

Protection of Personal Information of Private Citizens Who Provide Health Crisis Information : What Personal Information of People Providing such Information do They not Want Governmental Agencies to Disclose ?

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Abstract : The general citizenry is the most important source of information concerning health crises. However, health crisis information includes information related to individuals, which must be handled with care. Judging from the results of the present study, the only personal information that can be disclosed is age, sex, and prefectural name. No difference was admitted between the results of a mail survey and the results of an Internet survey. This suggests that Internet surveys are an effective method available for surveys of health crisis information targeting the general citizenry.

Key words : Personal information, Health crisis, Governmental agency, Mass media

Introduction

The anthrax attacks that occurred in the United States are still fresh in our minds.¹⁾ When a large-scale spread of an infectious disease or contamination by a chemical substance occurs, whether or not the national or local government can swiftly devise a system to deal with the crisis will depend largely on how crisis management is handled following an outbreak of the crisis. Since it is extremely difficult to predict where and when a health crisis will occur, it is necessary to establish a system for handling crises before they occur. Establishing a system before a crisis occurs will thus minimize damage in the event of an emergency.

The most important factors regarding the management of health crises, whether it be before a crisis occurs or during a crisis, are collecting the

health crisis information submitted by local residents over a wide area as swiftly as possible, getting a grasp of the current situation and estimating the damage based on the information, and then sharing the relevant information with local residents.²⁾ When a health crisis occurs, a large amount of information related to multiple incidents will flood in and be collected regardless of its importance, thus making it difficult to identify the most essential information. In addition, health crisis information includes information related to individuals, which must be handled with care. For governmental agencies which must swiftly respond when a health crisis occurs, the selection of necessary information and the protection of personal information thus pose a major obstacle.

The biggest source of information concerning health crises is private citizens, whether they are providing a governmental agency with information voluntarily or they are responding to an in-

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quiry by a governmental agency.³⁾⁴⁾ When a health crisis, such as a large-scale spread of infectious disease and contamination by a chemical substance, occurs in a certain area, the quality of the subsequent government response will differ depending on how swiftly the local populace, which is in a position to obtain information, provides governmental agencies such as public health centers with useful and accurate information. However, it cannot be denied that difficulty in obtaining accurate information is related to the fact that private citizens question whether governmental agencies will handle the personal information related to people who provide information in an appropriate and prudent manner.

The purpose of this study was to evaluate the personal information of the general citizenry, which will be a source of information when a health crisis occurs, which personal information governmental agencies should protect, and the conditions related to the handling of their personal information under which they will provide information to the local government, such as public health centers. An additional purpose was to evaluate the efficacy of Internet surveys, which are frequently being used recently, as they relate to health crisis information by comparing the results of a mail survey with the results of an Internet survey.

Materials and Methods

We conducted a mail-based survey and an Internet-based survey of the general citizenry. The number of people and the areas surveyed in the mail-based survey were 400 people in Sendai City, Miyagi Prefecture, 1,000 people in Setagaya Ward, Tokyo, 400 people in Osaka City, Osaka Prefecture, and 400 people in Fukuoka City, Fukuoka Prefecture. The respondents to the survey were selected at random from the Basic Resident Register. The survey period was the four-week period from March 12 to April 9, 2004, for the 1,000 people in Setagaya Ward and the four-week period from November 2 to November 30, 2004, for a total of 1,200 people in Sendai City, Osaka City, and Fukuoka City. The contents of the surveys were all identical.

As for the Internet-based survey, the respondents were persons who were registered with an organization that specializes in conducting Internet surveys. The survey period was the three-day period from November 15 to November 17, 2004. The contents of the survey were identical to the contents of the mail survey.

Both surveys centered on whether or not one would contact a governmental agency such as a public health center if infected with an unknown infectious disease and whether or not one would respond if personnel from a public health center, came asking questions about infected persons. The personal information surveyed included name, age, sex, address, occupation, where to make contact, and the names of people with whom one came into contact (Appendix 1). Sex, age, occupation, academic background, and telecommunications equipment were also surveyed as general information. The surveys were anonymous surveys, i.e., respondents did not give their name or address. As for informed consent, persons who responded to the survey were judged to have given their consent for this study.

