

## Using electronic patient records to assess the impact of swine flu (influenza H1N1) on mental health patients

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### Abstract

**Background.** Electronic patient records are increasingly used in primary care research, but rarely in psychiatric research. Little is known about how people with pre-existing mental illness respond to public health threats.

**Aims.** To outline the swine flu related concerns and behaviours of mental health patients and to determine whether marked concern was associated with any specific demographic or diagnostic groups.

**Methods.** We searched a database containing electronic patient records from a large mental health trust for references to swine flu made between 15 April and 15 July 2009. Thematic analysis was used to code swine flu related concerns and behaviours. A case-control approach sought to determine whether there were demographic or diagnostic associations with expressing moderate/severe concern about swine flu.

**Results.** A range of swine flu related behaviours were noted and considerable impact was recorded for some patients. Children and patients with neurotic and somatoform disorders were over-represented amongst those expressing moderate/severe swine flu concerns.

**Conclusion.** Research databases using electronic clinical records are a useful way to track responses to emerging public health threats. Children receiving mental health care and patients with neurotic and somatoform disorders may be particularly psychologically vulnerable to infectious disease epidemics.

**Keywords:** Swine flu, influenza H1N1, electronic patient records, emerging health threats, mental health

### Introduction

There is increasing interest in the use of electronic patient records as a basis for health research (Powell & Buchan, 2005), with most such research having been conducted in the general practice setting (Gibson-White & Majeed, 2009; Wellcome Trust, 2009). Electronic records have rarely been used to facilitate psychiatric research (Booth, 2006), although recent technical and procedural advances have now made this possible in certain regions of the UK (Stewart et al., 2009). This article outlines the novel use of a large electronic psychiatric case register to track patient responses to the recent swine flu (H1N1) pandemic.

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Swine flu is the first influenza pandemic to occur for 40 years. It was initially detected in April 2009 and rapidly spread around the world, with the first English case being reported on 29 April 2009. Initially, UK public health authorities adopted a containment strategy but by early July it was clear that community transmission was established (Health Protection Agency, 2009). The first three months of the pandemic were characterised by considerable media coverage and a public health campaign that encouraged the adoption of hygiene precautions, such as hand washing (NHS Choices, 2009). We were interested in the response of mental health patients to this novel emerging health threat. An advantage of studying the swine flu pandemic was that it had a clearly defined onset, which ensured that sampling could be comprehensive.

Little is known about the information needs, concerns and behaviours of people with established mental illness during times of increased health threat. Research from the aftermath of September 11 indicates that the attack had detectable although variable effects on mental health patients (Franz et al., 2009), whilst natural disasters have also been shown to have negative consequences on patient groups (Hayes et al., 2009; Horan et al., 2007). To our knowledge there is no research into the effect of infectious disease outbreaks on people with pre-existing mental health problems. Specific objectives of this study were to use electronic patient records to provide an overview of the concerns and behaviours expressed by mental health patients about swine flu in the early stages of the pandemic; and to determine whether heightened concern was associated with any specific demographic or diagnostic factors. The study used qualitative and quantitative approaches to address these objectives.

## Methods

### *Study design*

First, we undertook a descriptive assessment of patients' concerns about swine flu; second a case-control design was used to determine whether there were specific demographic factors or diagnoses associated with marked concern about swine flu.

*Study setting and population.* The study was set within a live database of patients receiving care from the South London & Maudsley Foundation NHS Foundation Trust (SLAM). The Case Register Interactive Search (CRIS) programme was developed through the SLAM Specialist Biomedical Centre for Mental Health and enables searches to be carried out of the fully electronic clinical records of every patient known to SLAM using specific demographic, clinical or other parameters (e.g. keyword searching). The Case Register is updated daily, has been designed to fully protect patient confidentiality by anonymising the records. Anonymised data can then be exported to standard packages for further analysis. The CRIS system has been described in detail in a previous open source publication (Stewart et al., 2009). In this previous publication, the legal and ethical issues pertinent to the development of an anonymised case register are described in detail. For example, during the development phase of CRIS, a working group was convened to develop the security and confidentiality procedures; this working group was chaired by a service-user and also included the Trust Caldicott Guardian and Child Protection Lead, thus ensuring strong stakeholder involvement.

