flu and one for each of the other outcomes. The smaller sample size for family members and the limited degree of association both counted against further analysis using logistic regression.

Focus groups

Design

Dual moderator focus groups.[44,45]

Sites

Focus groups were conducted at community-based meetings of BLF 'Breathe Easy' patient support groups across the North West; the aim was to undertake four to six groups. Selection of groups (from among the $n = 25$ in the region) was guided by the BLF's regional development team (who helped us to identify well-established, well-attended groups and advised regarding the

characteristics of these) and by the willingness of groups to participate (none was required to do so); none of the groups had been involved in the survey. Group Chairs were contacted to discuss possible participation of their group and to identify an appropriate meeting date to attend (or, if preferred, to set up a study-specific meeting). Groups were provided with information about the study and at which of their meetings it would take place, ahead of the focus group, in order to enable the group as a whole and individual members to decide regarding participation.

Sample

Focus groups typically involve 8–12 members per group.[44,45] Group sizes in the present study were determined by usual attendance at the BLF 'Breathe Easy' groups (typically $n = 8$–10 attendees, but up to $n = 30$ possible). The aim was to conduct 4–6 focus groups, with an expected sample size of 32–60 participants; this is typical of focus group studies and is at the higher end of recommended sample sizes for qualitative work.[46,47]

Methods

A 'focused conversation' style of interviewing was adopted.[46,47] Discussion was focused using a topic guide (see Appendix 4). Each focus group was, with participants' permission, audio recorded. A 'dual-moderator' focus group approach (whereby one moderator led discussion and another facilitated conduct of the group and took notes) was adopted.[44,45] Each focus group lasted approximately 1 hour and was conducted on one occasion.

Instrument

A topic guide was developed for the study. It addressed the main topics covered in the questionnaires (information needs, concerns and behaviours), the purpose of the focus groups being to explore these issues in greater depth. The guide was used to focus discussion, rather than being a compulsory list of topics to be addressed. Data collection was iterative, hence the topic guide was amended based on issues raised in/emerging from each focus group.

Data analysis

Each focus group was transcribed verbatim. Field notes for each focus group were typed up and appended to the relevant transcript. Framework analysis[48] was used; this is a well-recognised qualitative analysis technique, which is gaining increasing popularity in health services research. It involves the following stages: (1) familiarisation; (2) identifying a thematic framework; (3) indexing; (4) charting; and (5) mapping and interpretation. Analysis occurred within and across transcripts. At least two team members independently coded each transcript and agreed the final coding used. Standard approaches to maintain rigour in qualitative research were adopted.[46,47,49]

Interviews

Design

One-to-one audio-recorded interviews with a purposively selected subsample of survey and focus group participants.[46,47]

Sites

Interviews were conducted in participants' homes, or another location of the participant's choosing.

Sample

The aim was to recruit a purposive subsample[46,47] of up to $n = 20$ individuals from amongst survey and focus group participants; these could be patient–family member dyads or singletons from each group. Purposive sampling criteria primarily related to responses to questionnaire items regarding knowledge, concerns and behaviours. Age, gender, respiratory condition, patient/family member status were also considered. The goal was to secure a range of perspectives.

Methods

A 'focused conversation' style of interviewing was adopted.[46,47] Discussion was focused using a topic guide and by the individual participant's questionnaire responses or issues they raised in the focus group. Each interview was audio recorded, with the participant's permission.

Instrument

The topic guide was as described in 'focus groups' above (see Appendix 4). Additional, individualised questions regarding responses to the questionnaire or issues raised in the focus group were asked.

Data analysis

Data analysis and steps to ensure rigour was as described in 'focus groups' above.[46–49]

Chapter 3

Results: survey

Characteristics of the sample

Questionnaires were distributed to hospital chest clinics and BLF 'Breathe Easy' groups in the North West, typically at weekly intervals, between October 2009 and January 2010. The first patient questionnaire was completed on 12 October 2009 and the last on 5 February 2010, while the first family member questionnaire was completed on 17 October 2009 and the last on 2 February 2010. The number of questionnaires returned from each site varied considerably, which, in part, reflected the size of the respiratory patient population/number of chest clinics at each site. Two sites had very low returns ($n = 2$ and $n = 7$ patient questionnaires, and $n = 0$ and $n = 3$ family questionnaires, respectively), which reflected ongoing problems with staff commitment to distributing questionnaires. At other sites, the number of patient questionnaires returned ranged from $n = 21$ to $n = 83$ and family questionnaires from $n = 9$ to $n = 33$, the highest recruiter being the specialist centre that had the largest patient population/number of chest clinics.

A total sample of 355 patients and family members was recruited (*Table 1*); after exclusion of one very incomplete family member data set, the final sample was 354. The recruitment rate for patients was modest, but not atypical for surveys of this type,[50,51] while family member recruitment was very low and, despite vigorous efforts to increase it, did not reach the minimum of $n = 200$ which had been sought. The newspaper advertisement, which ran on 12 November 2009, yielded a very poor response, with only 16 enquiries, all from patients, although seven of these completed questionnaires (six postal returns and one completed by telephone). Although patients and family members aged < 18 years were excluded from the surveys, we anticipated that some parents of patients < 18 years might respond to the newspaper advertisement, but this did not occur. Placement of a second advertisement (and also of one focusing specifically on family members) was considered but rejected owing to the very poor initial response, high cost and the fact that it required a team member to be on hand all day for approximately 1 week to take calls, which was not considered a good use of time given the low response to the first advertisement.

Characteristics of the 354 participants who were included in the analysis are detailed in *Table 2*.

Table 3 details relationships that the family member sample ($n = 101$) had with their relative with a respiratory condition; more than one-half were spouses, although other relationships, including daughter/son, were also represented.

TABLE 1 *Patient and family recruitment rates for each route* (n = *355)*

Recruitment route	Distributed patient	Returned patient (*n*, %)	Distributed family[a]	Returned family (*n*, %)
Chest clinics	949	207 (22)	949	85 (9)
BLF 'Breathe Easy' group	207	39 (19)	207	17 (8)
Newspaper advertisement	16	7 (44)	7	0
Total	*1172*	**253 (22)**	*1163*	**102 (9)**[b]

a One family member questionnaire went out with each pack but not all will have been passed on by patients to family members.
b One family member questionnaire was excluded as incomplete, leaving $n = 101$ in the family member sample and a combined total sample (patient and family) of $n = 354$.

TABLE 2 *Characteristics of the sample*[a]

Characteristic	Patients (%)	Family members (%)
Age in years		
Median	66	62
Mean	62.9	58.7
SD	13.4	14.3
Range	20–87	18–84
Gender		
Male	99 (39.6)	36 (37.9)
Female	151 (60.4)	59 (62.1)
Highest level of education		
No formal qualifications	69 (30.1)	22 (25.6)
Subdegree level[b]	119 (50.1)	41 (47.6)
Degree level and above	34 (14.8)	23 (26.8)
Married/living with a partner		
Yes	183 (75.0)	75 (74.3)
No	61 (25.0)	17 (25.7)
Ethnicity		
White British	215 (91.1)	87 (98.9)
Other	21 (8.9)	1 (1.1)
Respiratory diagnosis		
	Self	**Of relative with chest problem**
COPD	74 (31.8)	19 (20.4)
Asthma	54 (23.2)	19 (20.4)
Other[c]	81 (34.7)	40 (43.0)
Don't know	24 (10.3)	15 (16.1)

SD, standard deviation.
a Most items had some missing data, hence numbers do not always equal total sample size; percentages given are of valid responses.
b Includes professional qualifications.
c Includes ILD, ABPA and bronchiectasis.

TABLE 3 *Relationships of family member sample (n = 101) with their relative with a respiratory condition*

Relationship	No. (%) of family members
Wife	30 (29.7)
Husband	26 (25.7)
Daughter	14 (13.9)
Son	4 (4.0)
Parent[a]	8 (7.9)
Other	9 (8.9)
Not specified	10 (9.9)

a Owing to inclusion criteria for patients, all were parents of an adult aged 18 years or over.

'Topline' data regarding information needs/knowledge, concerns and behaviours are provided within the main body of the report; more detailed data are provided in Appendix 5. Note that most items had some missing data; percentages given are of valid responses for each item unless otherwise stated.

Information needs and knowledge

Information needs and topics

Table 4 presents data regarding perceived level of knowledge about swine flu.

TABLE 4 *Perceived level of knowledge about swine flu*

How much do you know about swine flu?	Patients: *n* = 253 (*n*, %)	Family members: *n* = 101 (*n*, %)
None of the things I need or want to know	15 (5.9)	3 (3.0)
A bit but I'd like to know more	111 (43.9)	38 (37.6)
Quite a lot but I'd like to know more	47 (18.6)	17 (16.8)
As much as I need or want to know	62 (24.5)	37 (36.6)
No response	18 (7.1)	6 (5.9)

Most participants did not identify particular topics on which they would have liked additional information. Among those who did, the most common for patients were how swine flu would affect people with chest problems ($n = 27$), how serious swine flu is for people with an underlying chest problem ($n = 16$) and how to recognise swine flu symptoms ($n = 14$), and, for family members, the difference between swine flu and other types of flu ($n = 10$) and how to recognise swine flu symptoms ($n = 8$).

Participants' views on the importance of a range of information topics are presented in Appendix 5, *Tables 18* and *19*. All topics were rated as 'very important' by 50% or more of participants. Patient and family member responses were broadly comparable. The topic most commonly selected as 'very important' by both patients and family members was 'How "swine flu" might affect chest problems' (patients $n = 202$, 81.5%; family members $n = 86$, 86.0%). Other topics relating to the effect of swine flu on people with chest problems and recognition of swine flu symptoms also had high percentages rating them as 'very important'. The topic least often rated as 'very important' by patients was 'Whether the families of people with chest problems are more likely to catch swine flu than others' ($n = 128$, 52.7% compared with family members $n = 56$, 56.6%) and by family members was 'How likely it is that you will catch swine flu' ($n = 50$, 50.0% compared with patients $n = 158$, 64.0%).

Information sources

The majority of both patients ($n = 187$, 73.9%) and family members ($n = 78$, 77.2%) had already received information about swine flu. Detailed data regarding sources of information are presented in Appendix 5, *Table 20* (note: participants could indicate more than one source); patients' and family members' views on the importance of information sources were generally very similar.

The most common source for both patients and family members was 'leaflet delivered to my home' (patients $n = 125$, 49.4%; family members $n = 55$, 54.5%), followed by 'television' (patients $n = 116$, 45.8%; family members $n = 44$, 43.6%). Other common sources were 'poster displayed at GP surgery' (patients $n = 109$, 43.1%; family members $n = 37$, 36.6%) and 'newspaper' (patients $n = 91$, 36.0%; family members $n = 36$, 35.6%).

General practitioners (GPs) were the health professionals most often used as an information source (patients $n = 75$, 29.6%; family members $n = 21$, 20.8%). Lay advice from family members and relatives was used by sizeable percentages of both samples, and, indeed, was more commonly used than the GP by family members (patients $n = 54$, 21.3%; family members $n = 23$, 22.8%) Unsurprisingly, more patients than family members cited 'hospital consultant/specialist doctor' as an information source (patients $n = 48$, 19.0%; family members $n = 10$, 9.9%). Interestingly, very few patients or family members had used a community pharmacist as a source of information (patients $n = 12$, 4.7%; family members $n = 4$, 4.0%).

Modest use as an information source was made of resources such as the NPFS, the 'NHS Choices' website and NHS Direct (see Appendix 5, *Table 20*), although a little more use was made of the government's 'pandemic flu' website – www.direct.gov.uk/pandemicflu (patients $n = 26$, 10.3%; family members $n = 15$, 14.9%). None of those who selected 'other' (neither patients nor family members) specified what source this was.

Detailed data regarding the perceived usefulness of a range of information sources for people with respiratory problems and their families are presented in Appendix 5, *Tables 21* and *22* (figures in italics indicate whether individuals would personally have utilised a particular information source). Views on usefulness of information sources were broadly comparable in patients and family

members, as was reported likelihood of personally using a particular information source. Generally, fewer people (both patients and family members) indicated that they would personally 'definitely' have used an information source than rated it as 'very important' for people with respiratory problems and their families, although the differences were often small.

The two information sources most commonly identified as 'very useful' by both patients and family members were doctors, i.e. GPs (patients $n = 188$, 75.2%; family members $n = 78$, 77.2%) and hospital consultants (patients $n = 190$, 76.9%, $n = 73$, 72.3%). Despite being the most common source of information, only 79 patients (31.2%) and 35 family members (34.7%) identified leaflets as a 'very useful' information source. Similarly for television, only 80 patients (32.5%) thought it 'very useful' [and only $n = 49$ (21.0%) would personally 'definitely' have used it], whereas among family members only $n = 31$ (30.7%) considered television 'very useful' and only $n = 17$ (18.3%) would 'definitely' have used it personally. The NPFS was considered 'very useful' as an information source by 124 patients (51.0%) and 55 family members (55.0%), whereas the government's pandemic flu website was identified as a 'very useful' information source by only 79 patients (33.2%), but by a higher percentage of family members ($n = 45$, 45.5%).

Knowledge

To explore knowledge regarding swine flu, participants were asked a series of 'true/false' questions; these data are presented in Appendix 5, *Tables 23* and *24*. In most instances, the majority of both patients and family members could correctly identify which items were 'true' and 'false'. In line with official government information, most patients and family members identified statements regarding the value of hand-washing and use of antibacterial gels in preventing the spread of swine flu as 'true' (hand-washing – patients $n = 240$, 96.8%, family members $N = 96$, 99.0%; antibacterial gels – patients $n = 177$, 72.2%, family members $n = 68$, 70.1%).

There was some confusion about who was most at risk of developing swine flu. Most patients ($n = 153$, 63.0%) and family members ($n = 67$, 69.1%) incorrectly identified people with respiratory problems as being more likely than others to catch swine flu. However, both groups correctly identified these patients' greater likelihood of developing complications following contraction of swine flu. Most patients ($n = 171$, 70.7%) and family members ($n = 64$, 67.4%) incorrectly identified the very young as being most at risk of developing swine flu. A sizeable percentage of both patients (96, 39.8%) and, even more so, family members ($n = 44$, 45.8%) also incorrectly identified older people as having the greatest likelihood of developing swine flu.

There was also some confusion regarding antiviral medications, with 138 patients (56.3%) and 48 family members (50.5%) incorrectly identifying oseltamivir as a vaccine for swine flu, rather than as an antiviral medication. Similarly, 138 patients (59.0%) and 49 family members (51.6%) thought that family members of a person with swine flu would routinely be given antiviral medication, which was contrary to Health Protection Agency (HPA) guidance[52] and official government information for the public.[53]

Ability to identify swine flu symptoms was also explored (see Appendix 5, *Tables 25* and *26*); this is difficult, as there are few (arguably no) distinct symptoms of swine flu.[54] Official guidance to the public at the NHS Choice website[55] indicated that swine flu should be suspected in the presence of fever or high temperature (> 38°C/100.4°F) accompanied by one or more of the following: unusual tiredness, headache, runny nose, sore throat, shortness of breath or cough, loss of appetite, aching muscles, and diarrhoea or vomiting. The majority of both patients and family members identified most of these symptoms as possibly being due to swine flu. However, only 99 (44.6%) of patients identified 'diarrhoea or stomach upset' as possibly being associated with swine flu (although $n = 62$, 66.0% of family members did so) and only 43 (47.8%) of family members associated 'loss of appetite' with swine flu (although $n = 135$, 60.5% of patients did so). Some symptoms in the list had not been indicated in official literature as being suggestive of swine flu (e.g. rash, sudden inability to move limbs) and most patients and family members identified these as not being suggestive of swine flu (see Appendix 5, *Tables 25* and *26*).

Appropriateness of Information

Table 5 presents data regarding satisfaction with the amount of information received and *Table 6* presents participants' views on whether the information was helpful or not. Few in either group who thought that information was unhelpful gave

TABLE 5 *Satisfaction with the amount of information received about swine flu – patients (n = 253) and family members (n = 101)*

	How satisfied or dissatisfied are you with the amount of information available to you on swine flu from any source? (*n*, %)						
	Very satisfied	**Fairly satisfied**	**Neither satisfied nor dissatisfied**	**Fairly dissatisfied**	**Very dissatisfied**	**Don't know**	**No response**
Patients	50	83	58	28	19	9	6
	(19.8)	(32.8)	(22.9)	(11.1)	(7.5)	(3.6)	(2.4)
Family members	27	42	16	12	4	0	0
	(27.6)	(41.6)	(15.8)	(11.9)	(4.0)	(0)	(0)

TABLE 6 *Perceptions of helpfulness of information about swine flu – patients (n = 253) and family members (n = 101)*

	Do you think that the information currently available about swine flu is helpful or not? (*n*, %)			
	Yes	**No**	**Don't know**	**No response**
Patients	154	44	49	6
	(60.9)	(17.8)	(19.8)	(2.4)
Family members	77	10	14	0
	(76.2)	(9.9)	(13.9)	(0)

reasons why, but, among those who did, typical reasons were that there was insufficient information ($n = 29$) and that it was conflicting ($n = 12$).

As *Table 7* illustrates, slightly over one-half of both patients and family members believed that people with chest problems and their families need different information from others regarding swine flu. Few of either group specified exactly how this should differ, with the most common response across the two groups relating to how swine flu would affect the chest problem ($n = 28$).

Concerns

Tables 8 and *9* detail patients' and family members' concerns regarding swine flu and confidence in their ability to recognise and respond appropriately to the condition; *Table 10* presents data from family members with respect to patients.

Table 11 details patients' and family members' views regarding 'overhyping' of swine flu. The views of the two groups were broadly similar, and slightly more of each group indicated that swine

TABLE 7 *Views on whether information needs of people with chest problems and their families differ from those of others – patients (n = 253) and family members (n = 101)*

	Do people with chest problems (or their families) need different information about swine flu from other people, or not? (*n*, %)			
	Yes	**No**	**Don't know**	**No response**
Patients	141	61	46	5
	(55.7)	(24.1)	(18.2)	(2.0)
Family members	60	29	11	1
	(59.4)	(28.7)	(10.9)	(1.0)

TABLE 8 *Concerns and confidence – patients (n = 253)* (n, %)

Concerns/confidence	Very	Fairly	Not very	Not at all	Don't know
Worried about personally catching swine flu?	59 (23.4)	88 (34.9)	85 (33.7)	14 (5.6)	6 (2.4)
Believe self more likely to catch swine flu because of chest problem?	56 (22.1)	105 (41.5)	61 (24.1)	6 (2.4)	25 (9.9)
Believe self likely to develop complications of swine flu?	95 (37.7)	109 (43.3)	18 (7.1)	1 (0.4)	29 (11.5)
Worried that might die from swine flu?	52 (20.6)	81 (32.1)	62 (24.6)	41 (16.3)	16 (6.3)
Confident could recognise swine flu symptoms?	12 (4.8)	92 (36.8)	104 (41.6)	33 (13.2)	9 (3.6)
Confident would know what to do if thought had swine flu?	38 (15.2)	118 (47.2)	77 (30.8)	13 (5.2)	4 (1.6)
Confident could recognise complications of swine flu?	19 (7.6)	74 (29.6)	120 (48.0)	29 (11.6)	8 (3.2)
Confident that vaccination against swine flu will help?	60 (24.0)	111 (44.4)	50 (20.0)	14 (5.6)	15 (6.0)

Most items had some missing data.
Figures in parentheses = valid percentage.

TABLE 9 *Concerns and confidence – family members for themselves (n = 101)* (n, %)

Concerns/confidence	Very	Fairly	Not very	Not at all	Don't know
Worried about personally catching swine flu?	13 (12.9)	34 (33.7)	45 (44.6)	9 (8.9)	0 (0)
Believe self more likely than others to catch swine flu?	10 (9.9)	24 (23.8)	35 (34.7)	24 (23.8)	8 (7.9)
Believe self more likely than others to develop complications of swine flu?	7 (7.0)	23 (23.0)	40 (40.0)	16 (16.0)	14 (14.0)
Worried that they personally might die from swine flu?	7 (6.9)	21 (20.8)	35 (34.7)	34 (33.7)	4 (4.0)
Confident could recognise swine flu symptoms in self?	7 (6.9)	50 (49.5)	25 (24.8)	15 (14.9)	4 (4.0)
Confident would know what to do if thought they had swine flu?	21 (20.8)	59 (58.4)	12 (11.9)	7 (6.9)	2 (2.0)
Confident could recognise complications of swine flu in self?	10 (9.9)	45 (44.6)	31 (30.7)	11 (10.9)	4 (4.0)
Confident that vaccination against swine flu will help self?	21 (20.8)	49 (48.5)	18 (17.8)	4 (4.0)	9 (8.9)

Some items had some missing data.
Figures in parentheses = valid percentage.

TABLE 10 *Concerns and confidence – family sample regarding their family member with a chest problem (*n = *101)*(n, %)

Concerns/confidence	Very	Fairly	Not very	Not at all	Don't know
Worried about family member with chest problems catching swine flu?	45 (45.9)	31 (31.6)	20 (20.4)	2 (2.0)	0 (0)
Believe family member more likely than others to catch swine flu?	34 (34.3)	31 (31.3)	25 (25.3)	5 (5.1)	4 (4.0)
Family member more likely to develop complications of swine flu?	43 (43.4)	46 (46.5)	5 (5.1)	5 (5.1)	0 (0)
Worried that family member might die from swine flu?	30 (30.6)	35 (35.7)	24 (24.5)	4 (4.1)	5 (5.1)
Confident could recognise swine flu symptoms in family member?	8 (8.1)	48 (48.5)	32 (32.3)	8 (8.1)	3 (3.0)
Confident would know what to do if thought family member had swine flu?	21 (21.2)	50 (50.5)	21 (21.2)	5 (5.1)	2 (2.0)
Confident could recognise swine flu complications in family member?	14 (14.1)	42 (42.4)	32 (32.3)	8 (8.1)	3 (3.0)
Confident that vaccination against swine flu will help family member?	33 (33.5)	48 (48.5)	9 (9.1)	3 (3.0)	6 (6.1)

Some items had some missing data.
Figures in parentheses = valid percentage.

TABLE 11 *Views on whether swine flu has been 'overhyped' or not – patients (*n = *253) and family members (*n = *101)*

	'Too much fuss is being made about the risk of swine flu' (*n*, %)						
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know	No response
Patients	15 (5.9)	73 (28.9)	56 (22.1)	51 (20.2)	47 (18.6)	8 (3.2)	3 (1.2)
Family members	6 (5.9)	25 (24.8)	26 (25.7)	24 (23.8)	17 (16.8)	0 (0)	3 (3.0)

flu had not been overhyped than considered it had, with around one-quarter of each group being uncommitted.

Behaviours

Impact on daily living activities

Tables 27 and *28* in Appendix 5 present detailed data regarding reported impact of concerns about swine flu on daily living activities, including both health-promoting activities (e.g. increasing exercise, reducing smoking) and activity limitations (e.g. reducing social activities, limiting travel); family members were also asked if their relative with a chest problem had altered behaviour – these data are presented in the final column. Neither patients nor family members reported high levels of alteration of daily activities, and levels were generally even lower for family members than for patients. The most commonly reported behaviour changes in patients were avoiding crowded places ($n = 55$, 21.7%), trying to get more exercise ($n = 53$, 20.9%) and being more careful about taking regular medications ($n = 52$, 20.6%). In family members, the only behaviour changes that more than 10% of the sample indicated having made were avoiding crowded places ($n = 11$, 10.9%) and trying to get more exercise ($n = 14$, 13.9%).

Sizeable percentages of both patients and family members indicated that because of worries

about swine flu they were more anxious about the patient's chest problem (patients $n = 87$, 34.4%; family members $n = 39$, 38.6%), more aware of it than usual (patients $n = 81$, 32.0%; family members $n = 38$, 37.6%) and, especially among family members, constantly on the alert for changes in the patient's respiratory condition (patients $n = 89$, 35.2%; family members $n = 44$, 43.6%). One-quarter of patients also indicated that they were more self-conscious about their chest problem ($n = 64$, 25.3%); family members much less commonly reported feeling self-conscious about their relative's respiratory condition ($n = 13$, 12.9%).

It is important to note that these are self-reported, rather than observed, behaviour changes, and it is also possible that, although asked to consider behaviour specifically with regard to swine flu, some participants may have responded in more general terms.