For the questionnaire survey, respondents were asked to circle the appropriate response, not to write their response. In both surveys, respondents were first asked whether or not they would cooperate with governmental agencies. Those who responded that they would cooperate with governmental agencies were then asked questions concerning personal information. The three choices for each question were “I would answer and I would not mind if the information was made public,” “I would answer, but I would not want the information made public,” and “I would not answer.” Respondents were asked to circle the answer that applied. In this study, items for which fewer than 10% of respondents answered they would not mind the information being made public were defined as items that citizens do not want made public as personal information. A Statistical Analysis System (SAS Institute, Cary, NC) was used for the statistical analysis. A *p*-value less than 0.05 was considered to be a significant difference.

Results

Excluding questionnaires that were returned marked address unknown, the number of responses in the mail survey was 112 for Setagaya Ward (11.6% response rate), 74 for Sendai City (18.8%), 58 for Osaka City (15.1%), and 85 for Fukuoka City (22.4%). Overall, there were 329 total responses (143 men, 178 women, and 8 unknown) for a response rate of 15.7%. The number of responses in the Internet survey was 1,088 (526 men and 562 women). The number of people who responded to the mail survey or the Internet survey and their ratios are shown in Table 1 by sex, age, and highest level of education attained. A significant difference ($p=0.049$) was seen in the age distribution of the junior high school graduates, but no statistical difference was found in terms of sex and age distribution for other academic backgrounds.

The ratio of those who responded that they would not contact a governmental agency when there was a possibility that they were infected with an unknown infectious disease was 11.6% (38

cases). The main reason given for this was that they did not want their private information made public, which was cited by 44.7% of the respondents. Other reasons given were they did not want to get involved with a governmental agency, their activities would be restricted, it would inconvenience their family, it would affect their workplace, and they did not want to the neighbors to find out, which were each cited by 20% to 25% of respondents. Table 2 shows the data for 284 respondents who responded that they would voluntarily contact a governmental agency when there was a possibility that they were infected with an unknown infectious disease. It shows the number and ratios of respondents who “would not mind if the information was made public,” “would answer, but would not want the information made public,” and “would not answer because they would not like the information made public,” with regard to various types of personal information, when asked by a governmental agency. Personal information that respondents would not like made public (ratio of those who would allow disclosure was less than 10%) was name, employer, home or office tele-

Table 1 Comparison of respondents to mail survey and Internet survey by sex, age, and level of education

Education	Junior high school graduate		High school graduate		Junior college graduate		College graduate									
	MS		IN		MS		IN									
	n	%	n	%	n	%	n	%								
Sex																
Male	8	5.6	17	3.2	43	30.1	137	26.0	21	14.7	57	10.8	69	48.3	314	59.7
Female	8	4.5	21	3.7	55	30.9	184	32.7	66	37.1	191	34.0	45	25.3	165	29.4
	p=0.772				p=0.907				p=0.883				p=0.328			
Age (years)																
20-29	0	0	8	4.5	17	36.2	36	20.2	16	34.0	55	30.9	14	29.8	79	44.4
30-39	1	1.7	8	4.4	11	19.0	42	23.1	20	34.5	61	33.5	25	43.1	71	39.0
40-49	0	0	1	0.5	22	31.9	54	24.5	20	29.0	52	23.6	26	37.7	113	51.4
50-59	3	4.7	4	1.9	17	26.6	67	31.9	19	29.7	34	16.2	25	39.1	104	49.5
60 and over	14	16.3	17	5.7	32	37.2	122	40.9	12	14.0	46	15.4	24	27.9	112	37.6
	p<0.05				p=0.314				p=0.389				p=0.387			

Pearson's chi-squared test

MS : mail survey, n=329

IN : Internet survey, n=1,088

Junior high school graduate : junior high school graduates, elementary school and higher elementary school graduates under the old system

High school graduate : high school graduates, junior high school and higher girls' school graduates under the old system

Junior college graduate : junior college graduates, technical college graduates, high school and vocational school graduates under the old system

College graduate : college and graduate school graduates

Respondents were excluded when the information was unknown

phone number, cell phone number, and e-mail address. Information that 60% or more of respondents answered they would not mind having made public was age, sex, and prefecture name.

