

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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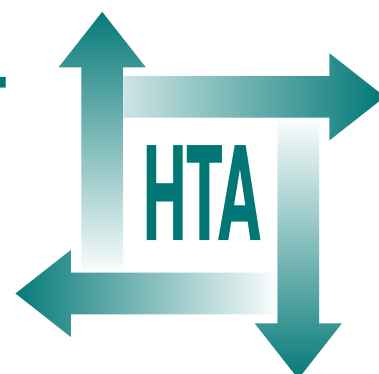
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Executive summary

Health Technology Assessment 2010; Vol. 14: No. 34, 1–108
DOI: 10.3310/hta14340-01

Health Technology Assessment
NIHR HTA programme
www.hta.ac.uk





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%, $\chi^2_{\text{TREND}} = 9.25$, $df = 1$, $p = 0.002$). 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 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%, $\chi^2_{\text{TREND}} = 12.65$, $df = 1$, $p < 0.001$). This was also true for feeling that they knew as much as they needed to (66.7% versus 34.2% versus 13.6%, $\chi^2_{\text{TREND}} = 12.74$, $df = 1$, $p < 0.001$). 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).

Publication

Caress A-L, Duxbury P, Woodcock A, Luker K, Ward D, Campbell M, *et al.* 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. *Health Technol Assess* 2010;**14**(34): 1–108.



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This themed issue of the *Health Technology Assessment* journal series contains a collection of research commissioned by the NIHR as part of the Department of Health's (DH) response to the H1N1 swine flu pandemic. The NIHR through the NIHR Evaluation Trials and Studies Coordinating Centre (NETSCC) commissioned a number of research projects looking into the treatment and management of H1N1 influenza.

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ISSN 1366-5278

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