Adoption of preventative measures

Self-reported levels of adoption of preventative measures are detailed in *Tables 12* and *13*.

Vaccination intentions

More than three-quarters of patients ($n = 197$, 77.8%) and almost two-thirds of family members ($n = 63$, 62.4%) reported having had flu once or more in the past; of these, 140 patients (55.3%) and 32 family members (31.7%) had done so more than once. Patients had more recent experience of flu, with $n = 107$ (42.3%) having had a flu bout within the past 5 years, the comparable figure for family members being $n = 27$ (26.8%).

Previous levels of regular uptake and current intentions regarding the annual seasonal influenza vaccination are provided in Appendix 5, *Tables 28* and *29*. *Tables 14* and *15* present data on intentions and views regarding swine flu vaccination.

Help-seeking

Only 98 patients (38.7%) and 39 family members (38.6%) reported having chosen someone to act as a 'swine flu friend/buddy'. Of those who had not, 58 patients (22.9%) and 29 family members (28.7%) did not think they needed one, while 74 patients (29.2%) and 26 family members (25.7%) did not know what one was. Fifteen patients (5.9%) and four family members (4.0%) did not know

TABLE 12 *Self-reported adoption of preventative measures – patients (*n = *253)* (n, %)

Preventative measure	More frequently	Less frequently	The same	Have not done it at all	Don't know
Washed hands with soap and water	107	1	141	1	0
	(42.8)	(0.4)	(56.4)	(0.4)	(0)
Carried tissues with you	72	5	144	28	0
	(28.9)	(2.0)	(57.8)	(11.2)	(0)
Avoided crowded spaces or large crowds	53	16	142	32	1
	(21.7)	(6.6)	(58.2)	(13.1)	(0.4)
Avoided public transport at peak times	42	11	109	73	3
	(17.6)	(4.6)	(45.8)	(30.7)	(1.3)
Used sanitising hand gel	100	1	92	54	0
	(40.5)	(0.4)	(32.7)	(21.9)	(0)
Worn a surgical mask	4	1	22	219	1
	(1.6)	(0.4)	(8.9)	(88.7)	(0.4)
Avoided touching your face with your hands	18	22	118	81	7
	(7.3)	(8.9)	(48.0)	(32.9)	(2.8)
Disinfected spaces where you live or work	64	6	127	51	0
	(25.8)	(2.4)	(51.2)	(20.6)	(0)
Avoided kissing or hugging people	35	28	130	55	0
	(14.1)	(11.3)	(52.4)	(22.2)	(0)

Some items had some missing data.
Figures in parentheses = valid percentage.

TABLE 13 *Self-reported adoption of preventative measures – family members (n = 101)* (n, %)

Preventative measure	More frequently	Less frequently	The same	Have not done it at all	Don't know
Washed hands with soap and water	38	3	60	0	0
	(37.6)	(3.0)	(59.4)	(0)	(0)
Carried tissues with you	22	3	67	9	0
	(21.8)	(3.0)	(66.3)	(8.0)	(0)
Avoided crowded spaces or large crowds	16	9	54	20	0
	(16.2)	(9.1)	(54.5)	(20.2)	(0)
Avoided public transport at peak times	15	8	40	32	5
	(15.0)	(8.0)	(40.0)	(32.0)	(5.0)
Used sanitising hand gel	37	2	45	17	0
	(36.6)	(2.0)	(44.6)	(16.8)	(0)
Worn a surgical mask	2	6	16	76	1
	(2.0)	(5.9)	(15.8)	(75.2)	(1.0)
Avoided touching your face with your hands	10	6	48	36	1
	(9.0)	(5.9)	(47.5)	(35.6)	(1.0)
Disinfected spaces where you live or work	21	4	53	23	0
	(20.8)	(4.0)	(52.5)	(22.8)	(0)
Avoided kissing or hugging people	11	9	53	27	1
	(10.9)	(8.9)	(52.5)	(26.7)	(1.0)

Some items had some missing data.
Figures in parentheses = valid percentage.

TABLE 14 *Intentions regarding uptake of swine flu vaccination in patients (n = 253) and family members (n = 101)* (n, %)

	Very likely	Fairly likely	Not very likely	Not at all likely	Don't know	No response
Patients	174	38	16	8	13	4
	(68.8)	(15.0)	(6.3)	(3.2)	(5.1)	(1.6)
Family members	53	16	14	10	7	1
	(52.5)	(15.8)	(13.9)	(9.9)	(6.9)	(1.0)

TABLE 15 *Family members' views regarding whether their relative with a chest problem should have the swine flu vaccine (n = 101)*

'Should your family member have the new swine flu vaccine or not?' (*n*, %)						
Definitely	**Probably**	**Not sure**	**Probably not**	**Definitely not**	**Don't know**	**No response**
64	20	10	1	1	2	3
(63.4)	(19.8)	(9.9)	(1.0)	(1.0)	(2.0)	(3.0)

whether they had an identified 'flu friend' or not. Eight patients (3.2%) and three family members (3.0%) gave no response.

Tables 16 and *17* present data regarding initial help-seeking intentions ('what would you do first?') by patients' family members if swine flu was suspected (*Table 16*) and, in the presence of swine flu, if complications were suspected (*Table 17*); family members were also asked to indicate what they would have advised their relative with a chest problem to do – these data are presented

TABLE 16 *Initial help-seeking intentions if swine flu was suspected – patients (n = 253) and family members (n = 101)*

Help-seeking behaviour	Patients (self) (*n*, %)	Family members (self) (*n*, %)	Family members (for patient) (*n*, %)
Go to A&E	19 (7.5)	4 (4.0)	7 (6.9)
Go to GP's surgery	22 (8.7)	7 (6.9)	7 (6.9)
Call GP/health centre	81 (32.0)	29 (28.7)	61 (60.4)
Call a health helpline	62 (24.5)	30 (29.7)	13 (12.9)
Call 'Swine Flu Information'	70 (27.7)	24 (23.8)	11 (10.9)
Stay at home and self-treat	53 (20.9)	31 (30.7)	2 (2.0)
Visit health-related website	12 (4.7)	7 (6.9)	1 (1.0)
Go to community pharmacist	2 (0.8)	1 (1.0)	1 (1.0)
Contact hospital chest clinic	45 (17.8)	N/A	8 (7.9)
Go to hospital walk-in chest clinic	5 (2.0)	N/A	0 (0)
None of these	5 (2.0)	3 (3.0)	0 (0)
Don't know	12 (4.7)	4 (4.0)	1 (1.0)
Other	4 (1.6)	1 (1.0)	0 (0)

N/A, not applicable.

TABLE 17 *Initial help-seeking intentions if complications of swine flu were suspected – patients (n = 253) and family members (n = 101)*

Help-seeking behaviour	Patients (self) (*n*, %)	Family members (self) (*n*, %)	Family members (for patient) (*n*, %)
Go to A&E	23 (9.1)	13 (12.9)	19 (18.8)
Go to GP's surgery	29 (11.5)	11 (10.9)	8 (7.9)
Call GP/health centre	136 (53.8)	56 (55.4)	57 (56.4)
Call a health helpline	22 (8.7)	10 (9.9)	7 (6.9)
Call 'Swine Flu Information'	25 (9.9)	10 (9.9)	6 (5.9)
Stay at home and self-treat	7 (2.8)	4 (4.0)	1 (1.0)
Visit health-related website	2 (0.8)	4 (4.0)	1 (1.0)
Go to community pharmacist	1 (0.4)	0 (0)	0 (0)
Contact hospital chest clinic	24 (9.5)	N/A	8 (7.9)
Go to hospital walk-in chest clinic	4 (1.6)	N/A	2 (2.0)
None of these	0 (0)	0 (0)	1 (1.0)
Don't know	4 (1.6)	0 (0)	1 (1.0)
Other	4 (1.6)	2 (2.0)	1 (1.0)

N/A, not applicable.

in the final column of each table. Note that these data represent behavioural intentions, not observed behaviour.

Participants were also asked to indicate help-seeking behaviour in relation to a list of symptoms, some of which were 'typical' swine flu symptoms (e.g. sore throat, aching muscles), others representing potential complications of swine flu (e.g. change of sputum colour, drowsiness/confusion) or being a 'red flag' symptom (e.g. haemoptysis) – these data can be found in Appendix 5, *Tables 30* and *31*. Family members were additionally asked about help-seeking for their relative with a chest problem in relation to these (Appendix 5, *Table 22*). Phrasing of respiratory symptoms was chosen to minimise confusion with 'usual' respiratory symptoms. Again,

it should be noted that these were self-reported/hypothetical, rather than observed, behaviours.

The vast majority of patients and family members reported that they would seek help in the presence of such symptoms as tachypnoea/dyspnoea (patients $n = 211$, 90.2%; family members for self $n = 82$, 86.3%; family members for relative with chest problems $n = 89$, 94.7%) and haemoptysis (patients $n = 211$, 90.2%; family members for self $n = 82$, 86.3%; family members for relative with chest problems $n = 89$, 94.7%). Interestingly, the percentage of patients who would have sought help for aching muscles ($n = 121$, 53.1%) and a sore throat ($n = 115$, 50.4%) were similar to the percentage who would have sought help for the more clinically significant symptom of drowsiness/confusion ($n = 135$, 59.7%). This was not the case for family members, either on their own or on behalf of their relative with a chest problem.

For all symptoms, family members reported being more likely to help-seek on behalf of their relative with a chest problem than on their own behalf – although the difference was minimal for haemoptysis.

Antiviral medication

Most patients and family members would have preferred to get oseltamivir on prescription (patients $n = 214$, 84.6%; family members $n = 73$, 72.3%), although around one in 10 patients ($n = 31$, 12.3%) and one-fifth of family members ($n = 21$, 20.8) would have welcomed 'over-the-counter' availability. Very few would have wanted to acquire oseltamivir without having to contact a health professional, for example via the internet or from a health food shop (patients $n = 3$, 1.2%; family members $n = 2$, 2.0%). One patient (0.4%) and one family member (1.0%) selected 'other', but did not specify what this would have been, while two family members (2.0%; no patients) chose 'don't know'. Four patients (1.6%) and three family members (3.0%) gave no response.

Self-reported behaviour with respect to obtaining a supply of oseltamivir, if needed, are presented in Appendix 5, *Table 33*; family members were also asked to indicate what they would have advised their relative with a chest problem to do – these data are presented in the final column. By far the most common action for patients and family members (on their own and their relative's behalf) would have been to telephone their GP (patients $n = 152$, 60.1%; family members on own behalf $n = 58$, 57.4%; family members for relative with a chest problem $n = 64$, 63.4%). Other commonly selected options were calling a health helpline (patients $n = 62$, 24.5%; family members on own behalf $n = 23$, 22.8%; family members for relative with a chest problem $n = 24$, 23.8%) and calling the NPFS (patients $n = 62$, 24.5%; family members on own behalf $n = 29$, 28.7%; family members for relative with a chest problem $n = 31$, 31.7%) and, for patients only, going to the GP's surgery ($n = 60$, 23.7%). Only 12 patients (4.7%) and one family member (1.0% on own behalf; none on relative's behalf) reported not knowing how to obtain a supply of oseltamivir if needed.

Bivariable analyses

Out of all of the bivariable associations between participant characteristics and key outcomes (perceived knowledge about swine flu, concern about the 'fuss' raised over swine flu and intention to have the swine flu vaccination) investigated for patients, only three were statistically significant at the 5% level. Participants educated to degree level or above were more likely to feel that, in terms of their perceived level of knowledge about swine flu, they knew as much as they needed to or knew quite a lot (66.7%) compared with those educated to a lower level (50.0%) and those with no formal qualifications (34.4%, $\chi^2_{\text{TREND}} = 9.25$, df = 1, $p = 0.002$). Participants living alone were more likely to agree that 'Too much fuss is being made about the risk of swine flu' than those living with a partner (45.9% versus 31.5%, $\chi^2 = 4.16$, df = 1, $p = 0.041$). Fewer of those from an ethnic minority background responded that they were very likely to have a swine flu vaccination (47.6% versus 71.7%, $\chi^2 = 5.23$, df = 1, $p = 0.022$).

Out of all the bivariable associations investigated for family members, four different combinations of characteristic and outcome were statistically significant at 5%. Those considering that they knew as much as they needed to or knew quite a lot about swine flu tended to be younger [mean age 55.4 years, standard deviation (SD) 62.7] than those who did not (mean 62.7 years, SD 12.8, $t = 2.43$, df = 87, $p = 0.017$). Participants educated to degree level or above were again more likely to feel that, in terms of their perceived level of knowledge about swine flu, they knew as much as they needed to or knew quite a lot (85.7%) compared with those educated to a lower level (59.7%) and those with no formal qualifications (31.8%, $\chi^2_{\text{TREND}} = 12.65$, df = 1, $p < 0.001$). This

was also true for feeling that they knew as much as they needed to (66.7% versus 34.2% versus 13.6%, $\chi^2_{TREND} = 12.74$, df = 1, $p < 0.001$). The respiratory diagnosis of the patient was not significantly associated with intention of the family member to have a swine flu vaccination when the miscellaneous 'other' category of diagnoses was included ($\chi^2 = 5.22$, df = 2, $p = 0.074$). However, when patients with diagnoses of asthma and COPD only were compared, more family members of asthma patients said that they were very likely to have the vaccination (73.7%) than family members of COPD patients (36.8%, $\chi^2 = 5.22$, df = 1, $p = 0.022$).

Chapter 4

Results: interviews and focus groups

Characteristics of the sample

Three focus groups, coded FG1–3, were conducted with BLF 'Breathe Easy' patient/carer support groups in the North West of England, between November 2009 and January 2010. These included a total of 30 participants, with an approximately equivalent number of males and females and a mix of ages and socioeconomic backgrounds; no focus group participants were from black and minority ethnic (BME) groups. We did not collect data regarding diagnosis from focus group participants, but from our knowledge of BLF 'Breathe Easy' group membership in the North West, we know that most members have COPD or are a family member of someone with this condition.

- FG1 was conducted on 18 November 2009. It lasted 45 minutes (with a further 15 minutes for introductions, etc.) and had seven participants (five patients and two family members).
- FG2 was conducted on 19 November 2009. It lasted 30 minutes (with a further 15 minutes for introductions, etc.) and had 14 participants (10 patients and four family members).
- FG3 was conducted on 19 January 2010. It lasted 40 minutes (with a further 15 minutes for introductions, etc.) and had nine participants (six patients and three family members).

A further three focus groups were planned, but were cancelled by the groups – two for local reasons affecting the group (hence rescheduling was not appropriate) and one owing to the poor weather in January 2010 (next meeting too late to reschedule).

Twenty one-to-one interviews were conducted between November 2009 and January 2010. Interviewees were purposively selected from survey participants, to reflect a range of age, gender, diagnosis and swine flu-related information needs, concerns and behaviours, including vaccination intentions. Nineteen interviews took place in participants' homes and one, at the participant's request, was conducted by telephone. Interviews typically lasted about 20 minutes (range 10–36 minutes); the short duration appeared to reflect the interviews being quite focused, interviewees having had prior opportunity (through completion of questionnaires) to consider their responses. Interviewees' median age was 67 years (range 34–85); 10 were male, 10 were female and 18 were 'white British'. Diagnoses (of patients or family members' relatives with a respiratory condition) were asthma ($n = 4$), COPD, including those who described their diagnosis as 'emphysema' ($n = 7$), ABPA ($n = 2$), ILD, specifically interstitial pulmonary fibrosis and sarcoidosis ($n = 2$), and others, including bronchiectasis and multiple respiratory diagnoses ($n = 4$), while one participant did not know the name of his/her diagnosis. Fourteen interviewees were patients and six were family members.

As they are complementary, and similar themes emerged, data from the one-to-one interviews and focus groups have been combined. Interviewees are identified as 'Int', followed by their identification number and an indication of whether they are a patient (P) or family member (F). Focus group members are identified by FG and the number of their focus group (1–3), followed by an identification number (in parentheses) where it was possible to determine the speaker. The main themes that emerged mirrored those in the survey data (information, concerns and behaviours), with 'hype' emerging as a notable category within information needs.

Information

Adequacy of information

The majority of participants considered the volume of information available in relation to swine flu to be sufficient and had accessed information from a range of sources, both formal and informal (*Box 1*). The government was, on the whole, considered to have done a good job regarding information provision (*Box 1*).

Some participants felt that there was an over-reliance on internet-based information:

BOX 1 Typical views on adequacy of information

I don't think there's any excuse for people not having this information 'cos for people who are not on line there's sort of leaflets and doctors' surgeries have got notices up and things have appeared in the national press. So I think it's well covered … I've tended to concentrate on the website, I find that's excellent, so I don't bother to look anywhere else.

[Int17P]

I don't think they could really have done much better, the advertisements and everything [you know] exactly where you should be going to, and what to and not to do under [different] circumstances … I think it's all out there … It was coming from you from all directions … it was just there.

[Int13P]

> Some people haven't got a computer, there should have been more on the TV that told people what was going to happen and how they could have it, the symptoms … if there'd been more information on the TV it might have stopped people from panicking. [The internet] – was better for me because I could read what the symptoms were …
>
> [FG3(7)]

A small number felt that the information available was insufficient, their views being typified by this participant:

> Only just what I've seen on the TV, and that isn't much information really … just basically that you can catch it off other people, make sure you wash your hands … the government ain't really doing that much if I don't know anything about it! … I watch a lot of TV and if I don't know it, there's going to be an awful lot of people out there don't do as well.
>
> [Int2P]

However, what became evident during interviews was that even those who reported having received little information did seem aware of the key messages included in formal information sources, such as the importance of hand hygiene, protecting others when sneezing, and not placing others at risk of infection if symptomatic.

It was also apparent that there were still outstanding information needs, even among those who felt reasonably well informed. One of the main areas participants would have liked to know more about was how to distinguish between swine flu and other forms of flu or symptoms relating to their respiratory condition (*Box 2*). Other areas in which people felt in particular need of information related to how swine flu was likely to impact on them, given that they had an underlying chest condition, and the suitability of the vaccine for them (*Box 2*).

There were also some misunderstandings and misconceptions revealed, as this data extract from one of the focus groups illustrates:

> R: I'm under the impression that all the swine flu injection is for is to give you one less day of the symptoms if you should get it.
>
> I: Right, so it's specifically information about what benefits there are from the injection itself.
>
> R: Yeah, or COPD.
>
> R: I thought the injection was for prevention rather than cure, the same as the flu injection is …
>
> R: It's what I say about who do you believe you see?
>
> [FG1]

A sizeable number of participants did believe that specific information should have been targeted towards people with an underlying chest condition (or indeed any other long-term health condition), as the general information was not considered to indicate how serious swine flu could be in individuals already predisposed to infections (*Box 3*).

Credibility of information

Some sources of information were viewed as more credible than others, with health-care professionals and formal sources (such as government information) being viewed to be generally of a better quality:

BOX 2 *Typical data extracts regarding additional information needs*

I think the vagueness of the symptoms could be confused with perhaps ordinary flu, or just your condition really. You know, if you've got COPD, then it's not necessarily swine flu at all. And I don't really know how you can say it's swine flu without having any tests [others in group agreeing].

[FG1(6)]

[if I] catch it or get it, would I die from it? … 'cos it's quite, really worrying. I mean there's a lot of people out there who's not bothered really, they're not bothered about getting the injection and all that, but to me I think it is important because it's like, obviously it's on the news, it's mentioned a lot, so obviously it is serious … would I be able to fight it off or like, would I die from it or be really, really poorly?

[Int3P]

BOX 3 *Specific information needs for people with chest problems and their families*

It might be helpful if one could tie specific complaints into the swine flu scene … I have … bronchiectasis … I'm just wondering if I did get swine flu whether that would make the symptoms worse, whether it would complicate matters. I find I haven't got any information on that It might be possible to expand the website. Because looking at it now there doesn't seem to be any section that covers that.

[Int17P]

Certain people, like the people from my group for a start with bronchial problems and things … I think the fact that as soon as you have real breathing complications or you felt you couldn't breathe, this should have been highlighted in some way, because you were concerned about being very poorly, tired, high temperatures, feeling unwell, but I can't remember seeing anything where they indicated that if you had like critical things coming up, what you had to do with them … I do think [info should have come] through doctors and things like that perhaps people with heart disease, diabetes, lung disease, any of these categories, for people with long term conditions.

[Int 20P]

> I do take more notice if it comes by post, if it came from the doctor's or it came from, you know, anything with the NHS, I would take more notice of that than I would of the television.
>
> [Int12F]

> They should have an official government site or leaflet with the proper information rather than [media].
>
> [FG3(9)]

> The internet, that's another thing that might have had damaging side effects … if you don't check whose site you're reading from it can be exceedingly misleading.
>
> [Int20P]

However, some participants indicated that even 'official' sources might lack credibility:

> I mean some people still don't believe the official data 'cos they think the government are just lying basically. One of my own brothers thinks that they're just making it up. And I said well, you know, if they did they're going to kill a lot of people and if nothing else the compensation claims would be horrendous, so, you know, it's, unlikely, but I think it is a problem what people get told.
>
> [Int10F]

Many participants referred to the unreliability of information from media sources, in particular given the media focus on promoting viewing or sales figures, as opposed to disseminating balanced advice:

> It's a bit of bunkum a lot of what they say on there [TV] … the trouble with the television is they only give you a certain aspect of it, what they want to tell you … a lot of the things that come through on the news, news bulletins aren't strictly true are they?
>
> [Int4P]

> Well if the government put it into the newspaper it should have a government stamp on, and that's the only bit they can put in to the newspaper, is what the government's told [them, not] … we'll put that in, that'll make it more exciting … an official stamp, so that I

> can say, well that's from the government … it's not from the *Express*, it's not from the *Mirror* making their own bits on … and I think that would be the best idea.
>
> [FG3(8)]

Many participants believed that there had been a considerable amount of hype in relation to swine flu, most of it emanating from the media. This was felt to have had led to a considerable amount of anxiety, and even panic:

> Yeah, at the beginning we thought everybody would die, especially us like with a bad chest. But … I think it made everybody panic … there was a lot of hysteria … I think it was just too much publicity.
>
> [Int9P]

> … the television's the problem isn't it really. Where years ago we would just hear about something in Mexico, sort of like in the early 50s where only a few people had TVs they would have just been saying, oh there's some kind of epidemic up in Mexico, nobody would have bothered about it. But now the TV brings it in to your front room, maybe, it's sensationalism isn't it really.
>
> [Int18F]

Some participants felt that a certain amount of hype was perhaps necessary in order to prevent people from being too complacent about swine flu:

> I feel they've a lot of hype with a lot of things, not just the swine flu, and particularly the media, they like to blow things up, don't they? They like to scare people really. On the other hand I suppose scaring people is only one way to get them to move.
>
> [Int16P]

Others, however, considered that 'overhyping', including by the government, was leading to cynicism and blunting the impact of messages:

> Well, this is one of the problems with this, the civil service get up, things get overhyped, it seems to me that they, this present government doctor over exaggerates everything. I mean … this pandemic has been going to arrive here for the last how many months now, you know? And you get to the point where you're thinking they're just winding us up.
>
> [Int4P]

> I think at first people watch it and at first it's a shock thing, but after a while it's just an advert …
>
> [Int18F]

This perception was reinforced by the fact that the potential impact of swine flu, presented at the outset of the pandemic, did not appear to have materialised in the months that followed. Some felt, however, that 'downplaying' of swine flu, particularly by the media, was premature:

> But with this new thing I find this far more threatening that the media are getting now because they're inferring that it's not as serious as we thought. Which is absolute rubbish, people have died, some people have been left permanently damaged and I think it's rubbish, and they're giving the impression that it's all gone away which it may not have done, I think they're a little premature.
>
> [Int 20P]

Another perceived negative impact of media hype was the fact that key messages were unable to get through as they were hidden amongst the sheer volume of information that was presented to people, a view typified by this data extract:

> Well basically there's tons of information I would say, but unfortunately the newspapers tend to exaggerate it all I think. And what you find you're struggling to do is to pick through what actually you need be watching for, and what you don't … so there's kind of a manic picture of this, people are frightened and I think there are just too many sources of information, that's the impression I get.
>
> [Int15F]

Inconsistency of information was also identified as an issue by some participants:

> The most useful was the television to be honest … 'cos they more or less spelt it out, the only thing was that it kept changing week by week, different criteria, one minute it was specific groups, then it was another group.
>
> [Int1P]