The ratio of those who responded that they would not cooperate if personnel from the municipal government such as a public health center came asking questions about infected persons, regardless of whether or not they knew any information about any infected persons, was only 3.6% (12 cases). The most common reason given was that

they did not want to get involved. Table 3 shows the numbers and ratios of respondents to a mail survey who “would not mind if the information was made public,” “would answer, but would not want the information made public,” and “would not answer because they would not like the information made public,” with regard to various types of personal information, when personnel from a public health center, came asking questions about infected persons and asked for their cooperation. Personal information that respondents

Table 2 Personal information that can be disclosed when a person voluntarily contacts a governmental agency (mail survey, n=284)

	Will respond to governmental agencies				Will not respond to governmental agencies	
	Will allow disclosure		Will not allow disclosure		Will not allow disclosure	
	n	%	n	%	n	%
Name	21	7.4	238	83.8	20	7.0
Age	171	60.2	104	36.6	4	1.4
Sex	190	66.9	87	30.6	3	1.1
Occupation	129	45.4	126	44.4	20	7.0
Workplace	25	8.8	195	68.7	51	18.0
Address (only prefectural name)	175	61.6	91	32.0	7	2.5
Address (prefectural and city name)	123	43.3	139	48.9	15	5.3
Phone number (home)	14	4.9	218	76.8	47	16.5
Phone number (office)	12	4.2	178	62.7	79	27.8
Phone number (cell phone)	13	4.6	179	63.0	80	28.2
E-mail address	12	4.2	152	53.5	104	36.6
Activity history	109	38.4	151	53.2	15	5.3
Names of persons with whom one has come into contact	30	10.6	222	78.2	25	8.8

Note : Nonresponses were excluded.

Table 3 Personal information that can be disclosed when questioned by a governmental agency (mail survey, n=311)

	Will respond to governmental agencies				Will not respond to governmental agencies	
	Will allow disclosure		Will not allow disclosure		Will not allow disclosure	
	n	%	n	%	n	%
Name	23	7.4	254	81.7	28	9.0
Age	154	49.5	140	45.0	12	3.9
Sex	175	56.3	122	39.2	8	2.6
Occupation	106	34.1	152	48.9	42	13.5
Workplace	19	6.1	202	65.0	78	25.1
Address (only prefectural name)	161	51.8	128	41.2	12	3.9
Address (prefectural and city name)	113	36.3	158	50.8	30	9.6
Phone number (home)	13	4.2	217	69.8	75	24.1
Phone number (office)	8	2.6	186	59.8	103	33.1
Phone number (cell phone)	8	2.6	168	54.0	119	38.3
E-mail address	7	2.3	151	48.6	136	43.7
Activity history	74	23.8	195	62.7	34	10.9
Names of persons with whom one has come into contact	25	8.0	236	75.9	43	13.8

Note : Nonresponses were excluded.

Table 4 Personal information that can be disclosed when a person voluntarily contacts a governmental agency (mail survey, n=1088)

	Will respond to governmental agencies				Will not respond to governmental agencies	
	Will allow disclosure		Will not allow disclosure		Will not allow disclosure	
	n	%	n	%	n	%
Name	103	9.5	920	84.6	65	6.0
Age	730	67.1	347	31.9	11	1.0
Sex	795	73.1	284	26.1	9	0.8
Occupation	493	45.3	509	46.8	86	7.9
Workplace	142	13.1	734	67.5	212	19.5
Address (only prefectural name)	723	66.5	348	32.0	17	1.6
Address (prefectural and city name)	417	38.3	594	54.6	77	7.1
Phone number (home)	49	4.5	844	77.6	195	17.9
Phone number (office)	48	4.4	662	60.8	378	34.7
Phone number (cell phone)	40	3.7	645	59.3	403	37.0
E-mail address	44	4.0	628	57.7	416	38.2
Activity history	325	29.9	687	63.1	76	7.0
Names of persons with whom one has come into contact	82	7.5	916	84.2	90	8.3

Note : Nonresponses were excluded.

Table 5 Personal information that can be disclosed when questioned by a governmental agency (mail survey, n=1088)

	Will respond to governmental agencies				Will not respond to governmental agencies	
	Will allow disclosure		Will not allow disclosure		Will not allow disclosure	
	n	%	n	%	n	%
Name	98	9.0	931	85.6	59	5.4
Age	655	60.2	414	38.1	19	1.7
Sex	712	65.4	359	33.0	17	1.6
Occupation	424	39.0	571	52.5	93	8.5
Workplace	123	11.3	746	68.6	219	20.1
Address (only prefectural name)	630	57.9	429	39.4	29	2.7
Address (prefectural and city name)	362	33.3	624	59.0	84	7.7
Phone number (home)	50	4.6	867	79.7	171	15.7
Phone number (office)	50	4.6	679	62.4	359	33.0
Phone number (cell phone)	40	3.7	641	58.9	407	37.4
E-mail address	42	3.9	637	58.5	409	37.6
Activity history	283	26.0	722	66.4	83	7.6
Names of persons with whom one has come into contact	78	7.2	905	83.2	78	7.2

Note : Nonresponses were excluded.

would not like made public (the rate of those who would allow disclosure was less than 10%) were name, employer, home or office telephone number, cell phone number, e-mail address, and the names of people with whom they had contact. There was no information that 60% or more of respondents answered they would not mind having made public.