SLAM provides general and specialist mental health services across the age range to a population of approximately 840,000 people in South East London and substance misuse services for a further 719,600 people (South London & Maudsley NHS Foundation Trust,

2009). The local population is ethnically and socially diverse and this is reflected in the patients referred to the trust (Stewart et al., 2009). Approximately, 35,000 patients were under active care by SLAM services at the time of the study.

*Ethical approval.* Ethical approval was granted by an independent NHS Research Ethics Committee (Oxfordshire C) for use of anonymised databases derived using CRIS. A local Oversight Committee then reviewed the present study protocol to ensure that it constituted an appropriate use of the database before the study could commence.

*Identification of cases and controls.* Cases were defined as patients who had expressed concern about their own (or close others) risk of contracting swine flu. Everyone on the database for whom the key words 'swine flu' or 'pandemic flu' (or misspellings) were recorded within their clinical records between 15 April 2009 and 15 July 2009 was eligible for inclusion. Patients were excluded if the reference to swine flu originated from a member of staff rather than the patient (e.g. if a staff member had used swine-flu to test knowledge of current affairs). Patients were also excluded if the reference was made by a relative or carer rather than the patient and there had been no discernible concern from the patient. For the case-control analysis, only the subgroup of cases for whom 'moderate/severe concerns' had been recorded were used (see below for how this subgroup was defined). Control participants were selected randomly from all SLAM patients for whom 'swine flu' had not been recorded in their electronic records. All controls were receiving active care from SLAM.

*Coding of swine flu references.* For each case, the section of notes in which the reference to swine flu had been made was retrieved. The notes were read closely and an iterative coding scheme was developed. Early in the process it became clear that many patients' concerns about swine flu were minimal, whilst others' were more substantial. We developed the coding scheme shown below and two of the study team (LP and SS) then classified cases independently. Cases for which there was disagreement on classification were discussed until consensus was reached. A third researcher was available in case of unresolved disagreement.

*Mild concerns.* Concern about swine flu was verbalised but did not appear persistent or preoccupying. Also included cases where, unprompted, a patient raised the subject of swine flu, but no concern was recorded and no other indication of the level of concern was provided.

*Moderate/severe concerns.* Concern was verbalised and referred to recurrent and/or intrusive thoughts about swine flu; or the patient was described as becoming more agitated when discussing swine flu. Many of these patients asked specific questions about the spread of swine flu and required a significant degree of reassurance.

#### *Demographic and diagnostic information*

Standard demographic information including gender, age, marital status and ethnicity were available for all cases and controls, as was ICD-10 diagnosis as recorded by the clinician.

#### *Thematic analysis*

A thematic analysis of the textual data related to swine flu concerns was undertaken. First the data were thoroughly read and re-read for each case and classified (as above) into those

exhibiting ‘mild concern’ and ‘moderate /severe concern’. We were interested in evidence of behavioural change due to the threat of swine flu and a typology of behaviours was drawn up to reflect this. Further analysis focussed on themes that emerged around impact on psychological symptoms.

### *Statistical analysis*

Where current ICD-10 diagnosis was available, these were collapsed into one of six major ICD-10 categories of mental disorder (see Table II); there were three diagnostic categories which applied to fewer than 5% of study participants (learning disability, eating disorder and organic disorder) and these were grouped together as ‘other’.

An *a-priori* decision was made to compare all cases demonstrating ‘moderate/severe concern’ to controls (i.e. cases demonstrating only mild concern were not included in this analysis). Unadjusted logistic regression was used to test for associations between demographic variables, diagnostic category and caseness. Gender and ethnicity have been previously highlighted as associated with swine flu related behaviour change (Rubin et al., 2009), therefore a second (exploratory) analysis entered gender and ethnicity as potential confounding variables in the association between (a) age and (b) diagnosis and the expression of moderate/severe concerns about swine flu.