Although many participants had reservations around how the swine flu pandemic had been presented in the media, they did not consider the pandemic as a whole to have been overhyped by the government, particularly given the potential impact of swine flu. In many ways the government

was viewed as being in a 'no-win' situation, whichever course of action they had taken, as this data extract highlights:

> I don't think the government can basically do anything to get it right basically, because they'd just be wasting more money, you didn't need to have all that printing [of new leaflets] and yet if it goes really wrong and nobody takes any notice and say hey, it was only mild, and then they all get it and lots more die, then they'll say, the government should have warned us. So really, like, they're between the devil and the deep blue sea.
>
> [Int20P]

Anxieties and concerns

Overall, participants did not indicate high levels of anxiety or concern about swine flu, although some did indicate that early in the pandemic they and others had been very concerned:

> Alright, a lot of them panicked, but then you can't help panicking can you? If it's somebody, your child or your husband or whoever's close to you, you're bound to panic.
>
> [Int11F]

> I only knew what I knew from the news and the papers, like thousands were going to die and all this … [at] the time you believe what you're hearing because you don't know any different and it's quite frightening … 'cos people saying it [vaccine] hadn't been tested and all this, that loads of people were going to die. Well sadly loads of people die of seasonal flu and it was no higher or lower in particular than anything.
>
> [Int10F]

The presence of an underlying condition in patients and family members, and awareness of how seriously ill patients could be if they developed an infection, was a common source of anxiety:

> … when swine flu kicked off and we thought, well it's a bit more pertinent to us than perhaps to a normal healthy person and to our two sons, they weren't bothered at all, but we were a little bit more worried I think.
>
> [Int19F]

> [with seasonal flu] we all feel quite safe because we've got a protection and we know ordinary seasonal flu can be serious. But we've got our jab and it's protected us. And suddenly there's a flu out there what there hasn't been a jab for, and we can catch it as quick as anybody else. And nobody quite knows what really effect it's going to have on us and I think this has been some of it, because right at this time we're vulnerable, we've no protection given us. And we all feel as we need that protection to get through this … And I think that's making us worry.
>
> [FG1(7)]

Although a number of participants voiced concerns regarding swine flu, very few appeared to be extremely anxious – indeed several indicated that they were not concerned at all or appeared quite fatalistic:

> Well if we get it we get it don't we? But … we're not putting ourselves into a position knowingly that we'll get it, that we'll catch it off anybody else.
>
> [Int4P]

> Well [if I catch it] then I move from here to the graveyard, the cemetery, what the hell, it doesn't really matter [laughing] I've had my three score years and ten, so I'm not bothered.
>
> [Int 5P]

> No, I mean obviously it crossed my mind and I thought, you can't just isolate yourself, you can't make the front door a barrier because there's germs out there, you've just got to get on with it, just got to get on with your life.
>
> [Int18F]

For others, their underlying condition was of greater concern to them than swine flu:

> [My wife's] got such bad problems anyway, it's the least of her problems. I mean she's got sarcoidosis and she's got aspergillosis, there's a third one as well … So the least of her problems is swine flu, I mean she's having to cope with just living with them.
>
> [Int15F]

> I can't eat properly and while I'm eating I'm gasping for breath … so swine flu is the least of my worries, if you know my meaning … this [chest problem] is the priority. If I can get this right, if I can at least walk a little bit more than I can do now, I'd be happy.
>
> [Int5P]

Many of the concerns expressed by participants revealed gaps in information, or failings in information received by individuals, as can be seen from the preceding data extracts, and the role of quality information-giving in allaying concerns was highlighted:

> So when you get informed facts it does make a big, big difference.
>
> [Int10F]

Types of concern

A concern commonly expressed by both patients and family members was how they would know if they actually had swine flu:

> [Re. leaflet] … it just had swine flu on it, like information, like the symptoms, how to recognise it, which is very much like the normal flu what you get. That makes you panic a bit more, thinking god, if you had normal flu, would you have swine flu, or would it just be the normal flu? … I mean I know they say you get a really high temperature, but sometimes you get a high temperature with a normal cold, so it makes it complicated again, so you're thinking, where do I stand?
>
> [Int3P]

> I think that's the main concern of not knowing more than anything. You think to yourself, if you started with a sore throat and aching, that's normal flu. Sore throat, runny nose, you know, aching bones, I mean that's all the normal symptoms of swine flu, so I suppose then if you've got three of them, they say two of them, but surely to god two of them is not swine flu. I mean we could have had it already and we don't know we've had it. And this is the thing, you're still worrying about it, but you could have had it if you've had flu.
>
> [Int11F]

Another common area of concern related to the swine flu vaccine (*Box 4*), even amongst individuals who normally had the annual seasonal influenza vaccine. Safety was viewed as an issue given that it was a new vaccine. Others were concerned that the vaccination could impact on their underlying condition and/or interact with the medications required for their respiratory problem.

One participant was especially anxious about the vaccine and the interview was dominated by discussion of this topic. This participant's fear of the vaccine was greater than that of swine flu, even though she had direct experience, through her daughter, of how ill swine flu could cause someone to become:

> I was a bit concerned when my daughter had it [swine flu], because she was poorly, she was poorly with it … but she did get the Tamiflu and yet, even though I saw her like she was, I still at that time didn't think, 'Oh well, you should have that [vaccine]'.
>
> [Int7P]

Conversely, fear of swine flu itself had led some participants to decide to have the vaccine, or to encourage family members to do so, as a means of alleviating anxiety:

> I was a bit concerned over that because they were saying it's not been checked out enough … and then anyway I just ended up having it … because I don't want to die having swine flu, I don't want to be poorly.
>
> [Int3P]

BOX 4 *Typical data extracts regarding concerns about the swine flu vaccine*

R: How, how has it been tested, has it really and truly been tested as well as we're led to believe it has shall we say?

R: That's the question, yes.

R: Has it been rushed through or, you know, how, how safe is it?

[FG2]

I've been dithering about whether I should have an inoculation or not, but I suppose I really ought to, but – I mean I'm so ill otherwise that I wondered whether it would do me any good [unsure] whether it would make me ill or not really. But if not I don't object to one, it's just I know I'm not very well so, you know, it's going to – if it's going to affect anybody I think it probably will bump me off.

[Int8P]

> I think once he's had it I can relax a bit … psychologically it will do him better because of the complications he's got.
>
> [Int11F]

Behaviour change

Preventative measures

The general lack of anxiety amongst individuals was reflected in the fact that most reported little, if any, change in their behaviour as a result of swine flu. However, it was apparent in most interviews that behaviours recommended by official sources had been taken up, hand hygiene in particular, as the following data extracts illustrate:

> I thought, you've just got to carry on with your life, you know what I mean, I wasn't one of those that sat down and worried myself to death about it. If you're going to get something you get it … I just took extra care. I always carried one of these hand things around with me, always, I still do now. So apart from that I just steer clear of anybody that's sneezing or something, you know what I mean, things like that. You can't avoid it, you've got to carry on with your life. Well that's my philosophy anyway.
>
> [Int16P]

> No, it's not altered me at all, no. I've just carried on normally … yes, I've started washing my hands regular, I have done that … But as far as being in crowds, no, that hasn't bothered me.
>
> [Int14P]

While participants on the whole had not isolated themselves, some were more conscious when in public places or around people who might have been symptomatic:

> I have uh cut down going out, because, I mean I live on my own as well, I've nobody to look after me, and I've just been trying to keep myself protected without shutting myself off, for just thinking a little bit, should I go there.
>
> [FG1(7)]

> I won't go if there's a lot of people – if anyone's say got a cold, it could be a general cold or anything like that: 'don't come into my house' … and I feel a bit rude by saying it, but I'm just scared … I don't know if it's being paranoid or just being cautious.
>
> [Int3P]

Help-seeking

When asked, most participants indicated that they would telephone their GP, an NHS helpline or their respiratory consultant for advice if they felt that they had symptoms which could indicate swine flu:

> I would have phoned the doctor's and asked their advice, but I know there's advice centres, isn't there? And I would have phoned them. And, 'cos I realise that going to surgeries, going to hospitals, is just taking it there, so I wouldn't, the one thing I wouldn't have done was have gone there.
>
> [Int18F]

> Well, straight, I'd phone the doctor straight away and probably be advised by them. If for any reason I suppose I couldn't get through to the doctor I'd probably phone the helpline, the NHS [Direct] helpline … and see what advice they gave me.
>
> [Int12F]

However, other views differentiated between appropriate help-seeking for a person with a long-term condition and the general public (*Box 5*).

> Amongst others, however, there was some confusion about what was appropriate action for people with a respiratory condition:
> I know that they say you can't [go to doctors], but there's a difference between – and this is where I think the problem is, they weren't told what you did if you got really, really poorly with it … [Son, has asthma and was ill with confirmed swine flu. He said 'I can't go', and I said 'Well I'm sorry but I'm taking you in', [daughter in law] said,' oh you can't take him in because they won't let you in'. I said 'look [name] if I don't do something he'll be dead tomorrow'.
>
> [Int20P]

There was considerable reticence about using hospital services, and some confusion about when or whether this would have been appropriate, typified by this data extract:

BOX 5 *Views on appropriate health-seeking for people with long-term conditions*

Well hers would probably be more complicated [if symptomatic] She's got a consultant she sees at hospital, and she's got very complex breathing problems … But that would be her port of call, to me, the consultant would be the expert who would know … [if complications] well there's a chest specialist clinic at [hospital] and he's a recognised world expert in that area, so he'd be the first port of call [by telephone] … I wouldn't move anywhere till we knew what was going on.

[Int15F]

If it was [my wife], I would have been inclined to call an ambulance and get her to hospital quick, because on the two occasions that she's had pneumonia now she's gone down hill very, very quickly … If it was my eldest son, who's a fit and healthy 20 year old, and he wasn't getting better, then I would ring the GP and say, well this stuff either isn't working or – what shall we do next?

[Int19F]

For people with lung disease I would have said … seek advice from your GP or from the hospital … because I think the risk of dying from breathing related things and the pneumonia and the other things were very high … OK don't go to your doctor and put others at risk, but ring and speak to your GP or the hospital regarding this change in your already existing condition, and that would be right across the board [for long-term conditions].

[Int20P]

> I know you could take them to hospital, but I don't know whether it's always a good thing. Unless, I mean it's different if you've got complications of course, I think you'd have to, you know.
>
> [Int12F]

Those who had sought help had typically had positive experiences:

> I thought I was starting with it once, and I did phone the swine flu line up. And they told me to go back to [NHS] Direct, to phone them up, because they felt I needed to talk to somebody with more experience, because of the existing conditions I had. So as soon as I mentioned that, they passed it on. And then from there they said I had to phone my doctor up because of the underlying condition I had, which I did. And the doctor come out to me and they also give you a prescription for the Tamiflu … But that was done for me straight away … the locum was out within an hour, so it was good.
>
> [FG1(7)]

Vaccination uptake

A variety of factors appeared to influence whether participants were likely to have the swine flu vaccine or not. Perception of risk from swine flu was one such factor:

> She [my wife] doesn't, doesn't seem to want to go … she's always had the 12 months' influenza jab … I think it's a good idea to have it if you're offered it. But she seems to think that maybe it's not as bad an epidemic as it's been built up to be in the media and therefore it's probably no greater risk than normal 12 monthly, you know, the annual winter flu that anybody can get. So I think it's on the basis of, 'I probably won't get it', kind of thing.
>
> [Int19F]

> No. The, the surgery asked me if, if I was interested in getting that swine flu uh … And I said what for? I said I've never had a cold in all these years, I've never – I mean I get my usual flu jab … [for] ten years I've been getting [that].
>
> [Int5P]

Others felt that it was better to rely on the body's natural defences to fight off infections:

> I don't worry about medical issues, I tend to find they take care of themselves as long as you look after yourself I think sometimes you're better off letting your body … do its work.
>
> [Int13P]

Information-giving about the vaccine was felt to be lacking, most indicating that they had simply been informed that they were eligible to have the vaccine, rather than being given more detailed information to help them decide on the appropriateness of the vaccine for them:

> I said, what for? I mean I've had my flu jab like, I said isn't that good [enough]. [They said], you're not forced to do it. So I said if it's optional, no thanks … That was on the phone and that was it. No more.
>
> [Int5P]

Some who had already received the vaccine also indicated that they had received little in the way of information at the time of vaccination, as clinics specifically set up for the vaccination programme were very busy:

> Basically it was just like, go in, get the jab, and then out again. No explanations or anything … because everybody come into the surgery at once to get the swine flu and we were like queuing up and it was just jab and out.
>
> [Int2P]

The influence of health-care professionals on the uptake of the vaccine also became apparent during some of the interviews, although participants were not asked directly about this. Some had been encouraged, either by their hospital specialist or their GP to have the vaccine, given that they had an underlying condition:

> Well I was just called up for it from … the doctor's. They asked us if we wanted to have it … I'd already had recommended that we did [from specialist]. Well I did. I was vulnerable. And I was in one of the first batches to go out … You're in and out. You only see the nurses for that anyway.
>
> [Int4P]

> … in my condition, he [doctor] advises that I should, but he's not saying you've definitely got to, I think it's a random choice, you either do it or you don't. The flu, I mean, and warfarin, I mean and things like that, I've got to do it … but he said I would advise that you did.
>
> [Int7P]

A small number of participants had felt slightly pressurised into having the vaccine, even although they had some reservations about taking it:

> … so I said to her, do we have to come? Well she said, well – in other words yeah … my husband's been going for years, but I wouldn't go … Because we had an auntie what died about a week after she'd had one, and I knew somebody else who'd died about a month after having one, 'cos you get, with the flu injection you get like a bit of flu don't you? … they more or less said we had to have it.
>
> [Int9P]

> … even the receptionist pushed me to have it and I said no, I'll have to wait till the doctor decides … so the receptionists are actually pushing you to come in and have your injection, and that's without medical, you know, from the doctor [with] knowledge of what you're on. So any side effects might be more refer to you because you've got a chest problem. They're just thinking because I've got a chest problem you should have it.
>
> [FG3(R8)]

The influence of health-care professionals was also apparent in other ways, their actions having an impact, either positive or negative, on the perceived safety of the vaccine:

> R: I think a lot of it, you know, when you read it in the press … I think reports in the press when they say, only 25% of national health workers, the nurses, what have you, have agreed to have it. That then makes me think they know something I don't or – so to me it's very negative the way it's been put into the press, very negative.
>
> R: But surely I think the ordinary flu jab was very low in the take up from NHS workers anyway, so there's nothing very different in that is there really? Maybe they're anti-injections.
>
> [FG2]

> R: I don't think they know enough about it, and obviously my GP's in the clinic, they've all had it, and obviously they must have done their research into it else they wouldn't have done, and all the receptionists have had it, and I thought, well he wouldn't – you know, going through the doctors, 'cos there's seven, well he wouldn't have had it, you know, things like that. And I felt a bit easier after talking to him, but I'm still not sure. Can you get it twice?
>
> [Int7P]

Although by the time of data collection the majority of participants had been invited to have the vaccine by their general practice, some felt that there had been inappropriate delay in the

vaccine becoming available for them or their family member:

> [My sister's not had it as] there's not been enough vaccines coming through, they've got 500 and the GP has three and a half thousand at risk patients … but of course they've got to fit clinics in, you know, everybody's overworked with the swine – you know, all the surgeries, and they just can't get the clinics … she wouldn't have done it if I hadn't told her to.
>
> [Int 10F]

> I'm 66, and [my GP] said, 'sorry, you don't qualify for it, it's only up to 65, and we're not giving it to other people at the moment, regardless of the, the risk group they're in,' and if I phone him again in January to see if you may get it. Now to me that is a disgrace, it's also going against what the government has said, that it must be for people over six months who are not at the risk group you should be working off [sic], and [locality] has put a limit on them being 65. And this is scary.
>
> [FG1(R7)]

Oseltamivir use

A number of interviewees made reference to oseltamivir when discussing help-seeking. There appeared, amongst the sample, to be reservations about both the efficacy and safety of this product.

> I mean I've heard there's a lot of side effects with them and you can end up poorly with the Tamiflu tablets and I didn't fancy like taking 'em if I didn't have it, if it wasn't necessary.
>
> [Int3P]

> No we accepted that she needs to take protection, so it's silly not to take [the vaccine] – where the Tamiflu thing is I think a totally different thing. I think the injection's more to help you build up the antibodies and so on, whereas the Tamiflu stuff is more you've got it and take this and hopefully it will sort your problems out.
>
> [Int15F]

> I don't even know if Tamiflu works.
>
> [Int18F]

The media appeared to have influenced some participants' views, whereas others were influenced by concerns about interplay with their existing respiratory condition and treatment:

> [Newspaper suggested] it could make you really ill for a few days. Now whether that was a deterrent just to stop people getting it just for the sake of it I don't know. But nevertheless, when it came to me, I mean I was quite concerned about it, because I've got complex needs as you know.
>
> [Int20P]

> I've sort of heard conflicting information about them, so I'm not sure that I would necessarily dash off to get a dose of Tamiflu. Because I mean the thing is it all comes back to this one point that I've made, that really I'm not quite sure what the effect would be with my own particular problem … there is some doubt [from the press] as to whether it is effective and also whether in fact, whether it had any bad side effects.
>
> [Int17P]

At the other extreme, some interviewees made reference to people having obtained oseltamivir as a precautionary measure; this was typically viewed as inappropriate:

> And I know people were stupid, I remember I heard on the radio about a guy whose wife and his daughter, they thought they had the swine flu, but he didn't seem to have the symptoms yet, but he lied over the telephone knowing what the symptoms were. So … that the minute he got it he would start taking the medication, and I think that's what a lot of people have done. And I think people are just – selfishness is just – something like this, a pandemic, brings out the worse [sic] in people. So my view is, I'm glad I didn't take it earlier, than panic. If I did get symptoms now, yeah, I'd take it.
>
> [Int15F]

There was also some confusion about eligibility for and appropriate use of oseltamivir:

> I must admit I've been a bit puzzled by that because many people were treated with Tamiflu when it all started to explode in the first quarter of this year and then we were told after you took it that if you got hit by the second wave you can't take the Tamiflu again. That's really bad.
>
> [Int15F]

Chapter 5
Discussion

Sample

There was a reasonable representation from most demographic groups, although participation of BME groups was modest. The representation of diagnostic groups is fairly typical of that seen in hospital chest clinics; the slight bias towards 'other' diagnoses in the family member sample reflects the relatively high level of participation of family members of patients with ABPA ($n = 9$), mainly from the tertiary centre. Although the high percentage of participants who did not know the name of their own/family member's diagnosis may seem surprising, our previous work has indicated that this is fairly common.[56] The sample's mean age was over 60 years, although there was a good age range that included representation of young adults. The greater incidence of some respiratory conditions (e.g. COPD and ILD) in older people[1,2] may have contributed to the sample's relatively high mean age, as may recruitment through BLF 'Breathe Easy' groups in the North West region, as these are typically attended by more older than younger people. The swine flu pandemic has mainly affected people younger than our sample's mean age. However, age was a secondary consideration in this study. The chosen population was a high-risk group, because of their chest problems, hence, regardless of the high mean age, the sample's needs, concerns, behaviours and views on the adequacy of the government's response to the pandemic remain of relevance. The impact of the smaller than planned family member group sample size is considered under 'Limitations'.

Information

Patients' and family members' responses regarding information were broadly comparable. Many participants, both patients and family members, would have welcomed further information about swine flu, although few felt completely uninformed. There was, however, an interesting contradiction in the data (apparent in survey and qualitative data, but particularly well highlighted in the latter): many respondents reported feeling uninformed/not having received information yet were aware of key messages (e.g. regarding prevention). This suggests that information may have been 'absorbed' from a general background, which is encouraging from the perspective of penetration of messages. It does, however, highlight a well-recognised issue in provision of health-related information regarding retention and recall of material.[57,58]

More participants were 'very' or 'fairly' satisfied with the amount of information they had received about swine flu than were dissatisfied. Likewise, the majority of patients and family members thought that the information they had received about swine flu was helpful. Factors that could have improved the usefulness of information related to volume (with both lack and excess of information being commented upon); credibility, particularly the need for mechanisms to help lay people better identify trustworthy information; and consistency. The last of these is particularly challenging in the context of a pandemic, where the situation is constantly changing and being reviewed,[18–20] which some participants did recognise.

High importance ratings were given to most information topics and responses from patients and family members were broadly similar, although family members were consistently less likely to rate items as 'not at all important'. This apparent lack of discrimination regarding 'important' and 'unimportant' information presents a challenge for information developers when selecting what to focus on or include. Internet-based material may offer the most flexibility in this regard, as readers can be provided with links to allow them to read more widely. However, as some participants noted, there are issues with respect to 'reach' and accessibility of internet-based information (although this may become less of an issue over time and with the government's focus on improving internet access). Written information is arguably the most limited in this respect – yet participants cited this as their main information medium.

Information relating to the risk of developing swine flu and help-seeking was less commonly identified as being of high importance in both groups; this was particularly so for information relating to family members' risk. Interview data suggest that this may have been due, at least in part, to fatalism,

which has implications for education regarding, and uptake of, preventative measures, as was noted in an earlier swine flu outbreak, some decades ago.[59]

Perhaps unsurprisingly, the item in both groups with the highest percentage rating it as 'very important' was 'how swine flu might affect chest problems'. Overall, however, importance ratings for information specifically related to chest problems did not differ markedly from those of more general information (although this may be due to a 'ceiling effect'). This is interesting, as more than one-half of both patients and family members in the survey felt that people with chest problems and their family members needed targeted information and this was also an important theme in the focus group/interview data. Although some information targeted towards people with long-term conditions, including respiratory problems, did emerge during the course of the pandemic (e.g. on government and health-care charity websites[4,7,60,61]), the volume of such information remained low. Providing such targeted information is challenging. Web resources are clearly feasible although, as participants highlighted, may not be accessible to all (and, in this sample, had only modest levels of uptake). Organisations such as the BLF or Asthma UK could be a resource of targeted information, both via websites and to members – but may not have wide 'reach', may have limited resources and, as our data suggest, may not be widely used. Use of primary care disease registers as a means of targeting information is a possibility but primary care services were already heavily stretched in the pandemic[30] and may not, therefore, be able to resource such an endeavour.

The most common medium through which information was received was a leaflet delivered to the participant's home. Although these leaflets were widely delivered to UK households, about one-half of the sample did not appear to have received such a leaflet – or were not aware of having done so. This was actually a slightly higher percentage than reported receiving the leaflet in a UK-based general population survey conducted in May 2009.[16]

Mass media sources were also widely used – but their credibility was limited, which is problematic. The need to ensure that key messages are delivered through the mass media to patients and their family members in a way that is perceived as credible and 'untainted' is apparent. For participants in this study, health professionals, particularly those in primary care, were identified as a key actual and potential information source. Perhaps unsurprisingly, hospital consultants featured relatively highly for patients, but less so for family members. The perceived importance of health professionals regarding information-giving may reflect participants' perceptions of 'special needs' with respect to information and also that they may come into regular contact with health-care services. Only modest numbers had used official websites or telephone helplines – although interview/focus group data suggested that these were perceived as an appropriate 'first line' of information-seeking. The NPFS had been established for several months by the time data collection commenced[31] and more participants considered it to be useful than not. Low levels of usage may therefore reflect perceived and actual need, rather than being a reflection on usefulness.

Participants were asked a series of 'true/false' questions, which enabled understanding of swine flu 'facts' (in so far as these existed) and 'myths'. These questions also enabled some exploration of risk perception and penetration of key messages being disseminated by official sources.[4,7,24,60,61] Both groups were readily able to identify 'myths' (e.g. regarding eating pork products and 'swine flu parties') and some key messages, for example regarding hand-washing. Some of the recommendations in official information for patients/the public had a strong evidence base.[25] In some instances it is perhaps unsurprising that participants were confused, for example on the issue of prophylaxis for close contacts, official guidance from the HPA was that these should be given only to at-risk close contacts on the basis of 'case-by-case' assessment,[52] but even reports aimed at health professionals were sometimes misreporting this guidance.[62]

There was some confusion regarding antiviral treatment (both what it was and who would be eligible for it); the high level of misperception of oseltamivir as a vaccine for swine flu is particularly notable and suggests a need for improved future information-giving. Similarly, a lack of information about the swine flu vaccine was noted, even at the point of administration, which is a cause for concern. The challenge of ensuring fully informed consent in the context of a pandemic, with attendant pressure on services, is apparent. Participants rightly identified themselves as being in an at-risk group, but some then had their expectations confounded by finding themselves in the 'wrong' at-risk group, which led to confusion

and frustration; these data suggest that future information about eligibility for vaccination in at-risk groups needs to be clearer.