The thoughts regarding disclosure of personal information of people who responded to an Internet survey that they would voluntarily contact a go-

vernmental agency when there was a possibility that they were infected with an unknown infectious disease are shown in Table 4. Personal information that respondents would not like made public (the rate of those who would allow disclosure was less than 10%) were name, home or office telephone number, cell phone number, e-mail address, and the names of people with whom they had contact. Information that 60% or more of respondents said they would not mind having made public

was age, sex, and prefecture name.

The feelings of respondents to an Internet survey regarding handling of personal information in the event that personnel from a public health center, came asking questions about infected persons and asked for their cooperation are shown in Table 5. Personal information that respondents would not like made public (the rate of those who would allow disclosure was less than 10%) were name, employer, home or office telephone number, cell phone number, e-mail address, and the names of people with whom they had contact. Information that 60% or more of respondents said they would not mind having made public was age and sex.

Discussion

The range of health crises is wide including infectious diseases, food poisoning, chemical and toxic substances, pharmaceuticals and even terrorism involving nuclear, biological, chemical, and radioactive threats. However, it is not an exaggeration to say that it is almost impossible to predict a health crisis in everyday life. Since it is very difficult to predict such things as the location and time of a health crisis, damage is minimized by establishing a response and structural plans before one occurs.⁵⁾ Making a mistake in the selection and use of various information that pours in during the early stages of a crisis makes adequate decisions regarding the status of an outbreak unclear, causing mistakes to be made in the selection of priority information to be fed back to the affected area.⁶⁾ Handling of accurate information is crucial to the subsequent response.⁷⁾⁸⁾ The most important element in the management of a health crisis is to collect information on the health crisis from the area as promptly and over as wide an area as possible and to accurately ascertain and judge the current situation based on the information.²⁾⁹⁾ Furthermore, in order to accurately predict damage and minimize the spread of damage, utilization and sharing of accurate information are crucial.¹⁰⁾ Those with whom information will be shared include not only municipalities and public health centers but also the target local populace and the media. Sharing adequate information with local residents is important for preventing needless

confusion. The use of news organizations is essential because of their ability to convey accurate information to many people. However, the collection of health crisis information in Japan is carried out with the Ministry of Health, Labor and Welfare playing a central role, but it is still hardly adequate. One reason for this is that it is extremely difficult to predict a health crisis.

Health crisis information will be shared not only with the government but also with local residents and the mass media such as newspapers and television¹¹⁾. The information includes not a small amount of personal information, which must be handled with care. However, it is true that there have been too few studies concerning the protection of personal information of local residents, who are the source of such information. Therefore, in this study we surveyed the thoughts of private citizens, who are providers of information, regarding the handling of their personal information that is included in health crisis information.

Without exception, respondents did not want governmental agencies to make public their name, workplace, telephone number (home, office, and cell phone), and e-mail address, which could all be used to track an individual. Persons associated with a governmental agency must avoid leaking this personal information to the mass media at any cost. Access to personal information should be limited to the least number of relevant parties as possible, including within governmental agencies. Namely, access to personal information should be limited as much as possible within governmental agencies. Persons who do not have a need to know should never be involved with personal information. As shown by the results of this survey, information given to the mass media and other unauthorized personnel should be limited to age, sex, and prefectural name.

Mail surveys that target the general citizenry have the drawback of a low recovery rate.¹²⁾ The recovery rate of the mail survey in this study was 15.7%. The target number of respondents for the Internet survey conducted for this study was 700 in three days, but we ended up receiving responses from over 1,000 subjects. In the present fact-finding survey, the contents of the mail survey and the Internet survey were the same. Regarding per-

sons who responded to the two surveys, a significant difference ($p < 0.05$) was seen between ages only in junior high school graduates. No statistical differences were found in the composition by age and sex for the remaining academic backgrounds, and no significant differences were admitted in the results obtained. This suggests that Internet surveys are useful as an alternative to mail surveys, which have heretofore been conducted. We demonstrated that Internet surveys, the results of which can be obtained within a short time, can be used in the future as an effective means of conducting questionnaire surveys of health crisis information targeting the general citizenry, compared with mail surveys, which take more time and effort and have a low response rate.