## **Results**

In total, 196 patients had the key-word ‘swine flu’ or ‘pandemic flu’ entered in their clinical notes during the study period. Of these, 144 patients were included in the study as they were judged to have made spontaneous expressions of concern about swine flu – see Figure 1.

### *Thematic results*

*Behaviour.* A summary of swine flu related behavioural responses is shown in Table I. There were examples of appointments being cancelled due to concerns about swine flu:

*“[a] man on the bus was sneezing and ZZZZZ felt that the sneeze was going on her, ZZZZZ reported she opened the window but . . . needed to get off the bus. ZZZZZ reported this situation is made worse by the current Swine flu situation. ZZZZZ . . . cannot leave the house today.” [adolescent female with obsessive compulsive disorder (OCD)].*

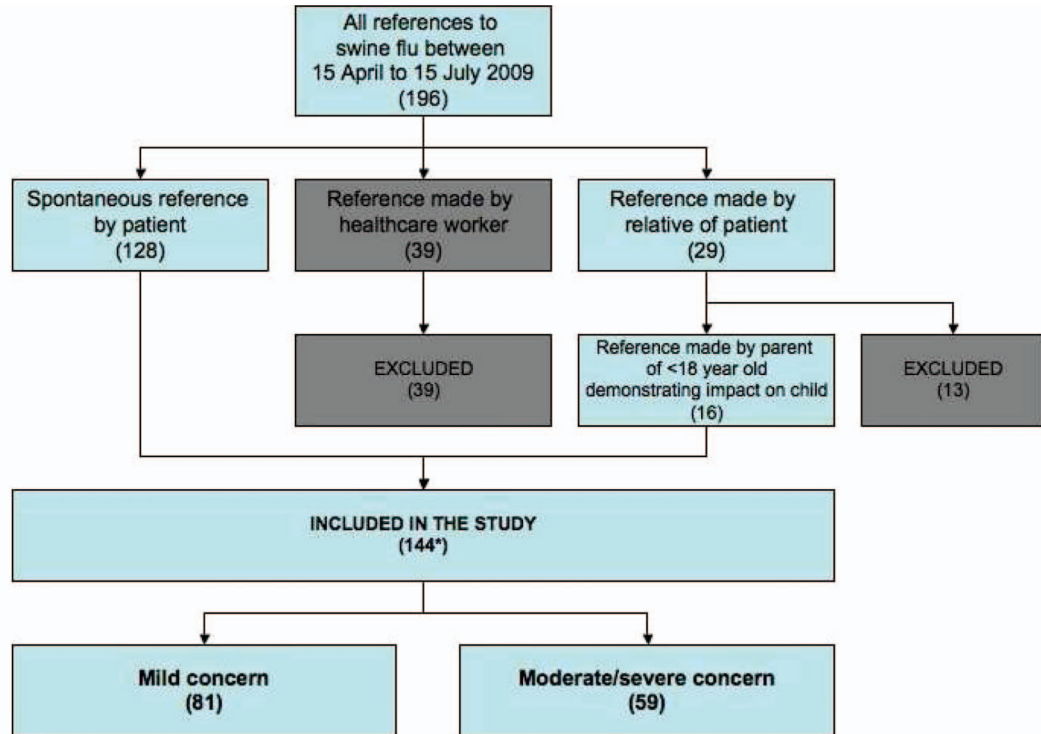
Whilst other patients reported being symptomatic and keen not to expose others:

*“ZZZZZ stated that she was not feeling well and was worried that she might have ‘Swine flu’ so did not want to come to the centre and ‘infect us all’.” [adult female with depression].*

However, swine flu related impacts on mental health services were complex, with other patients seeking additional appointments with services as a consequence of their concerns.