There was appropriate recognition of the greater risk posed by swine flu to people with chest problems, in terms of complications and mortality.[4,60,61] However, most patients and family members also considered people with chest problems to be at increased risk of developing swine flu, which was not consistent with key messages being delivered either to the general public or to this group specifically.[4,7,24,60,61] Indeed, there appeared to be limited awareness overall of who was most likely to develop swine flu, as questions regarding particular age groups were also often answered incorrectly. The data highlight a need to improve future communication of information regarding susceptibility. Doing so would be challenging, especially in a media climate that focuses on 'high-impact' stories and may therefore skew public perceptions of susceptibility.

Most patients and family members appropriately identified symptoms that had and had not been indicated as 'typical' of swine flu (e.g. sudden high fever) in authoritative patient information.[4,7,24,60,61] Some 'complications' (as opposed to 'typical' symptoms) of swine flu (e.g. confusion, change of sputum colour) were identified by sizeable numbers of both patients and family members as swine flu symptoms. Over one-half of the patient sample and one-third of the family members were not aware that diarrhoea/stomach upset could be a swine flu symptom. This group of items had the highest non-response rate, for both patients and family members. Participant fatigue is possible, although later questions were answered well. It is therefore possible that at least some of those who did not respond were unsure and hence unwilling to commit.

The importance of the mass media in shaping views on and responses to swine flu and its treatment was readily apparent, particularly in the qualitative data. This was particularly notable with respect to vaccination and, especially, oseltamivir. By the time of this study – and particularly towards the latter part of data collection (December 2009/January 2010), several highly critical articles, some underpinned by criticism from scientists, had appeared, especially in certain sections of the UK mass media, questioning the value of oseltamivir and alleging 'hyping' of the risk of swine flu by pharmaceutical companies to promote product sales.[63–67] A television programme in December 2009,[68] which related to a Cochrane review in a respected medical journal,[69] questioned the efficacy of oseltamivir; this was widely picked up in other sections of the media. Few participants mentioned specific media stories, and none highlighted the television programme noted above. However, many spoke in general terms about stories in the media and it was clear that these were raising doubts for some about whether or not to take oseltamivir, if prescribed, or to be vaccinated. There is a clear tension between the role of the media in tackling controversial issues and raising questions about government policy – legitimate activities within a democracy – and the need to ensure that important public health messages are not drowned out with associated implications for health-related behaviour.

Mass media appeared to have a conflicting role, being both a widely used and influential information source, but also one that lacked credibility and, at times, caused confusion and created anxiety. Participants were widely sceptical about information received through the media, both in terms of accuracy and intention. However, they also recognised the strength of mass media sources and their potential value as means of mass communication regarding swine flu. This duality is important from a policy perspective, with the need to recognise the strengths and limitations of mass media sources in communicating information regarding a pandemic being apparent. Participants made some interesting suggestions to improve the clarity and credibility of future messages, such as 'kite-marking' official information and limiting media sources to reporting only official information and 'facts'. Some of these would be unfeasible or unenforceable. However, the potential usefulness and acceptability of some approaches (e.g. 'kite-marking'), both to intended recipients and to media outlets, could be explored.

Concerns

In the patient sample, more were worried than not worried about swine flu and its associated risks, although interview/focus group data suggested that individuals were typically not highly anxious and, indeed, were sometimes fatalistic or even complacent. Overall, participants appeared to have taken a very measured stance with respect to swine flu, with their perceptions often being coloured by previous experience of ill health.

Almost two-thirds of the patients incorrectly identified themselves as being more likely than others to develop swine flu, but over three-quarters correctly identified their greater likelihood of developing complications.[4,7,24,60,61] There was a relatively low level of confidence in ability to recognise swine flu symptoms and complications, but more regarding taking action if swine flu was suspected.

There were lower levels of concern about personal risk of swine flu in the family sample. Nonetheless, almost one-half of the sample were 'very' or 'fairly' worried about catching swine flu, and one-third were concerned that they might die from it, while around one-third incorrectly identified themselves as being more at risk of catching swine flu or developing complications of it because of their having a family member with chest problems. By contrast, family members' levels of concerns about the risks posed to their relative with a chest problem by swine flu were high – this was supported by interview/focus group data, where family members more commonly spoke about risks for/needs of patients than themselves.

Data from study participants suggest that some key messages regarding risk had penetrated well, whereas others had not done so. The data regarding concerns and risk perceptions contrast with international general population surveys,[70–72] which indicated that by autumn and winter 2009–10 levels of concern about swine flu had dropped markedly and to quite low levels.

Confidence in the benefit of vaccination was high in both groups, and family members were particularly confident of the benefits for their relative with a chest problem – more so, indeed, than patients themselves. This contrasts sharply with general population surveys, though from outside the UK, which indicated lack of confidence in vaccination.[70–72] The UK-based Ipsos MORI poll did not specifically ask about swine flu vaccination (it was conducted in May 2009, well before vaccination programmes began), but at that point 84% of their 1000 respondents disagreed with the statement that 'there is nothing that can be done to treat people with swine flu'.[16] A recent systematic review of the effectiveness of antiviral medications in influenza (not specifically swine flu) showed that such drugs were effective in reducing symptom duration (by 0.5–1.5 days for general populations and 0.5–0.75 days for at-risk groups), although data reviewed were described as often being 'limited'.[69] Interestingly, participants in our study had greater confidence in vaccination than in antiviral treatment. It is not fully clear why this was the case, although in the qualitative data the influence of the media was readily apparent and concerns about interplay with existing symptoms/medications also came into play.

With respect to concerns, the role of the mass media was again apparent, particularly in the qualitative data, with media reports from the time of the initial outbreak in Mexico (April 2009) up to a few months after the pandemic being declared (June 2009) clearly having generated concern and later media treatment of the pandemic (from the latter part of 2009 and early 2010, which coincided with the data collection period for the present study) potentially contributing to complacency. There was some sense that the threat of swine flu had been overhyped – again a common theme in the media, even from before the declaration of the pandemic and certainly by late 2009/early 2010 (when data collection for our study was taking place), by which time it was apparent that the virus was milder than anticipated.[63,66,67] However, fewer in our study than in general population studies in the UK and USA considered that there had been 'overhyping' of the risk from swine flu.[16,70–73] For our participants, the sense of overhyping was tempered by recognition of the potential seriousness of swine flu – or, indeed, any flu – for people with respiratory conditions.

Participants in our study were generally supportive of the government's health services response to swine flu, recognising the tensions and uncertainties inherent in dealing with a pandemic. In this regard, they were similar to participants in the Ipsos MORI general population survey[16] – although this was conducted in May 2009 (and therefore preceded the declaration of the pandemic), hence the data are not entirely comparable. It is interesting that our participants remained so positive about the government's response as, by the time of data collection (and, in some instances, even before the declaration of the pandemic), some sections of the mass media in the UK and internationally – and even some scientists – were becoming increasingly hostile about the effectiveness of governments/the WHO and the perceived influence of pharmaceutical companies.[63–68] The government, the Council of Europe and the WHO are all conducting reviews of responses to the pandemic, in part to address the proportionality of these responses and the influence of the pharmaceutical industry.[74–76]

Behaviours

Our data, as with any survey, addressed self-reported, rather than observed, behaviour. However, particularly given the nature of the behaviours that it would have been necessary to observe in relation to the swine flu pandemic (use of tissues, hand-washing, changes to daily living activities, etc.), observational methods would have been completely unfeasible.

Overall, both groups reported only modest levels of adoption of preventative measures – this is consistent with general population survey data from before the start of the pandemic[16,17] and similar surveys conducted throughout the pandemic outside the UK.[70–72] However, the changes in behaviour reported by respondents were largely appropriate and reflected key health messages.[4,24]

Hand-washing and use of sanitising hand gel were the two most commonly reported preventative behaviours. Very few of either group reported wearing a surgical mask – perhaps unsurprising as this was not recommended by authoritative sources in the UK.[4,24] Patterns of preventative behaviour were similar in the two groups.

Levels of regular uptake of the annual seasonal influenza vaccination were higher among patients than family members, which is consistent with data regarding uptake patterns.[3] Previous vaccination levels in both groups were higher than is typically reported in people with chest problems and family members of people with long-term conditions.[3] Most patients, but fewer family members, intended having the swine flu vaccination – although the latter group were strongly in favour of their family member with a chest problem receiving the swine flu vaccine. The percentage of study participants intending to have swine flu vaccination (83.8% of patients and 68.3% of family members) was much higher than the percentage from clinical risk groups who actually took up the vaccine in North West England (37.3% at the end of February 2010; no data for family carers available[77]). Our data also contrasted with national figures for clinical risk groups both under 65 years and over 65 years (35.7% and 40.0% respectively, at the end of February 2010; no data for family carers available[78]) and with uptake by frontline NHS staff (40.6% in North West[79] and 39.9% nationally[78] at end of February 2010). Our data, collected between October 2009 and January 2010, relate to intended behaviour; we do not know how many actually did take up the vaccination. Those who respond to surveys are more likely to have an interest in the topic,[50] which may explain the exceptionally high levels of vaccination intent in the sample. It is also possible that recruitment through a network of patient support groups may have impacted on these data, as such patients may be more motivated with respect to health care.

Messages from official information sources regarding appropriate help-seeking[4,24] appeared to have been taken on board. If swine flu symptoms were suspected, the most common initial intended help-seeking action was to telephone a GP; the contrast in patients' and family members' self-related behaviour and family members' advice to patients was notable. Patients' and family members' proposed behaviour was consistent with advice from authoritative sources, which advised those in at-risk groups to make early recourse to professional help.[4,24] Although primary care sources and health help/telephone lines would more commonly have been used, it was still the case that more than one-quarter of patients would have sought help from hospital (either A&E department or chest clinic); the small numbers selecting 'walk-in chest clinic' may reflect the lack of availability of these at all sites. The modest use of websites and very low recourse to community pharmacists are notable. Encouragingly, and perhaps related to the reported levels of knowledge and information about swine flu, few patients or family members would not have known what to do on suspicion of swine flu. These data provide useful insights into likely demand on health-care services from this high-risk group and, as with information-giving, highlight the centrality of primary care services, especially GPs, during the pandemic.

Interview and focus group data revealed considerable reluctance to use emergency services and some confusion about when/whether it was appropriate to do so. This is notable, especially as people with respiratory conditions, particularly COPD, are known to be high users of emergency/hospital services, especially during the winter months.[2] The reasons for this reluctance may therefore merit further investigation, as they may have implications for information-giving in future comparable circumstances.

Patients and family members seemed generally able to discriminate between 'typical' swine flu symptoms[55] and 'red flag' symptoms such as chest pain or haemoptysis. However, some symptoms (e.g. confusion/drowsiness, change in sputum

colour and increased wheeze) elicited lower levels of intended help-seeking, despite being a potential cause for concern, particularly in patients. There were relatively high levels of intended help-seeking for problems such as aching muscles, sore throat and tiredness, which were identified in authoritative patient information as 'typical symptoms', rather than complications of swine flu.[55] Family members generally reported greater likelihood of help-seeking on behalf of their relative with a chest problem than on their own behalf, regardless of the symptom. This highlights the well-recognised contribution of family members and informal carers in the management of respiratory conditions, including surveillance/symptom monitoring.[80,81] It also highlights the practical and emotional burden – again well-recognised[80–82] – on family members.

Interestingly, with respect to behaviour, role modelling by health professionals, both directly experienced and as reported in the media,[83–86] also appeared to play an important role. This was particularly the case with respect to perceived credibility and hence likely uptake of swine flu vaccination. Health professionals also appeared to play an important role in persuading – sometimes to the point of perceived coerciveness – patients and family members to take up vaccination, but this was not always accompanied by information-giving to facilitate informed decision-making. Finding ways in which people with respiratory conditions and their family members can be supported in making informed decisions about vaccination is important for the future, particularly given the typically low levels of influenza vaccination uptake in this patient group.

Limitations

The study took place in one geographic region (North West England) and focused on one disease group (people with respiratory problems) and their family members. Survey data were cross-sectional, hence relate only to the time point at which they were collected and collated, in the UK autumn/winter of 2009–10. This was during the anticipated winter peak of the swine flu pandemic in the UK, but occurred several months after the first announcement of the pandemic and associated peak in both reported UK cases and media interest.

The target sample size for the patient group in the survey was exceeded. The response rate from the patient survey, though modest, was fairly typical of this type of survey;[50,51] low and declining response rates have been identified as a methodological issue in survey research for a number of years.[50,51] Our goal of recruiting $n = 200$ into the family sample was not achieved, hence this element of the study was underpowered for logistic regression. However, bivariable analyses on key variables indicated that this would not have been appropriate anyway (although the potential impact of the sample size itself is recognised here). Family members were selected by patients or self-selected, hence we were not able to ensure even numbers of different family relationships. These are acknowledged as limitations of the study. It is not fully clear why the response rate from family members was so poor – however, these are recognised as a 'hard-to-reach' group in health research, not least because of the challenges of accessing them, typically through third parties.[87,88] Possible explanations for the low response rate are that patients were reluctant to pass on questionnaires; that family members were aware of patients' having completed a questionnaire (and possibly even how they had responded), hence did not feel they had anything extra to add; that the extra length of the family member questionnaire was off-putting; or that the issue was not perceived as salient by family members. Sheehan[50] suggests that salience is a more important factor than questionnaire length. Likewise, it is not clear why the response to the newspaper advertisement was so poor; other studies that have used this approach have had a good response[89] and the advertisement was prominently placed in a high-circulation region-wide newspaper. The timing of the advertisement (November 2009) may have been a factor, as the level of media and public interest in the swine flu pandemic was waning by this time;[70–73] this is consistent, again, with Sheehan's[50] assertion regarding the importance of salience in survey response rates. We had planned to undertake between four and six focus groups. Only three were actually undertaken. However, analysis of the data from the three focus groups completed suggested that any additional groups would have been confirmatory, rather than adding any new data.

The sample had a relatively high mean age and only modest representation from BME groups. Poor participation in surveys by young adults and people from BME groups is recognised as a problem nationally and internationally.[90] Given the short duration of the study, our ability to use strategies known to increase participation from hard-to-reach

groups (e.g. through provision of questionnaires in alternative languages and formats[90]) was limited. Recruitment through BLF 'Breathe Easy' groups in the North West may also have had some impact on sample composition, as these are typically attended by more people with COPD than other conditions and most attendees will have moderate to severe disease. Attendees tend to be older individuals and, although there is typically a reasonable gender mix, carers/family members and people from BME groups tend to be under-represented. It must also be recognised that support group attendees may be more highly motivated/interested in their condition than others. These are acknowledged as limitations of this recruitment approach. They are, however, countered by the ready accessibility of the groups and by their being well established, which greatly enhanced questionnaire distribution, response rate and focus group dynamics/discussion. The respiratory clinics that were selected all had diverse patient populations, which included people with asthma. However, people with mild respiratory conditions, particularly asthma, are less likely to attend hospital chest clinics. We considered it inappropriate to collect data in primary care, given the pressure on services during the pandemic. Furthermore, our previous experience in conducting surveys of information needs and treatment decision-making in people with asthma in both primary and secondary care suggests that the response rate from those with mild disease would have been poor anyway, as they do not engage with these issues,[91,92] a key issue in promoting participation in surveys.[50,91]

The instruments used were developed specifically for the study, although they did draw upon existing literature, and, where possible, used questions/phrasing that mirrored those used in the national Ipsos MORI general population poll, conducted on behalf of the HPA.[16,17] They were developed in close collaboration with a User Reference Group, consisting of people with chest problems and their family members. The instruments were designed and tested for use only with people with respiratory conditions and their family members and were only available in English and written format. They would need further validation and revision before they could be used in future studies or developed into other languages/alternative formats. Survey participants were invited to provide 'any other comments', and some of these provided suggestions for future improvement of the questionnaires, including reducing their length, which could facilitate such revision.

The research approach

This project was part of a national programme of commissioned projects relating to swine flu. These were short studies, commencing in September 2009 and having to be completed by January 2010. The studies received expedited research ethics and governance approval and were adopted into the NIHR portfolio.

Expedited approval was invaluable in ensuring that the project could commence in a timely manner and was vital to its feasibility, given the short timescale. It was challenging, however, for both the researchers (with respect to rapidly preparing materials while still ensuring quality submissions, and for staff in research ethics and governance offices) and the committee members (who had to deal rapidly and at short notice with documents); this raises questions about how many such projects could be dealt with by these organisations at any one time. There were particular challenges for work of the sort reported here, which involved development and testing of instruments prior to commencement of the study and, importantly, ahead of submission for ethics and governance approval.

The short duration of the study highlighted numerous practical and organisational challenges. The slowness of many usual procedures (notably recruitment) was challenging and required innovative solutions – although some of these brought their own challenges, as they entailed working outside of usual procedures. Our experience suggests that if the 'rapid-turnaround' approach adopted for this call were to be more commonplace, organisations conducting research, such as universities, would need to adopt new, and in some instances more efficient, ways of working. Having short-duration projects would also have implications for how contract research staff are employed and work.

The short duration of the project meant that the level of direct involvement from the Principal Investigator was necessarily much higher than would otherwise have been the case, especially during the set-up and early stages of the study. If this approach were to be adopted more widely, it would therefore have implications for the Principal Investigators' time and the number of projects in which they could be involved. Principal Investigators and their employing organisations would need to carefully consider the 'cost–benefit' ratio of responding to such calls for research.

The short timescale also meant that there was very little scope for slippage. It is important for funders and researchers to recognise that any delay (even of only a few days), unforeseen circumstances (e.g. as in the our case, the severe winter weather, which affected BLF 'Breathe Easy' group meetings, clinic attendance rates and patients' health and hence ability to take part in the study) or, indeed, sickness within the project team (especially of the Principal Investigator) will have much more marked implications for a study than would usually be the case. Windows for data collection will also be much more circumscribed than usual, which has implications for project timelines and for what can feasibly be done during a study.

On a positive note, the rapid turnaround approach ensured that a large volume of data were collected in a short period of time – although it did circumscribe the extent to which these data could then be analysed and full use made of them. The approach should ensure that data are communicated much more rapidly, with more timely adoption of findings/recommendations, where appropriate.

Having rapid-turnaround projects has significant implications for user involvement in research. It highlights very clearly the importance of researchers developing strong and sustained relationships with users and user groups if they are to be meaningfully involved in such aspects as development of study protocols, instruments and patient information sheets. Had we not already had well-established links with patients and user groups, it would not have been possible to secure meaningful user involvement in such a short study. Likewise, having well-established clinical contacts and networks is vital to the successful setting up and conduct of rapid-turnaround studies. The approach also has implications for the ability to adopt measures to promote inclusion of hard-to-reach groups.

Conducting research during a pandemic was challenging and had implications for what could and could not be attempted. Pressure on services due to the pandemic was apparent – for example, at some sites outpatient clinics were heavily involved in staff vaccination programmes. Research, therefore, was not necessarily always a priority. It is our strong belief that undertaking survey research in primary care during the pandemic would not have been feasible – although we therefore ensured that distribution of questionnaires was minimally burdensome for frontline staff in clinics, we believe that even a small amount of extra burden would have been unacceptable to, and unfeasible for, primary care staff. The situation in a pandemic changes from week to week, which has implications for data collection methods and, especially, instruments – for example, some approaches, such as focus groups, may become unfeasible during a serious pandemic and questionnaires/interview topic guide content may need to be altered. Our survey data collection methods and questionnaires were not altered during the study (although steps were taken to encourage distribution of questionnaires at some sites). The iterative approach used in interviews and focus groups did enable us to feed issues raised by earlier participants/groups and in the media into data collection as appropriate.

The commissioning of studies was such that they were timed to commence and take place during the anticipated winter peak in swine flu. This did not emerge as anticipated. Although this could not have been foreseen, it did have implications for work of the type reported here, which focused on individuals' views and needs, and did, we believe, contribute to the low response rate, especially for the newspaper advertisement.

Chapter 6
Conclusions

Our data suggest that people with chest problems and their family members were generally well informed with respect to swine flu, but that some gaps in information-giving and knowledge remained and better targeting of information towards the specific needs of people with respiratory conditions and their families would have been welcomed. The need for information to help patients and family members discriminate between seasonal influenza, swine flu and symptoms of their respiratory problem was particularly highlighted; development of such information would be challenging, given the overlap between symptoms. Patients and family members also highlighted the importance of information being developed to aid them in understanding the likely impact of swine flu on their respiratory problem. As participants themselves noted, this need may extend to many long-term conditions.

The majority of patients were not highly anxious about swine flu and this was also true of family members. There was some confusion about who was at risk of developing swine flu, suggesting that messages regarding this issue were not as well communicated as they might have been. However, there was a clear recognition of people with respiratory problems as being at greater risk than the general population of swine flu complications. Despite this, survey response rates, particularly amongst family members, suggest that the topic of swine flu, by the time the study was commissioned and undertaken, may have had limited saliency.

Behaviour change was modest, but in line with recommendations from authoritative sources, and there appeared to be good levels of penetration of some key messages regarding prevention and help-seeking. Vaccination intent was very high in this sample, which may have been owing, in part, to effective communication of risk, but may also have been influenced by sample composition. Some concerns about vaccination, especially with regard to safety and interaction with underlying respiratory problems and associated medications, were apparent. This suggests that there is more to be done to ensure appropriate communication of risk. It is also somewhat paradoxical, given the high levels of vaccination intent.

The influence of the mass media on perceptions of and responses to the pandemic was apparent, especially within the qualitative data. In particular, questioning in the mass media of the effectiveness of antiviral medications may have affected views on and willingness to take these. Our data highlight a contradiction with respect to the role of the mass media as a communication medium within a pandemic, in that they were widely used but of questionable credibility. Likewise, the data highlight tensions between the use of mass media as a means of raising awareness versus its potential, through perceived oversaturation, 'hyping' or misrepresentation of issues, to reduce interest in a pandemic.

Recommendations for future research

Based on our findings, we make the following recommendations for future research:

- Work to identify effective means of delivering targeted information to high-risk groups during a pandemic would be of particular value.
- Follow-up work to establish whether vaccination intentions were followed through (and, if not, why this was the case) would be of value. It would also be interesting to seek to establish why these patients and family members were so highly motivated and whether this could provide lessons for future vaccination programmes.
- Further research to improve understanding of perception of risk (from the effects of swine flu and from vaccination) and its influence on decision-making in high-risk groups is needed, and could make a valuable contribution to the efficacy of future vaccination programmes.
- Future work is needed to establish whether issues identified by our participants regarding the role of the mass media would also be raised by people with respiratory conditions more widely or by other high-risk groups.
- Given the extensive reporting of the pandemic by the mass media and, indeed, the use by health-related agencies of the mass media to communicate pandemic-related messages,

work is urgently needed to explore further the influence of mass media reports on pandemic-related knowledge and behaviour in high-risk groups and to better understand how mass media can most effectively be used to communicate risk data, especially to high-risk groups in a pandemic.

- Issues of saliency suggest lessons for timing of future comparable research within a pandemic.
- Our experiences highlight the need to recognise and develop strategies to overcome the challenges of including hard-to-reach groups (including family members, BME groups and young adults) when undertaking short projects in the context of an ongoing pandemic.

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Contribution of authors

Ann-Louise Caress (Principal Investigator) led on development of proposal, instrument development, management of study, data analysis and writing report and also provided expertise in patient-focused research and user involvement.

Paula Duxbury (lay member) provided family member perspective and contributed to instrument development and interpretation of qualitative data

Ashley Woodcock (expert in respiratory disease) provided guidance on clinical issues and facilitated recruitment of study sites.

Karen Luker (methodological expert) provided input on selection and application of research methods.

Deborah Ward (infection control expert) provided expertise on the swine flu pandemic and public health issues.

Malcolm Campbell (statistical expert) provided guidance on study design, sample size calculation and data analysis methods and contributed to analysis of quantitative data.

Lynn Austin (postdoctoral research fellow) led on conduct of the study and day-to-day management of the research team, also led on analysis and writing up of qualitative data.