One limitation of this study was the fact that the number of subjects was a small. In particular, the number of responses to the mail survey was one-fourth that of the Internet survey. In order to demonstrate the effectiveness of Internet surveys, the number of responses to the mail survey needs to be increased in the future. We need to investigate to what extent personal information included in health crisis information obtained through collection of more reliable and accurate information can be fed back to the local populace for the sake of preventing the spread of damage while implementing countermeasures against a health crisis. The criteria or guidelines for handling disclosure of personal information therefore need to be studied in

the future. The need to protect personal information and the need to disclose personal information for crisis measures are often in conflict with each other. Further research is required to ascertain how to implement measures while balancing these two needs.

Conclusion

The disclosure of personal information of people who report information concerning a health crisis is a problem that should be handled delicately when formulating measures. It is important to protect personal information as best as possible while at the same time minimizing the health hazard. Judging from the results of the present study, the only personal information that can be disclosed is age, sex, and prefectural name. It was demonstrated that Internet surveys are an effective method available for surveys of health crisis information targeting the general citizenry.

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Survey to Gain an Understanding of Health Crisis Information

This survey is conducted under the assumption that an unknown infectious disease like the recent SARS has broken out.

Assume that a dangerous unknown infectious disease that is highly contagious and has a high mortality rate such as the recent SARS has occurred in Japan. Assume that the national government and local governments, etc., have asked people who may be infected to contact a public health center, etc., in order to prevent a massive spread of the disease and for treatment and countermeasures.

Please answer the questions beginning on the next page on the above-mentioned premise.

A. If there is a possibility that you are infected with an unknown infectious disease, would you report this to a governmental agency (city hall, public health center, etc.) ?

1. Yes 2. No

(1) This is for those who answered “No” to question A.

Circle the reasons why you would not contact a governmental agency (multiple answers allowed).

1. Because I don't want private information made public
2. Because it will inconvenience my family
3. Because it may affect my workplace
4. Because I don't want the neighbors to know
5. Because I don't want to have anything to do with a governmental agency
6. Because restrictions may be placed on my activities
7. Other ()

(2) This is for those who answered “Yes” to question A.

When you contact a governmental agency, how much personal information can you provide ?
Moreover, do you think that it would be all right for the information to be made public ?

	I would answer and I would not mind if the information was made public	I would answer, but I would not want the information made public	I would not answer
1. Name (example entry)		○	
1. Name			
2. Age			
3. Gender			
4. Occupation			
5. Workplace			
6. Address (only prefectural name)			
7. Address (prefectural and city name)			
8. Contact information (home phone number)			
9. Contact information (office phone number)			
10. Contact information (cell phone number)			
11. Contact information (e-mail address)			
12. Your activity history			
13. Names of persons with whom you have come into contact			

(3) Would you tell a third party other than a governmental agency that you may be infected with an infectious disease? Circle those that apply (multiple answers allowed).

1. Family 2. Hospital 3. Neighbors 4. Friends 5. Workplace
6. Mass media 7. I would tell nobody 8. Other ()

B. Would you cooperate if a personnel from a public health center, etc., came asking questions about the activities of infected persons in order to prevent the spread of infection?

1. I would cooperate if I knew any information
2. I would cooperate even if I did not know any information
3. I would not cooperate even if I knew some information
4. I would not cooperate if I did not know any information

(1) This is for those who answered 3 or 4 to question B.

Circle the reasons why you would not contact a governmental agency (multiple answers allowed)

1. Because I don't want to get involved
2. Because it's a bother
3. Because I don't like government offices
4. Because there is no money in it
5. Other ()

(2) This is for those who answered 1 or 2 to question B.

When you cooperate with the investigation, how much personal information can you provide? Moreover, do you think that it would be all right for the information to be made public?

	I would answer and I would not mind if the information was made public	I would answer, but I would not want the information made public	I would not answer
1. Name (example entry)		○	
1. Name			
2. Age			
3. Gender			
4. Occupation			
5. Workplace			
6. Address (only prefectural name)			
7. Address (prefectural and city name)			
8. Contact information (home phone number)			
9. Contact information (office phone number)			
10. Contact information (cell phone number)			
11. Contact information (e-mail address)			
12. Your activity history			
13. Names of persons with whom you have come into contact			

(3) Would you tell a third party any information that you received from a public health center? Circle those that apply. (multiple answers allowed)

1. Family 2. Hospital 3. Neighbors 4. Friends 5. Workplace
6. Mass media 7. I would tell nobody 8. Other ()

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