Avoidance of public places was recorded for 12 patients and was related to holding more substantial concerns about swine flu, for example:

*“ . . . ZZZZ has been excessively hand washing using antibacterial hand wash which he carries around with him. He doesn’t want to go to school or sit next to anyone on public transport in case he catches swine flu” [adolescent male with learning disability].*



\*144 entries were included in the study however, prior to case control analysis, 4 cases were dropped as no demographic data were available

Figure 1. Flowchart of patients included in the study.

Table I. Range of behavioural responses to swine flu amongst mental health patients ( $n = 144$ ).

Behaviour	Total	Mild concern	Moderate/severe concern
Information gathering about swine flu from staff or media sources	20	6	14
Cancelling or failure to make appointments	19	15	4
Making appointments with healthcare professionals for reassurance	15	8	7
Avoidance of public places (e.g. school, GP surgery, public transport)	12	3	9
Increased hand washing	11	1	10
Mask wearing	1	0	1
Other (e.g. extra showering, avoidance of pork, not touching door handles)	11	5	6
More than 1 of the above behaviours	12	3	9
More than 2 of the above behaviours	2	0	2

*Role of the media.* Twenty patients spontaneously discussed media references to swine flu. The mass media often appeared to be a source of concern and there were no examples of patients successfully countering swine flu related anxieties by accessing information sources on their own, although internet searches when guided by a mental health worker were sometimes reassuring:

Table II. Results of unadjusted case-control analysis, (where cases are patients expressing moderate /severe concern about swine flu).

	Cases		Controls		Odds ratio (95% CI)	p value
	n	%	n	%		
Total n = 314	59	100	255	100		
Gender						
Men	29	49.1	139	54.5	1.0 Ref	–
Women	30	50.9	116	45.5	1.2, 0.7–2.2	0.46
Age/years						
< 16	21	35.6	24	9.4	6.6, 2.6–16.8	<0.001
16–30	10	17.0	60	23.5	1.3, 0.5–3.4	0.66
30–40	11	18.6	51	20.0	1.6, 0.6–4.3	0.34
40–54	9	15.3	60	23.5	1.1, 0.4–3.1	0.82
> 54	8	13.6	60	23.5	1.0 Ref	–
Ethnicity						
White British (& white other)	37	62.7	137	53.7	1.9, 0.6–5.7	0.26
Black (Caribbean, African & other)	16	27.1	77	30.2	1.5, 0.4–4.7	0.53
Asian (Indian, Pakistani, Chinese & other)	2	3.4	13	5.1	1.1, 0.2–6.6	0.94
Mixed background (& not known)	4	6.8	28	11.0	1.0 Ref	–
Marital status* (cases = 38; controls = 231)						
Married	4	10.5	29	12.6	2.2, 0.2–20.3	0.48
Divorced/Separated/Widowed	6	15.8	35	15.2	1.8, 0.2–17.7	0.62
Single	27	71.1	154	66.7	2.3, 0.3–18.1	0.44
Not known	1	2.6	13	5.6	1.0 Ref	–
Diagnosis						
Unknown	13	22.0	58	22.9	2.2, 0.6–8.2	0.07
Child specific disorders	4	6.8	10	4.0	3.9, 0.7–20.3	0.11
Other†	6	10.2	39	15.4	1.5, 0.3–6.4	0.29
Mood disorders	7	11.9	39	15.4	1.7, 0.4–7.3	0.43
Neurotic and somatoform disorders	11	18.6	19	7.5	5.6, 1.4–22.7	0.02
Schizophrenia	15	25.4	59	23.3	2.5, 0.7–9.2	0.14
Substance misuse	3	5.1	29	11.5	1.0 Ref	–

\*If aged > 16 years.

†Other diagnoses made up of learning disability, eating disorder, organic, personality disorder.

“ZZZZZ and I accessed SLAM website and checked latest info regarding the matter . . . ZZZZZ was soon reassured that he did not display symptoms” [adult male with affective psychosis]

Children and adolescents seemed particularly vulnerable to media coverage of swine flu:

“ZZZZZ worries when he watches the news in relation to bad things happening and he will worry that that the same thing will happen to him and his family, examples given about Madeleine McCann and the Swine Flu.” [adolescent male unknown diagnosis].