All authors contributed to development of the study proposal and to writing of the final report.

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Appendix 1

Newspaper advertisement for participant recruitment

People with chest problems and swine flu

- Are you at least 18 years of age?
- Do you have a chest problem?

OR

- Do you a have a family member with a chest problem?

If 'Yes', we would like to invite you to take part in a research project about swine flu*

We'd like you to tell us about:

- what information people with chest problems and their family members want regarding swine flu and who they want it from
- whether people with chest problems and their family members have any worries and concerns about swine flu, and what these are
- whether people with chest problems and their family members are doing anything different in their daily lives because of swine flu

If you agree to participate, you will be asked to take part in a telephone survey – our researcher will phone you and it will take about 30–45 minutes to complete.

INTERESTED?

Please phone [NUMBER], so we can tell you more about the study and answer your questions.

*The study is being run by a team from the University of Manchester and Wythenshawe Hospital. It is funded by the National Institute for Health Research, on behalf of the Department of Health, as part of its national swine flu research programme.

Appendix 2

Patient questionnaire*

(*Not in original font/type size.)

People with chest problems and swine flu

Identification Number: _____

Date: _____

1. How much do you know about swine flu? (Please circle *one* answer.)
   1. None of the things I need or want to know
   2. A bit, but I'd like to know more
   3. Quite a lot, but I'd still like to know more
   4. As much as I need or want to know

2. What, if anything, is the 'number one' thing you would like to know about swine flu? (If nothing, please state.)

_____

3a. How important do you think it is for people who have a chest problem to receive information about each of the following topics? (Please circle *one* number *for each item*.)

	Not at all important			→	**Very important**
1. What swine flu is and what it does to your body	1	2	3	4	5
2. Whether swine flu is different from ordinary flu	1	2	3	4	5
3. How serious swine flu is and the outlook for people who catch it	1	2	3	4	5
4. Whether there is a vaccine (flu jab) available for swine flu yet and who will get it	1	2	3	4	5
5. The treatments available for swine flu and how effective they are	1	2	3	4	5
6. What the symptoms of swine flu are	1	2	3	4	5
7. How to recognise if you might have swine flu	1	2	3	4	5
8. What to do if you think you have swine flu	1	2	3	4	5
9. How to recognise complications of swine flu and what to do about them	1	2	3	4	5
10. How likely it is that you will catch swine flu	1	2	3	4	5
11. How to prevent the spread of swine flu	1	2	3	4	5
12. How to reduce your risk of catching swine flu	1	2	3	4	5
13. How swine flu might affect chest problems	1	2	3	4	5
14. Whether people with chest problems are more likely to catch swine flu than other people	1	2	3	4	5
15. Whether the families of people with chest problems are more likely to catch swine flu than other people	1	2	3	4	5
16. Whether people with chest problems are more likely to develop complications or die from swine flu	1	2	3	4	5

	Not at all important			→	Very important
17. Whether treatments for swine flu are safe for people with chest problems	1	2	3	4	5
18. Whether treatments for swine flu can interfere with treatments for chest problems	1	2	3	4	5
19. Where to get information, help or support (e.g. if you are worried or want to know more about swine flu)	1	2	3	4	5

3b. Are there any important items missing from the above list? If so, what are they?

_____

4. How useful do you think each of the following is/could be as a source of information about swine flu for people with chest problems? (Please circle *one* number *for each item*.)

	Not at all useful			→	Very useful
1. Friends/relatives	1	2	3	4	5
2. General practitioner (GP)	1	2	3	4	5
3. Hospital consultant	1	2	3	4	5
4. Other hospital doctor	1	2	3	4	5
5. Specialist nurse (hospital or community)	1	2	3	4	5
6. District nurse	1	2	3	4	5
7. Health visitor	1	2	3	4	5
8. Nurses on hospital wards/at hospital clinics	1	2	3	4	5
9. Practice nurse (GP's nurse)	1	2	3	4	5
10. A&E (casualty) department	1	2	3	4	5
11. Walk-in centre or minor injuries unit	1	2	3	4	5
12. Community pharmacist (chemist)	1	2	3	4	5
13. NHS Direct (staffed phone line)	1	2	3	4	5
14. The HPA	1	2	3	4	5
15. Television	1	2	3	4	5
16. Radio	1	2	3	4	5
17. Posters or billboards	1	2	3	4	5
18. Medical book/journal	1	2	3	4	5
19. Magazines	1	2	3	4	5
20. Newspapers	1	2	3	4	5
21. Leaflets	1	2	3	4	5
22. Government website (www.direct.gov.uk/pandemicflu)	1	2	3	4	5
23. NHS Choices website (www.nhs.uk)	1	2	3	4	5
24. Other website	1	2	3	4	5
25. Health-related charities	1	2	3	4	5
26. Patient support/self-help groups	1	2	3	4	5
27. National Pandemic Flu Service (website and phone line)	1	2	3	4	5

5. Now please tell us which of these items *you personally* would use as a source of information about swine flu. (Please indicate by circling *one* number *for each item.*)

	Not at all useful		→		**Very useful**
1. Friends/relatives	1	2	3	4	5
2. General practitioner (GP)	1	2	3	4	5
3. Hospital consultant	1	2	3	4	5
4. Other hospital doctor	1	2	3	4	5
5. Specialist nurse (hospital or community)	1	2	3	4	5
6. District nurse	1	2	3	4	5
7. Health visitor	1	2	3	4	5
8. Nurses on hospital wards/at hospital clinics	1	2	3	4	5
9. Practice nurse (GP's nurse)	1	2	3	4	5
10. A&E (casualty) department	1	2	3	4	5
11. Walk-in centre or minor injuries unit	1	2	3	4	5
12. Community pharmacist (chemist)	1	2	3	4	5
13. NHS Direct (staffed phone line)	1	2	3	4	5
14. The HPA	1	2	3	4	5
15. Television	1	2	3	4	5
16. Radio	1	2	3	4	5
17. Posters or billboards	1	2	3	4	5
18. Medical book/journal	1	2	3	4	5
19. Magazines	1	2	3	4	5
20. Newspapers	1	2	3	4	5
21. Leaflets	1	2	3	4	5
22. Government website (www.direct.gov.uk/pandemicflu)	1	2	3	4	5
23. NHS Choices website (www.nhs.uk)	1	2	3	4	5
24. Other website	1	2	3	4	5
25. Health-related charities	1	2	3	4	5
26. Patient support/self-help groups	1	2	3	4	5
27. National Pandemic Flu Service (website and phone line)	1	2	3	4	5

6a. Have you already had any information about swine flu? (Please circle *one* answer.)

– Yes
– No

6b. If YES, where from? (Please circle *all that apply.*)

1. Leaflet delivered to my home
2. Leaflet picked up somewhere else
3. Poster displayed at work
4. Poster displayed at GP surgery
5. Poster displayed at hospital
6. Internet – NHS Choices (www.nhs.uk)
7. Internet – government website (www.direct.gov.uk/pandemicflu)
8. Internet – health-care organisation or health-care charity website
9. Internet – other website
10. NHS Direct (phone line)
11. The Swine Flu Information Line (phone line, recorded information)
12. Other telephone helpline (e.g. health-care charity)

13. Friends or relatives
14. General practitioner (GP)
15. Practice nurse (GP's nurse)
16. Receptionist at GP's surgery
17. Community pharmacist (chemist)
18. Specialist nurse (hospital or community)
19. District nurse
20. Health visitor
21. Hospital consultant/specialist doctor
22. Other hospital doctor
23. Hospital doctor's secretary or clinic receptionist
24. Nurses on hospital wards or at clinics
25. Other health professional (e.g. physiotherapist, occupational therapist)
26. Minor injuries clinic or walk-in centre
27. A&E (casualty) department
28. National Pandemic Flu Service (website and phone line)
29. The HPA
30. Television
31. Radio
32. Newspaper
33. Magazine
34. Medical book/journal
35. Patient self-help or support group
36. Other (please state)

_____

7a. How satisfied or dissatisfied are you with the amount of information available to you on swine flu, from any source? (Please circle *one* answer.)
1. Very satisfied
2. Fairly satisfied
3. Neither satisfied nor dissatisfied
4. Fairly dissatisfied
5. Very dissatisfied
6. Don't know

7b. If DISSATISFIED, why is that?

_____

8a. Do you think that the currently available information about swine flu is helpful, or not? (Please circle *one* answer.)
1. Yes
2. No
3. Don't know

8b. If NO, why not?

_____

9a. Do people with chest problems need different information about swine flu from other people, or not? (Please circle *one* answer.)
1. Yes
2. No
3. Don't know

9b. If YES, what is/should be different about the information provided?

_____

10. Swine flu is a form of influenza that originated in pigs, but can be caught by, and spread among, people. How worried, if at all, would you say you are now about the possibility of personally catching swine flu? (Please circle *one* answer.)
    1. Very worried
    2. Fairly worried
    3. Not very worried
    4. Not at all worried
    5. Don't know

11. Because of your chest problem, do you think you are more likely than other people to catch swine flu, or not? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

12. If you caught swine flu, how likely do you think you would be to develop complications? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

13. How worried are you that you might die from swine flu? (Please circle *one* answer.)
    1. Very worried
    2. Fairly worried
    3. Not very worried
    4. Not at all worried
    5. Don't know

14. How confident are you that you could correctly recognise the symptoms of swine flu? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

15. How confident are you that you would know what to do if you thought you had swine flu? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

16. How confident are you that you could recognise the complications of swine flu and would know what to do about them? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

17. How confident are you that being vaccinated (having a jab) against swine flu would help you? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

18. Below is a list of behaviours or activities. For each, could you please tell me if, over the last week, you have done it more frequently, less frequently, or the same, as a result of swine flu? (Please circle *one* answer *for each item*.)

1. Washed hands with soap and water	More frequently	Less frequently	The same	Have not done it at all	Don't know
2. Carried tissues with you	More frequently	Less frequently	The same	Have not done it at all	Don't know
3. Avoided crowded spaces or large crowds	More frequently	Less frequently	The same	Have not done it at all	Don't know
4. Avoided public transport at peak times	More frequently	Less frequently	The same	Have not done it at all	Don't know
5. Used antibacterial gel	More frequently	Less frequently	The same	Have not done it at all	Don't know
6. Worn a surgical mask	More frequently	Less frequently	The same	Have not done it at all	Don't know
7. Avoided touching your face with your hands	More frequently	Less frequently	The same	Have not done it at all	Don't know
8. Disinfected spaces where you live or work	More frequently	Less frequently	The same	Have not done it at all	Don't know
9. Avoided kissing or hugging people	More frequently	Less frequently	The same	Have not done it at all	Don't know

19a. Have you ever had flu in the past? (Please circle *one* answer.)
    1. Yes, once
    2. Yes, more than once
    3. No, never
    4. Don't know/can't remember

19b. If YES, how long ago was your most recent bout? (Please circle *one* answer.)
    1. Within the last year
    2. More than a year ago, but within the last five years
    3. More than five years ago
    4. Don't know/can't remember

20. Have you had the regular winter flu jab in the past? (Please circle *one* answer.)
    1. Yes, regularly each year
    2. Yes, occasionally
    3. No, never
    4. Don't know/can't remember

21. Please indicate by circling *one* answer whether you agree or disagree with the following statement: 'As a result of swine flu, I am now more likely to get the regular winter flu jab'.
    1. Strongly agree
    2. Tend to agree
    3. Neither agree nor disagree
    4. Tend to disagree

5. Strongly disagree
6. Don't know

22. The Government recently announced that a swine flu vaccination programme will be rolled out across the UK starting this autumn. How likely, if at all, are you to take up a swine flu vaccination if offered it? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

23a. If you felt you had *swine flu symptoms*, which, if any, of the following would you do *first*? (Please circle *one* answer.)
    1. I would go to an A&E (casualty) department
    2. I would go to my family doctor/GP
    3. I would call my family doctor/GP
    4. I would call a health helpline for advice (e.g. NHS Direct)
    5. I would call Swine Flu Information
    6. I would stay at home and self-treat my symptoms
    7. I would visit an NHS, Department of Health or other health website for advice
    8. I would visit/go and see a community pharmacist (chemist)
    9. I would call the hospital chest clinic/my chest consultant's secretary
    10. I would go to the walk-in chest clinic at the hospital
    11. None of these
    12. Don't know
    13. Other (please specify)

_____

23b. And what else might you do? (Please circle *all that apply.*)
    1. I would go to an A&E (casualty) department
    2. I would go to my family doctor/GP
    3. I would call my family doctor/GP
    4. I would call a health helpline for advice (e.g. NHS Direct)
    5. I would call Swine Flu Information
    6. I would stay at home and self-treat my symptoms
    7. I would visit an NHS, Department of Health or other health website for advice
    8. I would visit/go and see a community pharmacist (chemist)
    9. I would call the hospital chest clinic/my chest consultant's secretary
    10. I would go to the walk-in chest clinic at the hospital
    11. None of these
    12. Don't know
    13. Other (please specify)

_____

24a. If you thought you were developing complications of swine flu, which, if any, of the following would you do *first*? (Please circle *one* answer.)
    1. I would go to an A&E (casualty) department
    2. I would go to my family doctor/GP
    3. I would call my family doctor/GP
    4. I would call a health helpline for advice (e.g. NHS Direct)
    5. I would call Swine Flu Information
    6. I would stay at home and self-treat my symptoms
    7. I would visit an NHS, Department of Health or other health website for advice

8. I would visit/go and see a community pharmacist (chemist)
9. I would call the hospital chest clinic/my chest consultant's secretary
10. I would go to the walk-in chest clinic at the hospital
11. None of these
12. Don't know
13. Other (please specify)

24b.And what else might you do? (Please circle *all that apply*.)

1. I would go to an A&E (casualty) department
2. I would go to my family doctor/GP
3. I would call my family doctor/GP
4. I would call a health helpline for advice (e.g. NHS Direct)
5. I would call Swine Flu Information
6. I would stay at home and self-treat my symptoms
7. I would visit an NHS, Department of Health or other health website for advice
8. I would visit/go and see a community pharmacist (chemist)
9. I would call the hospital chest clinic/my chest consultant's secretary
10. I would go to the walk-in chest clinic at the hospital
11. None of these
12. Don't know
13. Other (please specify)

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25. Have you chosen anyone to act as a 'Swine Flu Friend/Buddy' for you? (Please circle *one* answer.)
    1. Yes
    2. No, because I don't think I need one
    3. No, because I don't know what one is
    4. Don't know

26. As you may have heard, the antiviral medicines such as Tamiflu can sometimes help to reduce the symptoms of swine flu if taken right away. If you fell ill with swine flu, and wanted to obtain Tamiflu, how would you go about obtaining it, or how have you got it already? (Please circle *all* that apply.)
    1. I would go to an A&E (casualty) department
    2. I would go to my family doctor/GP
    3. I would call my GP/health centre
    4. I would call a health helpline for advice (e.g. NHS Direct)
    5. I would call the National Pandemic Flu Service (NPFS)
    6. I would ask a Flu Friend/Flu Buddy
    7. I would ask my local community pharmacist (chemist)
    8. I would look for information on news programmes on television
    9. I would look for information in the newspapers
    10. I would listen for information on news programmes on the radio
    11. I would look online – on news websites
    12. I would look online – on NHS, Department of Health or other health websites
    13. I would look online – on other websites
    14. I would look online – unspecified
    15. I would contact my chest consultant/the hospital chest clinic
    16. I would contact a chest specialist nurse (hospital or community)
    17. I already have a supply of Tamiflu
    18. None of these
    19. Don't know
    20. Other (please specify)

---

27. If you needed antiviral treatment for swine flu, from where would you prefer to get it? (Please circle *one* answer.)
    1. On prescription (from a GP/family doctor, hospital doctor, nurse, etc.)
    2. 'Over the counter' (from a community pharmacist/chemist)
    3. Without having to contact a health professional (e.g. internet, health food shop, etc.)
    4. Other (please state)

---

28. Please indicate, by circling *one* answer, whether you agree or disagree with the following statement: 'Too much fuss is being made about the risk of swine flu.'
    1. Strongly agree
    2. Tend to agree
    3. Neither agree nor disagree
    4. Tend to disagree
    5. Strongly disagree
    6. Don't know

29. Please tell us if you think each of the following statements is *true or false*. (Please circle *one* option for *each item*.)

1. Very young people are the most likely to get swine flu	True/False
2. Wearing a mask will stop me getting swine flu	True/False
3. People with chest problems are more likely than others to catch swine flu	True/False
4. Washing your hands is very important in preventing the spread of swine flu	True/False
5. The ordinary flu vaccine will protect me from swine flu	True/False
6. People with chest problems are more likely than others to develop complications of swine flu	True/False
7. Older people are the most likely to get swine flu	True/False
8. Tamiflu is a vaccine for swine flu	True/False
9. Swine flu may become more of a problem over the winter	True/False
10. People with chest problems are more likely to die from swine flu than others	True/False
11. It is possible to catch swine flu from eating pork	True/False
12. Using an antibacterial hand wash or gel will stop the spread of swine flu	True/False
13. If your doctor says you need antiviral treatment, you should send someone to collect a prescription for you, rather than going yourself	True/False
14. If someone in a household develops swine flu, all their family can get anti-swine flu treatment (e.g. Tamiflu or Relenza)	True/False
15. Swine flu is very contagious	True/False
16. 'Swine flu parties' are a good way of developing immunity to swine flu	True/False
17. Swine flu is different from ordinary flu	True/False

30. Please tell us if you think any of the following might be a symptom of swine flu or not (Please circle *one* option for *each item*.)

1. Sudden fever (high temperature)	True/False
2. Sudden cough (in people who don't usually have a cough)	True/False
3. Worsening of cough (in people who usually have a cough)	True/False
4. Headache	True/False
5. Tiredness	True/False
6. Producing more sputum (phlegm/mucus) than usual	True/False
7. Chills	True/False
8. Aching muscles	True/False
9. Limb or joint pain	True/False
10. Suddenly becoming breathless (in people who aren't usually breathless)	True/False
11. Worsening of breathlessness (in people who are usually breathless)	True/False
12. Dizziness	True/False
13. Diarrhoea or stomach upset	True/False

14.	Sore throat	True/False
15.	Blurred vision	True/False
16.	Runny nose	True/False
17.	Sputum (phlegm/mucus) turning a different colour than usual	True/False
18.	Loss of memory	True/False
19.	Rash	True/False
20.	Loss of appetite	True/False
21.	Sudden inability to move or control limbs	True/False
22.	Wheezing	True/False
23.	Confusion	True/False
24.	Sneezing	True/False
25.	Chest pains	True/False

31. If you had swine flu, would you get help if you developed any of the following symptoms? (Please circle *one* option for *each item*.)

1.	Fast breathing or feeling much more short of breath than usual	Yes/No
2.	Feeling very tired	Yes/No
3.	Chest pains	Yes/No
4.	Fever (high temperature) that didn't go down after 4 or 5 days	Yes/No
5.	Aching muscles	Yes/No
6.	Producing more sputum (phlegm/mucus) than usual	Yes/No
7.	Worsening of cough or cough that wouldn't go away	Yes/No
8.	Drowsiness or confusion	Yes/No
9.	Coughing up blood	Yes/No
10.	Sputum (phlegm/mucus) turning a different colour than usual	Yes/No
11.	Sore throat	Yes/No
12.	Feeling more wheezy than usual	Yes/No

32. We'd like to know whether worries about swine flu are making you do anything different or feel different (Please circle *all that apply*.)

Because of worries about swine flu:

1. I have stopped or cut down on travelling by public transport (buses, trains, etc.)
2. I am taking things like vitamins or food supplements
3. I am avoiding crowded places (e.g. shops, cinemas, sports events, etc.)
4. I am leaving the house less often
5. I am avoiding contact with my friends and family members
6. I feel that people are worried about being around me
7. I have cut down or stopped smoking
8. I have cancelled a holiday/rearranged travel plans
9. I am keeping my windows and doors closed
10. I feel more anxious than usual about my chest problem
11. I am avoiding contact with children
12. I would not take my medication/use my inhaler in a public place, even if I really needed it
13. I am trying to get more exercise
14. I am not leaving the house at all
15. I feel more self-conscious about my chest problem
16. I am avoiding contact with pets/animals
17. I am using my inhaler(s) more often
18. I would not wish to travel far within the United Kingdom
19. I am eating more healthy foods
20. I am much more aware of my chest problem than usual
21. I am not sleeping well
22. I would not wish to travel abroad
23. I have cut down my usual social activities (e.g. going to the pub, eating out, etc.)
24. I am avoiding contact with people who have been abroad

25. I am constantly on the alert for changes in my chest problem
26. I feel that other people are avoiding me
27. I am more careful about taking my regular medications as instructed
28. I am avoiding eating pork/ham/bacon, etc.
29. I have tried to buy/bought Tamiflu

Now please tell us a bit about yourself:

33. How old are you (in years)?

_____

34. What is your gender? (Please circle *one* answer.)
    30. Male
    31. Female

35. What would you consider your ethnic group to be?

_____

36. Are you married or living with a partner? (Please circle *one* answer.)
    32. Yes
    33. No

37a. What is your current occupation?

_____

37b. If retired or not working, what is your most recent previous occupation?

_____

38. Do you have any of the following? (Please circle *all that apply*.)
    1. CSE/O level/GCSE or equivalent
    2. A level or equivalent
    3. GNVQ
    4. Diploma
    5. Professional qualification (e.g. RGN, Cert Ed, City and Guilds)
    6. College/university degree (undergraduate/bachelor's)
    7. Higher degree (Masters, MRes, PhD)
    8. None of the above
    9. Other (please state which)

_____

39. What is the name of your chest problem? (If you are not sure, please write 'don't know'.)

_____

40. What kind of treatment do you currently receive for your chest problem? (Please circle *all that apply*.)
    1. Tablets
    2. Inhalers
    3. Nebulisers
    4. Oxygen
    5. None of these
    6. Other (Please state which.)

_____

41. How severe would you rate your chest problem as being? (Please circle *one* answer.)
    1. Very mild
    2. Mild
    3. Moderate
    4. Severe
    5. Very Severe
    6. Don't know

42. Do you smoke? (Please circle *one* answer.)
    1. Yes, I currently smoke
    2. No, but I used to smoke
    3. No, I have never smoked

43a. Apart from your chest problem, do you have any other health problems? (Please circle *one* answer.)
    1. Yes
    2. No

43b. If YES, what are these problems?

_____

44. How did you find out about our study? (Please circle *one* answer.)
    1. I was handed a questionnaire at chest clinic
    2. I saw a poster at chest clinic
    3. I saw the piece about the study in the newspaper
    4. Someone (e.g. a friend or relative) told me about the study
    5. Other (please state)

_____

45. Any other comments?

_____

If you want to contact us about this research, details are as follows:

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For independent information about this research, please contact:

The University of Manchester's Research Practice and Governance Co-ordinator
Tel: 0000 000 0000 or 0000 000 0000
E-mail: research-governance@manchester.ac.uk

Further information about swine flu can be found at:

National Pandemic Flu Service (NPFS): 0800 1 513 100
NPFS Textphone for people who are deaf/hard of hearing: 0800 1 513 200
The government's Pandemic Flu website: www.direct.gov.uk/pandemicflu
The NHS Choices website: www.nhs.uk

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

PLEASE RETURN THE QUESTIONNAIRE TO US IN THE ENCLOSED PRE-PAID ENVELOPE OR, IF COMPLETED WHILST AT CLINIC, ASK THE RECEPTIONIST (OR THE MEMBER OF CLINIC STAFF WHO GAVE YOU THE PACK) WHERE TO LEAVE IT – THANK YOU

YOU DO NOT HAVE TO PROVIDE ANY CONTACT INFORMATION. HOWEVER, IF YOU ARE WILLING TO DO SO (e.g. SO WE CAN SEND YOU A SUMMARY OF STUDY FINDINGS), PLEASE COMPLETE THE SEPARATE SHEET ATTACHED AND RETURN IT WITH YOUR COMPLETED QUESTIONNAIRE – THANK YOU

Appendix 3

Family member questionnaire*

(*Not in original font/type size)

People with chest problems and swine flu

Identification Number: _____

Date: _____

1. How much do you know about swine flu? (Please circle *one* answer.)
   1. None of the things I need or want to know
   2. A bit, but I'd like to know more
   3. Quite a lot, but I'd still like to know more
   4. As much as I need or want to know

2. What, if anything, is the 'number one' thing you would like to know about swine flu? (If nothing, please state.)

_____

3a. How important do you think it is for the families of people who have a chest problem to receive information about each of the following topics? (Please circle *one* number *for each item.)*

	Not at all important			→	**Very important**
1. What swine flu is and what it does to your body	1	2	3	4	5
2. Whether swine flu is different from ordinary flu	1	2	3	4	5
3. How serious swine flu is and the outlook for people who catch it	1	2	3	4	5
4. Whether there is a vaccine (flu jab) available for swine flu yet and who will get it	1	2	3	4	5
5. The treatments available for swine flu and how effective they are	1	2	3	4	5
6. What the symptoms of swine flu are	1	2	3	4	5
7. How to recognise if you might have swine flu	1	2	3	4	5
8. What to do if you think you have swine flu	1	2	3	4	5
9. How to recognise complications of swine flu and what to do about them	1	2	3	4	5
10. How likely it is that you will catch swine flu	1	2	3	4	5
11. How to prevent the spread of swine flu	1	2	3	4	5
12. How to reduce your risk of catching swine flu	1	2	3	4	5
13. How swine flu might affect chest problems	1	2	3	4	5
14. Whether people with chest problems are more likely to catch swine flu than other people	1	2	3	4	5
15. Whether the families of people with chest problems are more likely to catch swine flu than other people	1	2	3	4	5

	Not at all important			→	Very important
16. Whether people with chest problems are more likely to develop complications or die from swine flu	1	2	3	4	5
17. Whether treatments for swine flu are safe for people with chest problems	1	2	3	4	5
18. Whether treatments for swine flu can interfere with treatments for chest problems	1	2	3	4	5
19. Where to get information, help or support (e.g. if you are worried or want to know more about swine flu)	1	2	3	4	5

3b. Are there any important items missing from the above list? If so, what are they?