**Impact on anxiety symptoms.** There was evidence for some patients with anxiety disorders, particularly OCD, that swine flu had exacerbated their symptoms. For example, contamination fears and washing compulsions were worsened by concerns about swine flu:

“We discussed . . . ZZZZZ’s fear of getting swine flu . . . ZZZZZ became a little tearful at this point but was able to be reassured. She felt this fear was worse than her checking at the moment because she was too tired to do the checking as much.” [adolescent female with OCD]

Government guidelines had effectively normalised some compulsive OCD behaviours, for example the cleaning of door handles. In one case a young patient explained a period of compulsive hand washing, after receiving hygiene advice at school. Some parents and carers now felt ill-equipped to deal with behaviours previously categorised as senseless or exaggerated and asked advice of mental health workers:

*“[mother] asked me advice on dealing with ZZZZZ over reaction to . . . his current fear of germs and swine flu. I suggested that if her response to these fears is normal . . . her role modelling may be enough to challenge these exaggerated beliefs.” [male child with unknown diagnosis]*

*Impact on psychotic symptoms.* There were 11 examples of swine flu featuring in the delusions of patients with psychotic illnesses. Most of the delusional ideas were persecutory or nihilistic in nature and were mentioned as part of more established delusional systems, for example:

*“He . . . reported having significant problems with the Muslim spirit over the last few weeks. He believes the spirit wants to stop him achieving in his life and . . . the spirit recently gave him [swine] flu . . . [although] he was not diagnosed with swine flu” [adult male with schizophrenia]*

In one patient there was a suggestion that somatic hallucinations may have been attributed to swine flu:

*“Odd behaviour in the form of covering his face with a mask, when asked why said was concerned about swine flu, trying to wiggle into difficult places” [adult male with schizophrenia]*

#### *Case-control results*

Four cases were dropped prior to the case-control analysis, as no demographic data were available. Demographic and diagnostic details of cases are shown in the online Appendix. The results of unadjusted logistic regression are shown in Table II. Being aged less than 16 years was significantly associated with expressing ‘moderate/severe concerns’ about swine flu (OR 6.6 (2.6–16.8)), as was being diagnosed with a neurotic or somatoform disorder (OR 5.6 (95% CI 1.4–22.7)). Otherwise no other demographic or diagnostic variables were associated with moderate/severe swine flu concerns. When the analysis included gender and ethnicity as potential confounding variables, being aged less than 16 years remained strongly associated with expressing moderate/severe concerns about swine flu (OR 8.1 (95% CI 3.0–21.3)), as did being diagnosed with a neurotic or somatoform disorder (OR 6.6 (95% CI 1.5–28.7)). The estimate of effect did not substantially change or become statistically significant for any of the other variables.

## **Discussion**

To our knowledge this represents the first study to use a live database of mental health patients to track responses to an emerging health threat. Our thematic analysis of electronic patient records indicated that, within the first three months of the outbreak, mental health patients adopted a range of behaviours as a consequence of swine flu. For some patients, especially children, the swine flu outbreak had considerable impact. Thematic analysis also

revealed ways in which concerns about swine flu became enmeshed with patients' mental health symptoms – both neurotic and psychotic. A case-control approach demonstrated that, amongst the mentally ill population who are involved with services, children and those with neurotic/somatoform disorders were the groups most concerned about swine flu.

This study demonstrates that electronic patient records can be used successfully to address research questions about evolving public health threats. Case registers have recently been highlighted as powerful and yet neglected tools for psychiatric research (Perera et al., 2009) and this study represents a novel use of such a register. Being able to rapidly access detailed qualitative and quantitative information is particularly helpful when responding to an emerging health threat and offers a potential tool in the surveillance of such situations. The study provided a unique 'snapshot' into how patients within an entire regional service were affected by an emerging pandemic and enabled identification of vulnerable groups that would otherwise have been difficult to locate. The qualitative results highlight the extent to which mental health staff were expected to deliver and/or interpret public health messages for their patients.