_____

4. How useful do you think each of the following is/could be as a source of information about swine flu for the families of people with chest problems? (Please circle *one* number for each item.)

	Not at all useful			→	Very useful
1. Friends/relatives	1	2	3	4	5
2. General practitioner (GP)/family doctor	1	2	3	4	5
3. Hospital consultant	1	2	3	4	5
4. Other hospital doctor	1	2	3	4	5
5. Specialist nurse (hospital or community)	1	2	3	4	5
6. District nurse	1	2	3	4	5
7. Health visitor	1	2	3	4	5
8. Nurses on hospital wards/at hospital clinics	1	2	3	4	5
9. Practice nurse (GP's nurse)	1	2	3	4	5
10. A&E (casualty) department	1	2	3	4	5
11. Walk-in centre or minor injuries unit	1	2	3	4	5
12. Community pharmacist (chemist)	1	2	3	4	5
13. NHS Direct (phone line)	1	2	3	4	5
14. The HPA	1	2	3	4	5
15. Television	1	2	3	4	5
16. Radio	1	2	3	4	5
17. Posters or billboards	1	2	3	4	5
18. Medical book/journal	1	2	3	4	5
19. Magazines	1	2	3	4	5
20. Newspapers	1	2	3	4	5
21. Leaflets	1	2	3	4	5
22. Government website (www.direct.gov.uk/pandemicflu)	1	2	3	4	5
23. NHS Choices website (www.nhs.uk)	1	2	3	4	5
24. Other website	1	2	3	4	5
25. Health-related charities	1	2	3	4	5
26. Patient support/self-help groups	1	2	3	4	5
27. National Pandemic Flu Service (website and phone line)	1	2	3	4	5

5. Now please tell us which of these items *you personally* would use as a source of information about swine flu (Please indicate by circling *one* number *for each* item.)

	Definitely would use			→	**Definitely would not use**
1. Friends/relatives	1	2	3	4	5
2. General practitioner (GP)/family doctor	1	2	3	4	5
3. Hospital consultant	1	2	3	4	5
4. Other hospital doctor	1	2	3	4	5
5. Specialist nurse (hospital or community)	1	2	3	4	5
6. District nurse	1	2	3	4	5
7. Health visitor	1	2	3	4	5
8. Nurses on hospital wards/at hospital clinics	1	2	3	4	5
9. Practice nurse (GP's nurse)	1	2	3	4	5
10. A&E (casualty) department	1	2	3	4	5
11. Walk-in centre or minor injuries unit	1	2	3	4	5
12. Community pharmacist (chemist)	1	2	3	4	5
13. NHS Direct (phone line)	1	2	3	4	5
14. The HPA	1	2	3	4	5
15. Television	1	2	3	4	5
16. Radio	1	2	3	4	5
17. Posters or billboards	1	2	3	4	5
18. Medical book/journal	1	2	3	4	5
19. Magazines	1	2	3	4	5
20. Newspapers	1	2	3	4	5
21. Leaflets	1	2	3	4	5
22. Government website (www.direct.gov.uk/pandemicflu)	1	2	3	4	5
23. NHS Choices website (www.nhs.uk)	1	2	3	4	5
24. Other website	1	2	3	4	5
25. Health-related charities	1	2	3	4	5
26. Patient support/self-help groups	1	2	3	4	5
27. National Pandemic Flu Service (website and phone line)	1	2	3	4	5

6a. Have you already had any information about swine flu? (Please circle *one* answer.)
1. Yes
2. No

6b. If YES, where from? (Please circle *all that apply*.)
1. Leaflet delivered to my home
2. Leaflet picked up somewhere else
3. Poster displayed at work
4. Poster displayed at GP surgery
5. Poster displayed at hospital
6. Internet – NHS Choices (www.nhs.uk)
7. Internet – Government website (www.direct.gov.uk/pandemicflu)
8. Internet – health-care organisation or health-care charity website
9. Internet – other website
10. NHS Direct (phone line)
11. The Swine Flu Information Line (phone line, recorded information)
12. Other telephone helpline (e.g. health-care charity)
13. Friends or relatives

14. General practitioner (GP)
15. Practice nurse (GP's nurse)
16. Receptionist at GP's surgery
17. Community pharmacist (chemist)
18. Specialist nurse (hospital or community)
19. District nurse
20. Health visitor
21. Hospital consultant/specialist doctor
22. Other hospital doctor
23. Hospital doctor's secretary or clinic receptionist
24. Nurses on hospital wards or at clinics
25. Other health professional (e.g. physiotherapist, occupational therapist)
26. Minor injuries clinic or walk-in centre
27. A&E (casualty) department
28. National Pandemic Flu Service (website and phone line)
29. The HPA
30. Television
31. Radio
32. Newspaper
33. Magazine
34. Medical book/journal
35. Patient self-help or support group
36. Other (please state)

_____

7a. How satisfied or dissatisfied are you with the amount of information available to you on swine flu, from any source? (Please circle *one* answer.)
1. Very satisfied
2. Fairly satisfied
3. Neither satisfied nor dissatisfied
4. Fairly dissatisfied
5. Very dissatisfied
6. Don't know

7b. If DISSATISFIED, why is that?

_____

8a. Do you think that the information currently available about swine flu is helpful, or not? (Please circle *one* answer.)
1. Yes
2. No
3. Don't know

8b. If NO, why not?

_____

9a. Do the families of people with chest problems need different information about swine flu from other people, or not? (Please circle *one* answer.)
1. Yes
2. No
3. Don't know

9b. If YES, what is/should be different about the information provided?

_____

Questions on the next two pages are about *swine flu and you*

10. Swine flu is a form of influenza that originated in pigs, but can be caught by, and spread among, people. How worried, if at all, would you say you are now about the possibility of personally catching swine flu? (Please circle *one* answer.)
    1. Very worried
    2. Fairly worried
    3. Not very worried
    4. Not at all worried
    5. Don't know

11. Because of your family member's chest problem, do you think *you* are more likely than other people to catch swine flu, or not? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

12. If *you* caught swine flu, how likely do you think you would be to develop complications? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

13. How worried are you that *you* might die from swine flu?(Please circle *one* answer.)
    1. Very worried
    2. Fairly worried
    3. Not very worried
    4. Not at all worried
    5. Don't know

14. How confident are you that you could correctly recognise the symptoms of swine flu *in yourself*? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

15. How confident are you that you would know what to do if you thought *you* had swine flu? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

16. How confident are you that you could recognise the complications of swine flu *in yourself* and would know what to do about them? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

17. How confident are you that being vaccinated (having a jab) against swine flu would help *you*? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

Questions on the next two pages are about *swine flu and your family member with chest problems*

18. How worried, if at all, would you say you are now about the possibility of *your family member with chest problems* catching swine flu? (Please circle *one* answer.)
    1. Very worried
    2. Fairly worried
    3. Not very worried
    4. Not at all worried
    5. Don't know

19. Do you think *your family member with chest problems* is more likely than other people to catch swine flu, or not? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

20. If *your family member with chest problems* caught swine flu, how likely do you think they would be to develop complications? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

21. How worried are you that *your family member with chest problems* might die from swine flu? (Please circle *one* answer.)
    1. Very worried
    2. Fairly worried
    3. Not very worried
    4. Not at all worried
    5. Don't know

22. How confident are you that you could correctly recognise the symptoms of swine flu in *your family member with chest problems*? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

23. How confident are you that you would know what to do if you thought *your family member with chest problems* had swine flu? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

24. How confident are you that you could recognise the complications of swine flu *in your family member with chest problems* and would know what to do about them? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

25. How confident are you that being vaccinated (having a jab) against swine flu would help *your family member with chest problems*? (Please circle *one* answer.)
    1. Very confident
    2. Fairly confident
    3. Not very confident
    4. Not at all confident
    5. Don't know

26. Below is a list of behaviours or activities. For each, could you please indicate if, over the last week, you have done it more frequently, less frequently, or the same, as a result of swine flu? (Please circle *one* answer for *each item*.)

1. Washed hands with soap and water	More frequently	Less frequently	The same	Have not done it at all	Don't know
2. Carried tissues with you	More frequently	Less frequently	The same	Have not done it at all	Don't know
3. Avoided crowded spaces or large crowds	More frequently	Less frequently	The same	Have not done it at all	Don't know
4. Avoided public transport at peak times	More frequently	Less frequently	The same	Have not done it at all	Don't know
5. Used antibacterial gel	More frequently	Less frequently	The same	Have not done it at all	Don't know
6. Worn a surgical mask	More frequently	Less frequently	The same	Have not done it at all	Don't know
7. Avoided touching your face with your hands	More frequently	Less frequently	The same	Have not done it at all	Don't know
8. Disinfected spaces where you live or work	More frequently	Less frequently	The same	Have not done it at all	Don't know
9. Avoided kissing or hugging people	More frequently	Less frequently	The same	Have not done it at all	Don't know

27a. Have you ever had flu in the past? (Please circle *one* answer.)
    1. Yes, once
    2. Yes, more than once
    3. No, never
    4. Don't know/can't remember

27b. If YES, how long ago was your most recent bout? (Please circle *one* answer.)
    1. Within the last year
    2. More than a year ago, but within the last 5 years
    3. More than 5 years ago
    4. Don't know/can't remember

28. Have you had the regular winter flu jab in the past? (Please circle *one* answer.)
    1. Yes, regularly each year
    2. Yes, occasionally
    3. No, never
    4. Don't know/can't remember

29. Please indicate by circling *one* answer whether you agree or disagree with the following statement: 'As a result of swine flu, I am now more likely to get the regular winter flu jab.'
    1. Strongly agree
    2. Tend to agree
    3. Neither agree nor disagree
    4. Tend to disagree
    5. Strongly disagree
    6. Don't know

30a. The Government recently announced that a swine flu vaccination programme will be rolled out across the UK starting this autumn. How likely, if at all, are *you* to take up a swine flu vaccination if offered it? (Please circle *one* answer.)
    1. Very likely
    2. Fairly likely
    3. Not very likely
    4. Not at all likely
    5. Don't know

30b. When the new swine flu vaccine is produced, do you think *your family member with chest problems* should have it or not? (Please circle *one* answer.)
    1. They should definitely have it
    2. They should probably have it
    3. I am not sure whether they should have it or not
    4. They should probably not have it
    5. They definitely should not have it
    6. Don't know

Questions on the next two pages are about *swine flu and you*

31a. If you felt *you* had *swine flu symptoms*, which, if any, of the following would you do *first*? (Please circle one answer.)
    1. I would go to an A&E (casualty) department
    2. I would go to my family doctor/GP
    3. I would call my family doctor/GP
    4. I would call a health helpline for advice (e.g. NHS Direct)
    5. I would call Swine Flu Information
    6. I would stay at home and self-treat my symptoms
    7. I would visit an NHS, Department of Health or other health website for advice
    8. I would visit/go and see a community pharmacist (chemist)
    9. None of these
    10. Don't know
    11. Other (Please specify)

31b. And what else might *you* do? (Please circle *all that apply*.)
    1. I would go to an A&E (casualty) department
    2. I would go to my family doctor/GP
    3. I would call my family doctor/GP
    4. I would call a health helpline for advice (e.g. NHS Direct)
    5. I would call Swine Flu Information
    6. I would stay at home and self-treat my symptoms
    7. I would visit an NHS, Department of Health or other health website for advice
    8. I would visit/go and see a community pharmacist (chemist)

9. None of these
10. Don't know
11. Other (please specify)

32a. If you thought *you* were *developing complications of swine flu*, which, if any, of the following would you do *first*? (Please circle *one* answer.)
1. I would go to an A&E (casualty) department
2. I would go to my family doctor/GP
3. I would call my family doctor/GP
4. I would call a health helpline for advice (e.g. NHS Direct)
5. I would call Swine Flu Information
6. I would stay at home and self-treat my symptoms
7. I would visit an NHS, Department of Health or other health website for advice
8. I would visit/go and see a community pharmacist (chemist)
9. None of these
10. Don't know
11. Other (please specify)

32b. And what else might *you* do? (Please circle *all that apply*.)
1. I would go to an A&E (casualty) department
2. I would go to my family doctor/GP
3. I would call my family doctor/GP
4. I would call a health helpline for advice (e.g. NHS Direct)
5. I would call Swine Flu Information
6. I would stay at home and self-treat my symptoms
7. I would visit an NHS, Department of Health or other health website for advice
8. I would visit/go and see a community pharmacist (chemist)
9. None of these
10. Don't know
11. Other (please specify)

Questions on the next two pages are about *swine flu and your family member with chest problems*

33a. f your family member with chest problems felt they had swine flu symptoms, which, if any, of the following would you advise them to do *first*? (Please circle *one* answer.)
1. Go to an A&E (casualty) department
2. Go to their family doctor/GP
3. Call their family doctor/GP
4. Call a health helpline for advice (e.g. NHS Direct)
5. Call Swine Flu Information
6. Stay at home and self-treat their symptoms
7. Visit an NHS, Department of Health or other health website for advice
8. Visit/go and see a community pharmacist (chemist)
9. Call the hospital chest clinic/their chest consultant's secretary
10. Go to the walk-in chest clinic at the hospital
11. None of these
12. Don't know
13. Other (please specify)

33b. And what else might you advise them to do? (Please circle *all that apply*.)

1. Go to an A&E (casualty) department
2. Go to their family doctor/GP
3. Call their family doctor/GP
4. Call a health helpline for advice (e.g. NHS Direct)
5. Call Swine Flu Information
6. Stay at home and self-treat their symptoms
7. Visit an NHS, Department of Health or other health website for advice
8. Visit/go and see a community pharmacist (chemist)
9. Call the hospital chest clinic/their chest consultant's secretary
10. Go to the walk-in chest clinic at the hospital
11. None of these
12. Don't know
13. Other (please specify)

34a. If *your family member with chest problems* thought they were *developing complications of swine flu*, which, if any, of the following would you do *first*? (Please circle *one* answer.)

1. Go to an A&E (casualty) department
2. Go to their family doctor/GP
3. Call their family doctor/GP
4. Call a health helpline for advice (e.g. NHS Direct)
5. Call Swine Flu Information
6. Stay at home and self-treat their symptoms
7. Visit an NHS, Department of Health or other health website for advice
8. Visit/go and see a community pharmacist (chemist)
9. Call the hospital chest clinic/their chest consultant's secretary
10. Go to the walk-in chest clinic at the hospital
11. None of these
12. Don't know
13. Other (please specify)

34b. And what else might you advise them to do? (Please circle *all that apply*.)

1. Go to an A&E (casualty) department
2. Go to their family doctor/GP
3. Call their family doctor/GP
4. Call a health helpline for advice (e.g. NHS Direct)
5. Call Swine Flu Information
6. Stay at home and self-treat their symptoms
7. Visit an NHS, Department of Health or other health website for advice
8. Visit/go and see a community pharmacist (chemist)
9. Call the hospital chest clinic/their chest consultant's secretary
10. Go to the walk-in chest clinic at the hospital
11. None of these
12. Don't know
13. Other (please specify)

35a. Have you chosen anyone to act as a 'Swine Flu Friend/Buddy' *for you*?

1. Yes
2. No, because I don't think I need one
3. No, because I don't know what one is
4. Don't know

35b. Has your family member with a chest problem chosen anyone to act as a 'Swine Flu Friend/Buddy' *for them*?
1. Yes
2. No, because they don't think they need one
3. No, because they don't know what one is
4. Don't know

36a. As you may have heard, the antiviral medicines such as Tamiflu can sometimes help to reduce the symptoms of swine flu if taken right away. If *you* fell ill with swine flu, and wanted to obtain Tamiflu, how would *you* go about obtaining it, or how have *you* got it already? (Please circle *all* that apply.)
1. I would go to an A&E (casualty) department
2. I would go to my family doctor/GP
3. I would call my GP/health centre
4. I would call a health helpline for advice (e.g. NHS Direct)
5. I would call the National Pandemic Flu Service (NPFS)
6. I would ask a Flu Friend/Flu Buddy
7. I would ask my local community pharmacist (chemist)
8. I would look for information on news programmes on television
9. I would look for information in the newspapers
10. I would listen for information on news programmes on the radio
11. I would look online – on news websites
12. I would look online – on NHS, Department of Health or other health websites
13. I would look online – on other websites
14. I would look online – unspecified
15. I already have a supply of Tamiflu
16. None of these
17. Don't know
18. Other (please specify)

36b. If *your family member with chest problems* fell ill with swine flu, and wanted to obtain Tamiflu, how would you advise them go about obtaining it, or have they got it already? (Please circle *all that apply*.)
1. Go to an A&E (casualty) department
2. Go to their family doctor/GP
3. Call their GP/health centre
4. Call a health helpline for advice (e.g. NHS Direct)
5. Call the National Pandemic Flu Service (NPFS)
6. Ask a Flu Friend/Flu Buddy
7. Ask their local community pharmacist (chemist)
8. Look for information on news programmes on television
9. Look for information in the newspapers
10. Listen for information on news programmes on the radio
11. Look online – on news websites
12. Look online – on NHS, Department of Health or other health websites
13. Look online – on other websites
14. Look online – unspecified
15. Contact their chest consultant/the hospital chest clinic
16. Contact a chest specialist nurse (hospital or community)
17. They already have a supply of Tamiflu
18. None of these
19. Don't know
20. Other (please specify)

37a. If *you* needed antiviral treatment for swine flu, from where would *you* prefer to get it? (Please circle *one* answer.)

1. On prescription (from a GP/family doctor, hospital doctor, nurse, etc.)
2. 'Over the counter' (from a community pharmacist/chemist)
3. Without having to contact a health professional (e.g. internet, health food shop, etc.)
4. Don't know
5. Other (please state)

37b. If *your family member with chest problems* needed antiviral treatment for swine flu, from where do you think *they* would prefer to get it? (Please circle *one* answer.)

1. On prescription (from a GP/family doctor, hospital doctor, nurse, etc.)
2. 'Over the counter' (from a community pharmacist/chemist)
3. Without having to contact a health professional (e.g. internet, health food shop, etc.)
4. Don't know
5. Other (please state)

---

38. Please indicate, by circling *one* answer, whether you agree or disagree with the following statement: 'Too much fuss is being made about the risk of swine flu.'

1. Strongly agree
2. Tend to agree
3. Neither agree nor disagree
4. Tend to disagree
5. Strongly disagree
6. Don't know

39. Please tell us if you think each of the following statements is *true or false*. (Please circle *one* option for each item.)

1.	Very young people are the most likely to get swine flu	True/False
2.	Wearing a mask will stop me getting swine flu	True/False
3.	People with chest problems are more likely than others to catch swine flu	True/False
4.	Washing your hands is very important in preventing the spread of swine flu	True/False
5.	The ordinary flu vaccine will protect me from swine flu	True/False
6.	People with chest problems are more likely than others to develop complications of swine flu	True/False
7.	Older people are the most likely to get swine flu	True/False
8.	Tamiflu is a vaccine for swine flu	True/False
9.	Swine flu may become more of a problem over the winter	True/False
10.	People with chest problems are more likely to die from swine flu than others	True/False
11.	It is possible to catch the swine flu from eating pork	True/False
12.	Using an antibacterial hand wash or gel will stop the spread of swine flu	True/False
13.	If your doctor says you need antiviral treatment, you should send someone to collect a prescription for you, rather than going yourself	True/False
14.	If someone in a household develops swine flu, all their family can get anti-swine flu treatment (e.g. Tamiflu or Relenza)	True/False
15.	Swine flu is very contagious	True/False
16.	'Swine flu parties' are a good way of developing immunity to swine flu	True/False
17.	Swine flu is different from ordinary flu	True/False

40. Please tell us if you think any of the following might be a symptom of swine flu or not. (Please circle *one* option for each item.)

1. Sudden fever (high temperature)	True/False
2. Sudden cough (in people who don't usually have a cough)	True/False
3. Worsening of cough (in people who usually have a cough)	True/False
4. Headache	True/False
5. Tiredness	True/False
6. Producing more sputum (phlegm/mucus) than usual	True/False
7. Chills	True/False
8. Aching muscles	True/False
9. Limb or joint pain	True/False
10. Suddenly becoming breathless (in people who aren't usually breathless)	True/False
11. Worsening of breathlessness (in people who are usually breathless)	True/False
12. Dizziness	True/False
13. Diarrhoea or stomach upset	True/False
14. Sore throat	True/False
15. Blurred vision	True/False
16. Runny nose	True/False
17. Sputum (phlegm/mucus) turning a different colour than usual	True/False
18. Loss of memory	True/False
19. Rash	True/False
20. Loss of appetite	True/False
21. Sudden inability to move or control limbs	True/False
22. Wheezing	True/False
23. Confusion	True/False
24. Sneezing	True/False
25. Chest pains	True/False

41a. If *you* had swine flu, would *you* get help if *you* developed any of the following symptoms? (Please circle *one* option for each item.)

1. Fast breathing or feeling much more short of breath than usual	Yes/No
2. Feeling very tired	Yes/No
3. Chest pains	Yes/No
4. Fever (high temperature) that didn't go down after 4 or 5 days	Yes/No
5. Aching muscles	Yes/No
6. Producing more sputum (phlegm/mucus) than usual	Yes/No
7. Worsening of cough or cough that wouldn't go away	Yes/No
8. Drowsiness or confusion	Yes/No
9. Coughing up blood	Yes/No
10. Sputum (phlegm/mucus) turning a different colour than usual	Yes/No
11. Sore throat	Yes/No
12. Feeling more wheezy than usual	Yes/No

41b. If your family member with chest problems had swine flu, would you get help if *they* developed any of the following symptoms? (Please circle *one* option for each item.)

1. Fast breathing or feeling much more short of breath than usual	Yes/No
2. Feeling very tired	Yes/No
3. Chest pains	Yes/No
4. Fever (high temperature) that didn't go down after 4 or 5 days	Yes/No
5. Aching muscles	Yes/No
6. Producing more sputum (phlegm/mucus) than usual	Yes/No
7. Worsening of cough or cough that wouldn't go away	Yes/No
8. Drowsiness or confusion	Yes/No
9. Coughing up blood	Yes/No
10. Sputum (phlegm/mucus) turning a different colour than usual	Yes/No
11. Sore throat	Yes/No
12. Feeling more wheezy than usual	Yes/No

42. We'd like to know whether worries about swine flu are making *you* do anything different or feel different. (Please circle all that *apply to you*.)

Because of worries about swine flu:

1. I have stopped or cut down on travelling by public transport (buses, trains, etc.)
2. I am taking things like vitamins or food supplements
3. I am avoiding crowded places (e.g. shops, cinemas, sports events, etc.)
4. I am leaving the house less often
5. I am avoiding contact with my friends and family members
6. I feel that people are worried about being around me because of my family member's chest problem
7. I have cut down or stopped smoking
8. I have cancelled a holiday/rearranged travel plans
9. I am keeping my windows and doors closed
10. I feel more anxious than usual about my family member's chest problem
11. I am avoiding contact with children
12. I am avoiding contact with my family member with chest problems
13. I am trying to get more exercise
14. I am not leaving the house at all
15. I feel more self-conscious about having a family member with chest problems
16. I am avoiding contact with pets/animals
17. I would not wish to travel far within the United Kingdom
18. I am eating more healthy foods
19. I am much more aware of my family member's chest problem than usual
20. I am not sleeping well
21. I would not wish to travel abroad
22. I have cut down my usual social activities (e.g. going to the pub, eating out, etc.)
23. I am avoiding contact with people who have been abroad
24. I am constantly on the alert for changes in my family member's chest problem
25. I feel that other people are avoiding me because of my family member's chest problem
26. I am avoiding eating pork/ham/bacon, etc.
27. I have tried to buy/bought Tamiflu

43. We'd like to know whether you think worries about swine flu are making *your family member with chest problems* do anything different or feel different. (Please circle *all that you think apply to your family member with chest problems.*)

Because of worries about swine flu, *my family member with chest problems*:

1. Has stopped or cut down on travelling by public transport (buses, trains, etc.)
2. Is taking things like vitamins or food supplements
3. Is avoiding crowded places (e.g. shops, cinemas, sports events, etc.)
4. Is leaving the house less often
5. Is avoiding contact with their friends and family members
6. Feels that people are worried about being around them due to their chest problem
7. Has cut down or stopped smoking
8. Has cancelled a holiday/rearranged travel plans
9. Is keeping their windows and doors closed
10. Is more anxious than usual about their chest problem
11. Is avoiding contact with children
12. Will not take their medication/use their inhaler in public, even if they really need it
13. Is trying to get more exercise
14. Is not leaving the house at all
15. Is feeling more self-conscious about their chest problem
16. Is avoiding contact with pets/animals
17. Is using their inhaler(s) more often

18. Would not wish to travel far within the UK
19. Is eating more healthy foods
20. Is much more aware of their chest problem than usual
21. Is not sleeping well
22. Would not wish to travel abroad
23. Has cut down their usual social activities (e.g. going to the pub, eating out, etc.)
24. Is avoiding contact with people who have been abroad
25. Is constantly on the alert for changes in their chest problem
26. Feels that other people are avoiding them
27. Is more careful about taking their regular medications as instructed
28. Is avoiding eating pork/ham/bacon, etc.
29. Has tried to buy/bought Tamiflu

Now please tell us a bit about yourself:

44. What is your relationship with your family member with chest problems?
    1. Wife
    2. Husband
    3. Son
    4. Daughter
    5. Parent
    6. Other (please state which)

_____

45. How old are you (in years)?

_____

46. What is your gender? (Please circle *one* answer.)
    i. Male
    ii. Female

47. What would you consider your ethnic group to be?

_____

48. Are you married or living with a partner? (Please circle *one* answer.)
    i. Yes
    ii. No

49a. What is your current occupation?

_____

49b. If retired or not working, what is your most recent previous occupation?

_____

50. Do you have any of the following? (Please circle *all that apply*.)
    1. CSE/O level/GCSE or equivalent
    2. A level or equivalent
    3. GNVQ
    4. Diploma
    5. Professional qualification (e.g. RGN, Cert Ed, City and Guilds)
    6. College/university degree (undergraduate/bachelor's)
    7. Higher degree (Masters, MRes, PhD)
    8. None of the above
    9. Other (please state which)

_____

51. What is the name of your family member's chest problem? (If you are not sure, please write 'don't know'.)

_____

52. How severe would you rate your family member's chest problem as being? (Please circle *one* answer.)
    1. Very mild
    2. Mild
    3. Moderate
    4. Severe
    5. Very severe
    6. Don't know

53. Do you smoke? (Please circle *one* answer.)
    1. Yes, I currently smoke
    2. No, but I used to smoke
    3. No, I have never smoked

54. How did you find out about our study? (Please circle *one* answer.)
    1. My family member with a chest problem gave me the questionnaire
    2. I saw a poster at chest clinic
    3. I saw the piece about the study in the newspaper
    4. Someone (e.g. a friend or relative) told me about the study
    5. Other (please state)

_____

55. Any other comments?

_____

If you want to contact us about this research, details are as follows:

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For independent information about this research, please contact:

The University of Manchester's Research Practice and Governance Co-ordinator
Tel: 0000 000 0000 or 0000 000 0000
E-mail: research-governance@manchester.ac.uk

Further information about swine flu can be found at:

National Pandemic Flu Service (NPFS): 0800 1 513 100
NPFS Textphone for people who are deaf/hard of hearing: 0800 1 513 200
The government's Pandemic Flu website: www.direct.gov.uk/pandemicflu
The NHS Choices website: www.nhs.uk

THANK YOU FOR TAKING TIME TO COMPLETE THIS QUESTIONNAIRE

PLEASE RETURN THE QUESTIONNAIRE TO US IN THE ENCLOSED PRE-PAID ENVELOPE OR, IF COMPLETED WHILST AT CLINIC, ASK THE RECEPTIONIST (OR THE MEMBER OF CLINIC STAFF WHO GAVE YOU THE PACK) WHERE TO LEAVE IT – THANK YOU

YOU DO NOT HAVE TO PROVIDE ANY CONTACT INFORMATION. HOWEVER, IF YOU ARE WILLING TO DO SO (e.g. SO WE CAN SEND YOU A SUMMARY OF STUDY FINDINGS), PLEASE COMPLETE THE SEPARATE SHEET ATTACHED AND RETURN IT WITH YOUR COMPLETED QUESTIONNAIRE – THANK YOU

Appendix 4

Interview and focus group topic guide

Introductory question

- Have you heard about swine flu? (Probe: where/who from?)

Information needs

- What, if anything, is the number one thing you'd like to know about swine flu? (Probes: key information topics, priority information.)
- Do people with chest problems/family members need different information from other people? (Probe: specific topics, differences between patients and families.)
- How well informed to do feel about swine flu? (Probes: gaps in knowledge, usefulness of information, volume of information.)
- Which sources of information have you found most/least useful? (Probes: preferred sources, quality, accessibility and credibility of information.)

Concerns

- How worried are you about swine flu? (Probes: susceptibility, severity, consequences.)
- Are you more worried about swine flu because you have/your family member has chest problems? (Probes: susceptibility, severity, consequences.)

Behaviours

- Do you know what the government is recommending that people do to help stop swine flu spreading? (Probes: recommendations, behaviours regarding these.)
- What would you do if you thought you had swine flu? (Probes: awareness of recommendations, likely actions taken, use of health services.)
- What would you do if you thought you were developing complications of swine flu? (Probes: awareness of symptoms, likely actions taken, use of health services.)
- Are you doing anything different from normal because of swine flu? (Probes: avoidance behaviours, health promotion, medication use.)

Appendix 5

Additional survey data

TABLE 18 *Importance of information topics – patients, (n = 253)*

	Very important →				Not at all important
Information topic	**1**	**2**	**3**	**4**	**5**
What swine flu is and what it does to your body	181 (73.0)	45 (18.1)	18 (7.3)	2 (0.8)	2 (0.8)
Whether swine flu is different from ordinary flu	153 (62.2)	63 (25.6)	22 (8.9)	3 (1.2)	5 2.0)
How serious swine flu is and the outlook for people who catch it	185 (74.9)	48 (19.4)	12 (4.9)	0 (0)	2 (0.8)
Whether there is a vaccine available for swine flu yet and who will get it	180 (73.5)	42 (17.1)	20 (8.2)	0 (0)	3 (1.2)
The treatments available for swine flu and how effective they are	186 (76.2)	38 (15.6)	18 (7.4)	0 (0)	2 (0.8)
What the symptoms of swine flu are	186 (75.6)	48 (19.5)	8 (3.3)	2 (0.8)	2 (0.8)
How to recognise if you might have swine flu	188 (76.4)	45 (18.3)	9 (3.7)	1 (0.4)	3 (1.2)
What to do if you think you have swine flu	192 (78.7)	39 (16.0)	10 (4.1)	1 (0.4)	1 (0.4)
Recognising complications and what to do about them	189 (76.8)	48 (19.5)	7 (2.8)	0 (0)	2 (0.8)
How likely it is that you will catch swine flu	158 (64.0)	46 (18.6)	32 (13.0)	7 (2.8)	4 (1.6)
How to prevent the spread of swine flu	176 (71.3)	44 (17.8)	22 (8.9)	2 (0.8)	3 (1.2)
How to reduce your risk of catching swine flu	183 (74.4)	43 (17.5)	16 (6.5)	1 (0.4)	3 (1.2)
How swine flu might affect chest problems	202 (81.5)	35 (14.1)	8 (3.2)	1 (0.4)	2 (0.8)
Whether people with chest problems are more likely to catch swine flu than others	170 (69.1)	53 (21.5)	18 (7.3)	3 (1.2)	2 (0.8)
Whether the families of people with chest problems are more likely to catch swine flu than others	128 (52.7)	67 (27.6)	35 (14.4)	7 (2.9)	6 (2.5)
Whether people with chest problems are more likely to develop complications or die from swine flu	192 (78.4)	35 (14.3)	14 (5.7)	2 (0.8)	2 (0.8)

continued

TABLE 18 *Importance of information topics – patients, (n = 253) (continued)*

	Very important	→			Not at all important
Information topic	**1**	**2**	**3**	**4**	**5**
Whether treatments for swine flu are safe for people with chest problems	187 (76.0)	39 (15.9)	15 (6.1)	2 (0.8)	3 (1.2)
Whether treatments for swine flu can interfere with treatments for chest problems	181 (74.2)	42 (17.2)	15 (6.1)	4 (1.6)	2 (0.8)
Where to get information, help or support (e.g. if worried or want to know more about swine flu)	164 (66.7)	60 (24.4)	14 (5.7)	4 (1.6)	4 (1.6)

Most items had some missing data; figures in parentheses = valid percentage.

TABLE 19 *Importance of information topics – family members, (n = 101)*

	Very important	→			Not at all important
Information topic	**1**	**2**	**3**	**4**	**5**
What swine flu is and what it does to your body	71 (70.3)	21 (24.8)	5 (5.0)	0 (0)	0 (0)
Whether swine flu is different from ordinary flu	57 (56.4)	35 (34.7)	5 (5.0)	4 (4.0)	0 (0)
How serious swine flu is and the outlook for people who catch it	74 (73.3)	22 (21.8)	4 (4.0)	1 (1.0)	0 (0)
Whether there is a vaccine available for swine flu yet and who will get it	72 (72.0)	22 (22.0)	3 (3.0)	3 (3.0)	0 (0)
The treatments available for swine flu and how effective they are	70 (70.0)	23 (23.0)	6 (6.0)	1 (1.0)	0 (0)
What the symptoms of swine flu are	77 (76.2)	20 (19.8)	4 (4.0)	0 (0)	0 (0)
How to recognise if you might have swine flu	83 (83.0)	14 (14.0)	3 (3.0)	0 (0)	0 (0)
What to do if you think you have swine flu	77 (77.8)	18 (18.2)	2 (2.0)	2 (2.0)	0 (0)
Recognising complications and what to do about them	80 (80.8)	16 (16.2)	3 (3.0)	0 (0)	0 (0)
How likely it is that you will catch swine flu	50 (50.0)	31 (31.0)	18 (18.0)	1 (1.0)	0 (0)
How to prevent the spread of swine flu	74 (74.7)	16 (16.2)	8 (8.1)	1 (1.0)	0 (0)
How to reduce your risk of catching swine flu	72 (72.2)	22 (22.2)	5 (5.1)	0 (0)	0 (0)
How swine flu might affect chest problems	86 (86.0)	12 (12.0)	2 (2.0)	0 (0)	0 (0)
Whether people with chest problems are more likely to catch swine flu than others	78 (78.0)	18 (18.0)	4 (4.0)	0 (0)	0 (0)
Whether the families of people with chest problems are more likely to catch swine flu than others	56 (56.6)	27 (27.3)	15 (15.2)	0 (0)	1 (1.0)

TABLE 19 *Importance of information topics – family members, (n = 101) (continued)*

	Very important → Not at all important				
Information topic	**1**	**2**	**3**	**4**	**5**
Whether people with chest problems are more likely to develop complications or die from swine flu	80 (79.2)	15 (14.9)	6 (5.9)	0 (0)	0 (0)
Whether treatments for swine flu are safe for people with chest problems	81 (81.0)	14 (14.0)	4 (4.0)	1 (1.0)	0 (0)
Whether treatments for swine flu can interfere with treatments for chest problems	78 (78.0)	16 (16.0)	5 (5.0)	1 (1.0)	0 (0)
Where to get information, help or support (e.g. if worried or want to know more about swine flu)	61 (61.6)	29 (29.3)	8 (8.1)	1 (1.0)	0 (0)

Most items had some missing data; figures in parentheses = valid percentage.

TABLE 20 *Sources of information about swine flu for patients (n = 253) and family members (n = 101)*

Information source	**Patients**	**Family members**
Leaflet delivered to my home	125 (49.4)	55 (54.5)
Leaflet picked up somewhere else	29 (11.5)	17 (16.8)
Poster displayed at work	16 (6.3)	21 (20.8)
Poster displayed at GP surgery	109 (43.1)	37 (36.6)
Poster displayed at hospital	58 (22.9)	19 (18.8)
Internet – NHS Choices (www.nhs.uk)	22 (8.7)	9 (8.9)
Internet – Government website (www.direct.gov.uk/pandemicflu)	26 (10.3)	15 (14.9)
Internet – health-care organisation or health-care charity website	8 (3.2)	4 (4.0)
Internet – other website	6 (2.4)	6 (5.9)
NHS Direct (telephone line)	17 (6.7)	7 (6.9)
The Swine Flu Information Line (phone line, recorded information)	16 (6.3)	8 (7.9)
Other telephone helpline (e.g. health-care charity)	4 (1.6)	3 (3.0)
Friends or relatives	54 (21.3)	23 (22.8)

continued

TABLE 20 *Sources of information about swine flu for patients (n = 253) and family members (n = 101) (continued)*

Information source	Patients	Family members
General practitioner (GP)	75 (29.6)	21 (20.8)
Practice nurse (GP's nurse)	44 (17.4)	14 (13.9)
Receptionist at GP's surgery	13 (5.1)	6 (5.9)
Community pharmacist (chemist)	12 (4.7)	4 (4.0)
Specialist nurse (hospital or community)	18 (7.1)	7 (6.9)
District nurse	4 (1.6)	2 (2.0)
Health visitor	4 (1.6)	3 (3.0)
Hospital consultant/specialist doctor	48 (19.0)	10 (9.9)
Other hospital doctor	10 (4.0)	2 (2.0)
Hospital doctor's secretary or clinic receptionist	2 (0.8)	3 (3.0)
Nurses on hospital wards or at clinics	8 (3.2)	2 (2.0)
Other health professional (e.g. physiotherapist, occupational therapist)	7 (2.8)	2 (2.0)
Minor injuries clinic or walk-in centre	3 (1.2)	1 (1.0)
A&E (casualty) department	1 (0.4)	2 (2.0)
National Pandemic Flu Service (website and telephone line)	18 (7.1)	11 (10.9)
The Health Protection Agency	3 (1.2)	5 (5.0)
Television	116 (45.8)	44 (43.6)
Radio	47 (18.6)	25 (24.8)
Newspaper	91 (36.0)	36 (35.6)
Magazine	25 (9.9)	12 (11.9)
Medical book/journal	9 (3.6)	3 (3.0)
Patient self-help or support group	10 (4.0)	5 (5.0)
Other	9 (3.6)	6 (5.9)

Figures in parentheses = percentage selecting the option; participants could select multiple options.

TABLE 21 *Patients' perceptions of usefulness of information sources in general[a] and likelihood of personally using the source[b] (n = 253)*

	Very useful (definitely use)→Not at all useful (definitely not use)				
Information source	**1**	**2**	**3**	**4**	**5**
Friends/relatives	72 (30.3)	45 (18.9)	67 (28.2)	28 (11.8)	26 (10.9)
	55 (24.4)	*28 (12.4)*	*59 (26.2)*	*43 (19.1)*	*40 (17.8)*
General practitioner (GP)/family doctor	188 (75.2)	42 (16.8)	15 (6.0)	3 (1.2)	2 (0.8)
	197 (81.1)	*25 (10.3)*	*15 (6.2)*	*5 (2.1)*	*1 (0.4)*
Hospital consultant	190 (76.9)	36 (14.6)	17 (6.9)	2 (0.8)	2 (0.8)
	167 (70.2)	*28 (11.8)*	*28 (11.8)*	*9 (3.8)*	*6 (2.5)*
Other hospital doctor	146 (59.3)	64 (26.0)	27 (11.0)	4 (1.6)	5 (2.0)
	102 (43.6)	*57 (24.4)*	*46 (19.7)*	*17 (7.3)*	*12 (5.1)*
Specialist nurse (hospital or community)	150 (61.7)	66 (27.2)	15 (6.2)	6 (2.5)	6 (2.5)
	110 (46.6)	*63 (26.7)*	*38 (16.1)*	*13 (5.5)*	*12 (5.1)*
District nurse	107 (43.9)	78 (32.0)	38 (15.6)	13 (5.3)	8 (3.3)
	68 (29.8)	*57 (25.0)*	*48 (21.1)*	*31 (13.6)*	*24 (10.5)*
Health visitor	99 (40.6)	71 (29.1)	47 (19.3)	17 (7.0)	10 (4.1)
	54 (23.6)	*56 (24.5)*	*59 (25.8)*	*32 (14.0)*	*28 (12.2)*
Nurses on hospital wards/at hospital clinics	119 (48.6)	65 (26.5)	47 (19.2)	6 (2.4)	8 (3.3)
	62 (26.6)	*64 (27.4)*	*65 (27.9)*	*24 (10.3)*	*18 (7.7)*
Practice nurse (GP's nurse)	137 (55.9)	70 (28.6)	29 (11.8)	5 (2.0)	4 (1.6)
	117 (49.4)	*57 (24.1)*	*36 (15.2)*	*18 (7.6)*	*9 (3.8)*
A&E (casualty) department	106 (43.1)	61 (24.8)	55 (22.4)	17 (6.9)	7 (2.8)
	69 (30.1)	*43 (18.8)*	*62 (27.1)*	*26 (11.4)*	*29 (12.7)*
Walk-in centre or minor injuries unit	95 (39.3)	59 (24.4)	56 (23.1)	21 (8.7)	10 (4.1)
	61 (26.8)	*42 (18.4)*	*62 (27.2)*	*37 (16.2)*	*26 (11.4)*
Community pharmacist (chemist)	102 (41.3)	74 (30.0)	47 (19.0)	14 (5.7)	10 (4.0)
	66 (28.8)	*67 (29.3)*	*61 (26.6)*	*21 (9.2)*	*14 (6.1)*
NHS Direct (telephone line)	118 (48.6)	55 (22.5)	36 (14.8)	20 (8.2)	14 (5.7)
	77 (33.5)	*55 (23.9)*	*53 (23.0)*	*22 (9.6)*	*23 (10.0)*
The Health Protection Agency	94 (39.3)	64 (26.8)	51 (21.3)	16 (6.7)	14 (5.9)
	44 (19.5)	*55 (24.3)*	*57 (25.2)*	*32 (14.2)*	*38 (16.8)*
Television	80 (32.5)	70 (28.5)	49 (19.9)	29 (11.8)	18 (7.3)
	49 (21.0)	*53 (22.7)*	*57 (24.5)*	*40 (17.2)*	*34 (14.6)*
Radio	69 (28.3)	69 (28.3)	55 (22.5)	28 (11.5)	23 (9.4)
	34 (14.8)	*51 (22.3)*	*57 (24.9)*	*44 (19.2)*	*43 (18.8)*
Posters or billboards	53 (21.5)	58 (23.6)	68 (27.6)	36 (14.6)	31 (12.6)
	28 (12.1)	*42 (18.2)*	*57 (24.7)*	*53 (22.9)*	*51 (22.1)*
Medical book/journal	54 (22.2)	52 (21.4)	70 (28.8)	41 (16.9)	26 (10.7)
	34 (14.8)	*36 (15.7)*	*55 (24.0)*	*48 (20.9)*	*56 (26.5)*
Magazines	44 (18.0)	51 (20.9)	75 (30.7)	39 (16.0)	35 (14.3)
	19 (8.3)	*42 (18.4)*	*60 (26.3)*	*48 (21.1)*	*59 (25.9)*
Newspapers	65 (26.6)	54 (22.1)	65 (26.6)	36 (14.8)	24 (9.8)
	45 (19.4)	*45 (19.4)*	*52 (22.4)*	*50 (21.6)*	*40 (17.2)*
Leaflets	79 (31.2)	60 (23.7)	63 (25.9)	25 (10.3)	16 (6.6)
	66 (28.7)	*48 (20.9)*	*59 (25.7)*	*30 (13.0)*	*27 (11.7)*

continued

TABLE 21 *Patients' perceptions of usefulness of information sources in general[a] and likelihood of personally using the source[b] (n = 253)*

	Very useful (definitely use)→Not at all useful (definitely not use)				
Information source	**1**	**2**	**3**	**4**	**5**
Government website (www.direct.gov.uk/ pandemicflu)	79 (33.2)	64 (26.9)	56 (23.5)	16 (6.7)	23 (9.7)
	75 (33.8)	*34 (15.3)*	*51 (23.0)*	*25 (11.3)*	*37 (16.7)*
NHS Choices website (www.nhs.uk)	83 (34.9)	60 (25.2)	56 (23.5)	17 (7.1)	22 (9.2)
	61 (27.5)	*44 (19.8)*	*54 (24.3)*	*27 (12.2)*	*36 (16.2)*
Other website	41 (17.5)	41 (17.5)	79 (33.8)	31 (13.2)	42 (17.9)
	27 (12.3)	*31 (14.4)*	*56 (25.5)*	*50 (22.7)*	*56 (25.5)*
Health-related charities	49 (20.2)	43 (17.8)	82 (33.9)	36 (14.9)	32 (13.2)
	29 (12.8)	*27 (11.9)*	*64 (28.3)*	*50 (22.1)*	*56 (24.8)*
Patient support/self-help groups	58 (24.2)	65 (27.1)	73 (30.4)	24 (10.0)	20 (8.3)
	30 (13.3)	*48 (21.3)*	*63 (28.0)*	*37 (16.4)*	*47 (20.9)*
National Pandemic Flu Service	124 (51.0)	51 (21.0)	40 (16.5)	17 (7.0)	11 (4.5)
	90 (39.5)	*46 (20.2)*	*51 (22.4)*	*20 (8.8)*	*21 (9.2)*

a Non-italic text.
b Italic text.
All items had some missing data; figures in parentheses = valid percentage.