Children and adolescents were greatly over-represented amongst patients who expressed moderate/severe concerns about swine flu. This may partly be explained by the local situation at the time, as a number of schools in South East London temporarily closed in the early weeks of the pandemic because pupils had contracted swine flu. Therefore, children under the care of mental health services – like all schoolchildren in the area – would have been exposed to even more than the usual discussion about swine flu amongst siblings, parents, friends and school authorities. It seems possible that children in general may have experienced particularly strong fears or worries about swine flu, and yet general population behavioural research excluded children for ethical or pragmatic reasons (Goodwin et al., 2009; Holland Jones & Salathe, 2009; Rubin, et al., 2009; Seale, et al., 2009).

The study also highlights that patients with neurotic and somatoform disorders were particularly vulnerable to swine flu related concerns during the early part of the pandemic. This group included patients with OCD and it was clear that contamination fears and washing rituals were exacerbated by the outbreak. There were obvious examples of government recommendations, such as hand washing advice, being difficult to interpret for patients and carers. We suggest that such difficulties can be viewed as a potential adverse side effect of public health interventions of this sort. We suspect that the infectious nature of swine flu made it a particularly potent threat for people with OCD, as this group was not shown to be especially affected by the September 11 attacks (Riemann et al., 2004).

### *Study limitations*

We acknowledge that a number of filters were operating that may have prevented swine flu related concerns from being recorded in the clinical notes, for example perhaps not all patients discussed such concerns with mental health staff or not all staff recorded them – this may have led to some random misclassification of cases. We also stress that the records retrieved and analysed are best viewed as archival documents, as opposed to qualitative interviews. This reliance on 'routine' recording of swine flu related concerns can be seen as both a strength and weakness – it had the potential to reduce observer bias, whilst increasing the risk of misclassification. Second, bias could have been introduced into the case-control analysis if certain types of patients (i.e. children and those with neurotic/somatoform disorders) were under more intensive follow-up from services than others and therefore swine flu concerns had more opportunity to surface during their consultations.



## Conclusions

Research databases based on electronic patient record systems may be exploited to provide information on vulnerable patients groups. In this instance, we used a live database of mental health patients to assess the impact of an emerging health threat. Our findings were that mental health patients adopted a range of swine flu related behaviours during the first 3 months of the pandemic, with a substantial number expressing marked concern about the outbreak. Concerned patients were more likely to be children or those suffering from neurotic and somatoform disorders.

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## Appendix

Table: Demographic details of cases expressing concern about swine flu.

	Total		Mild concern, <i>n</i>	Mod/severe concern, <i>n</i>
	<i>n</i>	%		
Total	140	100.0	81	59
Gender				
Men	63	45.0	34	29
Women	77	55.0	47	30
Age/years				
< 16	49	35.0	28	21
16–30	26	18.6	16	10
30–40	22	15.7	11	11
40–54	24	17.1	15	9
> 54	19	13.6	11	8
Ethnicity				
White British (& white other)	81	57.9	44	37
Black (Caribbean, African & other)	41	29.3	25	16
Asian (Indian, Pakistani, Chinese & other)	5	3.6	3	2
Mixed background (& not known)	13	9.3	9	4
Marital status* ( <i>n</i> = 91)				
Married	7	7.7	3	4
Divorced/Separated/Widowed	12	13.2	6	6
Single	67	73.6	40	27
Not known	5	5.5	4	1
Diagnosis				
Unknown	36	25.7	23	13
Child specific disorder	12	8.6	8	4
Other <sup>†</sup>	18	12.9	12	6
Mood disorder	16	11.4	9	7
Neurotic/Somatoform disorder	18	12.9	7	11
Substance misuse	8	5.7	5	3
Schizophrenia	32	22.9	17	15
Patient status				
Inpatient	40	28.6	23	17
Outpatient	100	71.4	58	42

\*If aged &gt; 16 years.

<sup>†</sup>Other diagnoses made up of learning disability, eating disorder, organic, personality disorder.