TABLE 22 *Family members' perceptions of usefulness of information sources in general[a] and likelihood of personally using the source[b] (n = 101)*

	Very useful (definitely use)→Not at all useful (definitely not use)				
Information source	**1**	**2**	**3**	**4**	**5**
Friends/relatives	29 (29.3)	22 (22.2)	26 (26.3)	16 (16.2)	6 (6.1)
	22 (23.2)	*12 (12.6)*	*26 (27.4)*	*16 (16.8)*	*19 (20.0)*
General practitioner (GP)/family doctor	78 (77.2)	15 (14.9)	6 (5.9)	0 (0)	2 (2.0)
	74 (76.3)	*14 (14.4)*	*5 (5.2)*	*2 (2.1)*	*2 (2.1)*
Hospital consultant	73 (72.3)	11 (10.9)	12 (11.9)	3 (3.0)	2 (2.0)
	58 (60.4)	*14 (14.6)*	*10 (10.4)*	*7 (7.3)*	*7 (7.3)*
Other hospital doctor	47 (47.5)	22 (22.2)	19 (19.2)	6 (6.1)	5 (5.1)
	38 (40.4)	*19 (20.2)*	*20 (21.3)*	*10 (10.6)*	*7 (7.4)*
Specialist nurse (hospital or community)	57 (58.2)	28 (28.6)	9 (9.2)	2 (2.0)	2 (2.0)
	48 (50.5)	*23 (24.2)*	*9 (9.5)*	*9 (9.5)*	*6 (6.3)*
District nurse	46 (47.4)	23 (23.7)	21 (21.6)	7 (7.2)	0 (0)
	36 (38.3)	*16 (17.0)*	*19 (20.2)*	*13 (13.8)*	*10 (10.6)*
Health visitor	41 (41.8)	19 (19.4)	25 (25.5)	8 (8.2)	5 (5.1)
	35 (37.2)	*11 (11.7)*	*23 (24.5)*	*13 (13.8)*	*12 (12.8)*
Nurses on hospital wards/at hospital clinics	45 (45.0)	17 (17.0)	29 (29.0)	5 (5.0)	4 (4.0)
	33 (35.5)	*18 (19.4)*	*20 (21.5)*	*12 (12.9)*	*10 (10.8)*
Practice nurse (GP's nurse)	54 (54.5)	25 (25.3)	17 (17.2)	2 (2.0)	1 (1.0)
	52 (54.2)	*19 (19.8)*	*14 (14.6)*	*10 (10.4)*	*1 (1.0)*
A&E (casualty) department	41 (41.4)	18 (18.2)	26 (26.3)	9 (9.1)	5 (5.1)
	33 (34.7)	*15 (15.8)*	*24 (25.3)*	*7 (7.4)*	*16 (16.8)*
Walk-in centre or minor injuries unit	35 (36.1)	27 (27.8)	27 (27.8)	6 (6.2)	2 (2.1)
	25 (26.6)	*19 (20.2)*	*25 (26.6)*	*11 (11.7)*	*14 (14.9)*

TABLE 22 *Family members' perceptions of usefulness of information sources in general[a] and likelihood of personally using the source[b] (n = 101) (continued)*

	Very useful (definitely use)→Not at all useful (definitely not use)				
Information source	**1**	**2**	**3**	**4**	**5**
Community pharmacist (chemist)	40 (40.4)	26 (26.3)	24 (24.2)	8 (8.1)	1 (1.0)
	34 (35.8)	*26 (27.4)*	*18 (18.9)*	*14 (14.7)*	*3 (3.2)*
NHS Direct (telephone line)	53 (54.1)	20 (20.4)	18 (18.4)	2 (2.0)	5 (5.1)
	40 (43.0)	*19 (20.4)*	*17 (18.3)*	*7 (7.5)*	*10 (10.8)*
The Health Protection Agency	45 (46.4)	19 (19.6)	20 (20.6)	7 (7.2)	6 (6.2)
	29 (30.9)	*22 (23.4)*	*22 (23.4)*	*10 (10.6)*	*11 (11.7)*
Television	31 (30.7)	23 (22.8)	28 (27.7)	14 (13.9)	5 (5.0)
	17 (18.3)	*20 (21.5)*	*19 (20.4)*	*20 (21.5)*	*17 (18.3)*
Radio	25 (25.0)	22 (22.0)	32 (32.0)	14 (14.0)	7 (7.0)
	15 (16.1)	*16 (17.2)*	*22 (23.7)*	*22 (23.7)*	*18 (19.4)*
Posters or billboards	23 (23.5)	20 (20.4)	38 (38.8)	12 (12.2)	5 (5.1)
	14 (15.1)	*14 (15.1)*	*23 (14.7)*	*24 (25.8)*	*18 (19.4)*
Medical book/journal	19 (19.2)	27 (27.3)	32 (32.3)	12 (12.1)	9 (9.1)
	16 (17.2)	*17 (18.3)*	*23 (24.7)*	*19 (20.4)*	*18 (19.4)*
Magazines	20 (20.6)	24 (24.7)	29 (29.9)	16 (16.5)	8 (8.2)
	13 (14.0)	*15 (16.1)*	*21 (22.6)*	*24 (25.8)*	*20 (21.5)*
Newspapers	25 (25.2)	23 (23.2)	30 (30.3)	16 (16.2)	5 (5.1)
	12 (13.0)	*18 (19.6)*	*24 (26.1)*	*18 (19.6)*	*20 (21.7)*
Leaflets	35 (34.7)	30 (29.7)	28 (27.7)	6 (5.9)	2 (2.0)
	26 (28.0)	*26 (28.0)*	*21 (22.6)*	*14 (15.1)*	*6 (6.5)*
Government website (www.direct.gov.uk/ pandemicflu)	45 (45.5)	20 (20.2)	23 (23.2)	6 (6.1)	5 (5.1)
	38 (41.3)	*20 (21.7)*	*18 (19.6)*	*8 (8.7)*	*8 (8.7)*
NHS Choices website (www.nhs.uk)	35 (35.7)	21 (21.4)	24 (24.5)	10 (10.2)	8 (8.1)
	31 (34.1)	*19 (20.9)*	*21 (23.1)*	*9 (9.9)*	*11 (12.1)*
Other website	21 (21.4)	13 (13.3)	35 (35.7)	18 (18.4)	11 (11.2)
	10 (11.1)	*12 (13.3)*	*30 (33.3)*	*21 (23.3)*	*17 (18.9)*
Health-related charities	22 (22.4)	13 (13.3)	39 (39.8)	15 (15.3)	9 (9.2)
	11 (12.2)	*5 (5.6)*	*31 (34.4)*	*22 (24.4)*	*21 (23.3)*
Patient support/self-help groups	30 (30.0)	28 (28.0)	26 (26.0)	10 (10.0)	6 (6.0)
	18 (19.8)	*8 (8.8)*	*28 (30.8)*	*20 (22.0)*	*17 (18.7)*
National Pandemic Flu Service (website and telephone line)	55 (55.0)	26 (26.0)	11 (11.0)	4 (4.0)	4 (4.0)
	50 (52.1)	*16 (16.7)*	*16 (16.7)*	*3 (3.1)*	*11 (11.5)*

a Non-italic text.
b Italic text.
Most items had some missing data; figures in parentheses = valid percentage.

TABLE 23 *Patients' (n = 253) responses to items exploring knowledge of 'facts' and 'myths' regarding swine flu*

Please tell us if you think each of the following statements is *true* or *false*	**True**	**False**
Very young people are the most likely to get swine flu	171	71
False, although high incidence of death and hospitalisation in very young	(70.7)	(29.3)
Wearing a mask will stop me getting swine flu	41	202
False, and not recommended in official UK government advice	(16.9)	(83.1)
People with chest problems are more likely than others to catch swine flu	153	90
False	(63.0)	(37.0)
Washing your hands is very important in preventing the spread of swine flu	240	8
True, per official government advice	(96.8)	(3.2)
The ordinary flu vaccine will protect me from swine flu	19	226
False	(7.8)	(92.2)
People with chest problems are more likely than others to develop complications of swine flu	210	32
True	(86.8)	(13.2)
Older people are the most likely to get swine flu	96	145
False – older people had some residual immunity from previous pandemics	(39.8)	(60.2)
Tamiflu is a vaccine for swine flu	138	107
False	(56.3)	(43.7)
Swine flu may become more of a problem over the winter	218	27
True, per expectations/predictions at commencement of study	(89.0)	(11.0)
People with chest problems are more likely to die from swine flu than others	174	63
True – greater risk of death	(73.4)	(26.6)
It is possible to catch swine flu from eating pork	16	232
False	(6.5)	(93.5)
Using an antibacterial hand wash or gel will stop the spread of swine flu	177	68
True, per official government advice	(72.2)	(27.8)
If your doctor says you need antiviral treatment, you should send someone to collect a prescription for you, rather than going yourself	225	22
True	(91.1)	(8.9)
If someone in a household develops swine flu, all their family can get anti-swine flu treatment (e.g. Tamiflu or Relenza)	138	96
False – prophylaxis only recommended for at-risk close contacts	(59.0)	(41.0)
Swine flu is very contagious	205	33
True, per official government advice	(86.1)	(13.9)
'Swine flu parties' are good way of developing immunity to swine flu	17	227
False	(7.0)	(93.0)
Swine flu is different from ordinary flu	236	12
True	(95.2)	(4.8)

Indication of whether the item is true or false is given in italic text after each statement.
Most items had some missing data; figures in parentheses = valid percentage.

TABLE 24 *Family members' (n = 101) responses to items exploring knowledge of 'facts' and 'myths' regarding swine flu*

Please tell us if you think each of the following statements is *true or false*	**True**	**False**
Very young people are the most likely to get swine flu	64	31
False – although high incidence of death and hospitalisation in very young	(67.4)	(32.6)
Wearing a mask will stop me getting swine flu	15	82
False, and not recommended in official UK government advice	(15.5)	(84.5)
People with chest problems are more likely than others to catch swine flu	67	30
False	(69.1)	(30.9)
Washing your hands is very important in preventing the spread of swine flu	96	1
True, per official government advice	(99.0)	(1.0)
The ordinary flu vaccine will protect me from swine flu	9	88
False	(9.3)	(90.7)
People with chest problems are more likely than others to develop complications of swine flu	89	7
True	(92.7)	(7.3)
Older people are the most likely to get swine flu	44	52
False – older people had some residual immunity from previous pandemics	(45.8)	(54.2)
Tamiflu is a vaccine for swine flu	48	47
False	(50.5)	(49.5)
Swine flu may become more of a problem over the winter	86	10
True, per expectations/predictions at commencement of study	(89.6)	(10.4)
People with chest problems are more likely to die from swine flu than others	71	25
True – greater risk of death	(74.0)	(26.0)
It is possible to catch swine flu from eating pork	8	89
False	(8.2)	(91.8)
Using an antibacterial hand wash or gel will stop the spread of swine flu	68	29
True, per official government advice	(70.1)	(29.9)
If your doctor says you need antiviral treatment, you should send someone to collect a prescription for you, rather than going yourself	92	5
True	(94.8)	(5.2)
If someone in a household develops swine flu, all their family can get anti-swine flu treatment (e.g. Tamiflu or Relenza)	49	46
False – prophylaxis only recommended for at-risk close contacts	(51.6)	(48.4)
Swine flu is very contagious	74	22
True, per official government advice	(77.0)	(23.0)
'Swine flu parties' are good way of developing immunity to swine flu	9	88
False	(9.3)	(90.7)
Swine flu is different from ordinary flu	90	6
True	(93.7)	(6.3)

Indication of whether the item is true or false is given in italic text after each statement.
Most items had some missing data; figures in parentheses = valid percentage.

TABLE 25 *Identification of swine flu symptoms – patients (n = 253)*

Please tell us if you think any of the following might be a symptom of swine flu or not	True	False
Sudden fever (high temperature)	221 (94.8)	12 (5.2)
Sudden cough (in people who don't usually have a cough)	165 (73.7)	59 (26.3)
Worsening of cough (in people who usually have a cough)	164 (74.5)	56 (25.5)
Headache	185 (80.7)	44 (19.3)
Tiredness	174 (77.7)	50 (22.3)
Producing more sputum (phlegm/mucus) than usual	147 (66.2)	75 (33.8)
Chills	164 (72.9)	61 (27.1)
Aching muscles	206 (88.8)	26 (11.2)
Limb or joint pain	182 (78.8)	49 (21.2)
Suddenly becoming breathless (in people who aren't usually breathless)	142 (62.8)	84 (37.2)
Worsening of breathlessness (in people who are usually breathless)	173 (76.5)	53 (23.5)
Dizziness	78 (36.3)	137 (63.7)
Diarrhoea or stomach upset	99 (44.6)	123 (55.4)
Sore throat	181 (78.7)	49 (21.3)
Blurred vision	46 (21.3)	170 (78.7)
Runny nose	146 (65.8)	76 (34.2)
Sputum (phlegm/mucus) turning a different colour than usual	144 (64.9)	78 (35.1)
Loss of memory	10 (4.5)	210 (95.5)
Rash	26 (11.7)	196 (88.3)
Loss of appetite	135 (60.5)	88 (39.5)
Sudden inability to move or control limbs	52 (23.5)	169 (76.5)
Wheezing	139 (60.7)	90 (39.3)

TABLE 25 *Identification of swine flu symptoms patients (n = 253) (continued)*

Please tell us if you think any of the following might be a symptom of swine flu or not	True	False
Confusion	15 (17.2)	183 (82.8)
Sneezing	153 (66.2)	78 (33.8)
Chest pains	87 (38.8)	137 (61.2)

Most items had some missing data; figures in parentheses = valid percentage.

TABLE 26 *Identification of swine flu symptoms – family members (n = 101)*

Please tell us if you think any of the following might be a symptom of swine flu or not	True	False
Sudden fever (high temperature)	92 (96.8)	3 (3.2)
Sudden cough (in people who don't usually have a cough)	65 (71.4)	26 (28.6)
Worsening of cough (in people who usually have a cough)	69 (76.7)	21 (23.3)
Headache	80 (86.0)	13 (14.0)
Tiredness	72 (80.0)	18 (20.0)
Producing more sputum (phlegm/mucus) than usual	55 (61.1)	35 (38.9)
Chills	66 (74.2)	23 (25.8)
Aching muscles	82 (89.1)	10 (10.9)
Limb or joint pain	72 (79.1)	19 (20.9)
Suddenly becoming breathless (in people who aren't usually breathless)	67 (72.8)	25 (27.2)
Worsening of breathlessness (in people who are usually breathless)	68 (75.6)	22 (24.4)
Dizziness	36 (40.4)	53 (59.6)
Diarrhoea or stomach upset	62 (66.0)	32 (34.0)
Sore throat	67 (73.6)	24 (26.4)
Blurred vision	23 (25.6)	67 (74.4)

continued

TABLE 26 *Identification of swine flu symptoms – family members (n = 101)*

Please tell us if you think any of the following might be a symptom of swine flu or not	True	False
Runny nose	58 (64.4)	32 (35.6)
Sputum (phlegm/mucus) turning a different colour than usual	37 (40.2)	55 (58.8)
Loss of memory	10 (11.9)	80 (88.9)
Rash	20 (22.2)	70 (77.8)
Loss of appetite	43 (47.8)	47 (52.2)
Sudden inability to move or control limbs	32 (35.2)	59 (64.8)
Wheezing	37 (40.2)	55 (59.8)
Confusion	23 (25.3)	68 (74.7)
Sneezing	49 (53.8)	42 (46.2)
Chest pains	38 (42.2)	52 (57.8)

Most items had some missing data; figures in parentheses = valid percentage.

TABLE 27 *Impact of worries about swine flu on daily activities – patients (n = 253) and family members (n = 101)*

Because of worries about swine flu I am/have (my family member with chest problems is/has):	Patients (self)	Family members (self)	Family members (for patients)
Stopped or cut down on travelling by public transport (buses, trains, etc.)	43 (17.0)	10 (9.9)	11 (10.9)
Taking things like vitamins or food supplements	19 (7.5)	6 (5.9)	5 (5.0)
Avoiding crowded places (e.g. shops, cinemas, sports events, etc.)	55 (21.7)	11 (10.9)	16 (15.8)
Leaving the house less often	35 (13.8)	5 (5.0)	11 (10.9)
Avoiding contact with friends and family members	9 (3.6)	4 (4.0)	1 (1.0)
Feel(s) that people are worried about being around me/them because of my/their chest problem	12 (4.7)	3 (3.0)	8 (7.9)
Cut down or stopped smoking	15 (5.9)	7 (6.9)	5 (5.0)
Cancelled a holiday/rearranged travel plans	4 (1.6)	0 (0)	2 (2.0)

TABLE 27 *Impact of worries about swine flu on daily activities – patients (n = 253) and family members (n = 101) (continued)*

Because of worries about swine flu I am/have (my family member with chest problems is/has):	Patients (self)	Family members (self)	Family members (for patients)
Keeping windows and doors closed	3 (1.2)	3 (3.0)	0 (0)
More anxious than usual about my/their chest problem	87 (34.4)	39 (38.6)	35 (34.7)
Avoiding contact with children	11 (4.3)	6 (5.9)	6 (5.9)
Will not take my/their medication or use my/their inhaler in a public place, even if really needed	8 (3.2)	N/A	7 (6.9)
Avoiding contact with my family member with chest problems	N/A	2 (2.0)	N/A
Trying to get more exercise	53 (20.9)	14 (13.9)	14 (13.9)
Not leaving the house at all	3 (1.2)	1 (1.0)	4 (4.0)
Feel more self-conscious about my/their chest problem	64 (25.3)	13 (12.9)	17 (16.8)
Avoiding contact with pets/animals	10 (4.0)	1 (1.0)	4 (4.0)
Using my/their inhaler(s) more often	29 (11.5)	N/A	10 (9.9)
Would not wish to travel far within the UK	21 (8.3)	6 (5.9)	6 (5.9)
Eating more healthy foods	38 (15.0)	9 (8.9)	11 (10.9)
Much more aware of my/their chest problem than usual	81 (32.0)	38 (37.6)	23 (22.8)
Not sleeping well	27 (10.7)	8 (7.9)	10 (9.9)
Would not wish to travel abroad	44 (17.4)	10 (9.9)	11 (10.9)
Cut down my/their usual social activities (e.g. going to the pub, eating out, etc.)	24 (9.5)	7 (6.9)	8 (7.9)
Avoiding contact with people who have been abroad	7 (2.8)	2 (2.0)	4 (4.0)
Constantly on the alert for changes in my/their chest problem	89 (35.2)	44 (43.6)	29 (28.7)
Other people are avoiding me/them because of chest problem	5 (2.0)	0 (0)	2 (2.0)
More careful about taking my/their regular medications as instructed	52 (20.6)	N/A	15 (14.9)
Avoiding eating pork/ham/bacon, etc.	3 (1.2)	1 (1.0)	0 (0)
Tried to buy/bought Tamiflu	2 (0.8)	3 (3.0)	2 (2.0)

N/A, not applicable.

TABLE 28 *Previous uptake of annual seasonal influenza vaccination in patients (n = 253) and family members (n = 101)*

	Regularly each year	Occasionally	Never	Don't know/ can't remember	No response
Patients (*n*, %)	198	23	27	1	4
	(78.3)	(9.1)	(10.7)	(0.4)	(1.6)
Family members (*n*, %)	56	9	33	2	1
	(55.4)	(8.9)	(32.7)	(2.0)	(1.0)

TABLE 29 *Intentions regarding uptake this year of annual seasonal influenza vaccination in patients (n = 253) and family members (n = 101)*

	I am now more likely to get the regular winter flu jab:						
	Strongly agree	Tend to agree	Neither agree nor disagree	Tend to disagree	Strongly disagree	Don't know	No response
Patients (*n*, %)	98	37	54	23	28	7	6
	(38.7)	(14.6)	(21.3)	(9.1)	(11.1)	(2.8)	(2.4)
Family members (*n*, %)	29	12	30	15	6	7	2
	(28.7)	(11.9)	(29.7)	(14.9)	(5.9)	(6.9)	(2.0)

TABLE 30 *Help-seeking behaviour in response to specific symptoms – patients (n = 253)*

If you had swine flu, would *you* get help *if you developed* any of the following symptoms?	Yes	No
Fast breathing or feeling much more short of breath than usual	211	23
	(90.2)	(9.8)
Feeling very tired	90	139
	(39.3)	(60.7)
Chest pains	209	27
	(88.6)	(11.4)
Fever (high temperature) that didn't go down after 4 or 5 days	234	5
	(97.9)	(2.1)
Aching muscles	121	107
	(53.1)	(46.9)
Producing more sputum (phlegm/mucus) than usual	150	83
	(64.4)	(35.6)
Worsening of cough or cough that wouldn't go away	194	40
	(82.9)	(17.1)
Drowsiness or confusion	135	91
	(59.7)	(40.3)
Coughing up blood	213	21
	(91.0)	(9.0)
Sputum (phlegm/mucus) turning a different colour than usual	186	46
	(80.2)	(19.8)
Sore throat	115	113
	(50.4)	(49.6)
Feeling more wheezy than usual	181	53
	(77.4)	(22.6)

All items had some missing data; figures in parentheses = valid percentage.

TABLE 31 *Help-seeking behaviour in response to specific symptoms – family members for themselves (n = 101)*

If you had swine flu, would *you* get help *if you developed* any of the following symptoms?	**Yes**	**No**
Fast breathing or feeling very short of breath	82	13
	(86.3)	(13.7)
Feeling very tired	28	63
	(30.8)	(69.2)
Chest pains	80	14
	(85.1)	(14.9)
Fever (high temperature) that didn't go down after 4 or 5 days	88	6
	(93.6)	(6.4)
Aching muscles	37	58
	(38.9)	(61.1)
Producing more sputum (phlegm/mucus) than usual	49	42
	(53.8)	(46.2)
Worsening of cough or cough that wouldn't go away	78	15
	(83.9)	(16.1)
Drowsiness or confusion	57	34
	(62.6)	(37.4)
Coughing up blood	85	8
	(91.4)	(8.6)
Sputum (phlegm/mucus) turning a different colour than usual	67	22
	(75.3)	(24.7)
Sore throat	38	55
	(40.9)	(59.1)
Feeling very wheezy	67	27
	(71.3)	(28.7)

All items had some missing data; figures in parentheses = valid percentage.

TABLE 32 *Help-seeking behaviour in response to specific symptoms – family members on behalf of patients (n = 101)*

If *your family member with chest problems* had swine flu, would you get help *if they developed* any of the following symptoms?	**Yes**	**No**
Fast breathing or feeling much more short of breath than usual	89	5
	(94.7)	(5.3)
Feeling very tired	42	48
	(46.7)	(53.3)
Chest pains	87	8
	(91.6)	(8.4)
Fever (high temperature) that didn't go down after 4 or 5 days	89	6
	(93.4)	(6.6)
Aching muscles	45	49
	(47.9)	(52.1)
Producing more sputum (phlegm/mucus) than usual	74	16
	(82.2)	(17.8)

continued

TABLE 32 *Help-seeking behaviour in response to specific symptoms – family members on behalf of patients (n = 101) (continued)*

If *your family member with chest problems* had swine flu, would you get help *if they developed* any of the following symptoms?	**Yes**	**No**
Worsening of cough or cough that wouldn't go away	87 (93.5)	6 (6.5)
Drowsiness or confusion	68 (75.6)	22 (24.4)
Coughing up blood	86 (92.5)	7 (7.5)
Sputum (phlegm/mucus) turning a different colour than usual	73 (80.2)	18 (19.8)
Sore throat	53 (57.6)	39 (42.4)
Feeling more wheezy than usual	80 (84.2)	15 (15.8)

All items had some missing data; figures in parentheses = valid percentage.

TABLE 33 *Help-seeking – obtaining oseltamivir – patients (n = 253) and family members (n = 101)*

Source/action	**Patients (self) (*n*, %)**	**Family members (self) (*n*, %)**	**Family members (for patient) (*n*, %)**
Go to A&E	8 (3.2)	1 (1.0)	3 (3.0)
Go to GP's surgery	60 (23.7)	15 (14.9)	19 (18.8)
Call GP/health centre	152 (60.1)	58 (57.4)	64 (63.4)
Call a health helpline	62 (24.5)	23 (22.8)	24 (23.8)
Call the National Pandemic Flu Service	62 (24.5)	29 (28.7)	31 (31.7)
Ask a Flu Friend/Flu Buddy	46 (18.2)	21 (20.8)	24 (23.8)
Ask community pharmacist	20 (7.9)	14 (13.9)	12 (11.9)
Look for information on television news programmes	6 (2.4)	3 (3.0)	1 (1.0)
Look for information in newspapers	6 (2.4)	5 (5.0)	2 (2.0)
Listen for information on radio news programmes	10 (4.0)	3 (3.0)	3 (3.0)
Look on news websites	10 (4.0)	6 (5.9)	4 (4.0)
Look on health websites	25 (9.9)	15 (14.9)	8 (7.9)
Look on other websites	2 (0.8)	3 (3.0)	3 (3.0)
Look on unspecified websites	1 (0.4)	0 (0)	1 (1.0)
Contact chest consultant or hospital chest clinic	32 (12.6)	N/A	19 (18.8)
Contact a chest specialist nurse (hospital or community)	15 (5.9)	N/A	6 (5.9)
Already have a supply of oseltamivir	5 (2.0)	2 (2.0)	1 (1.0)
None of these	2 (0.8)	0 (0)	0 (0)
Don't know	12 (4.7)	1 (1.0)	0 (0)
Other	2 (0.8)	1 (1.0)	2 (2.0)

Note: participants could select more than one option.