

# Internet health information use by surrogate decision makers of patients admitted to the intensive care unit: a multicentre survey

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Next of kin (NOK) of patients admitted to the intensive care unit (ICU) are frequently required to act as surrogate decision makers. However, substantial clinical and structural barriers have been identified that may impair high quality decision making, including insufficient information and communication skills of both clinicians and NOK, unavailability of key family members, time constraints, and clinician turnover.<sup>1</sup>

The internet is a common source of health information that may address some of these barriers. However, patients frequently choose not to discuss information found online with their health care providers, and the abundant, unregulated, heterogeneous quality of health-related websites may contribute to misinformation, confusion and information overload.<sup>2,3</sup>

In NOK of patients admitted to the ICU, the frequency of internet use to inform surrogate decision making is uncertain. Although existing studies suggest substantial internet use among NOK, contemporary evidence of the association with understanding, trust and influence among NOK and a quantitative assessment of the quality of websites visited are lacking.<sup>4,5</sup> The aim of our study was to investigate the use, understanding, trust and influence of the internet and other sources of health information used by NOK when acting as surrogate decision makers of patients admitted to the ICU and to describe the related range and quality of internet sites accessed.

## Methods

### Survey development

The structured, predominantly closed-question survey was designed by the study investigators in consultation with health care consumers and according to established principles.<sup>6</sup> The survey questions were grouped into three sections: demographics, sources of health information, and

## ABSTRACT

**Objectives:** To investigate the use, understanding, trust and influence of the internet and other sources of health information used by the next of kin (NOK) of patients admitted to the intensive care unit (ICU).

**Design:** Multicentre structured survey.

**Setting:** The ICUs of 13 public and private Australian hospitals.

**Participants:** NOK who self-identified as the primary surrogate decision maker for a patient admitted to the ICU.

**Main outcome measures:** The frequency, understanding, trust and influence of online sources of health information, and the quality of health websites visited using the Health on the Net Foundation Code of Conduct (HONcode) for medical and health websites.

**Results:** There were 473 survey responses. The median ICU admission days and number of ICU visits by the NOK at the time of completing the survey was 3 (IQR, 2–6 days) and 4 (IQR, 2–7), respectively. The most commonly reported sources of health information used very frequently were the ICU nurse (55.6%), ICU doctor (38.7%), family (23.3%), hospital doctor (21.4%), and the internet (11.3%).

Compared with the 243 NOK (51.6%) not using the internet, NOK using the internet were less likely to report complete understanding (odds ratio [OR], 0.57; 95% CI, 0.38–0.88), trust (OR, 0.34; 95% CI, 0.19–0.59), or influence (OR, 0.58; 95% CI, 0.38–0.88) associated with the ICU doctor. Overall, the quality of the 40 different reported websites accessed was moderately high.

**Conclusions:** A substantial proportion of ICU NOK report using the internet as a source of health information. Internet use is associated with lower reported understanding, trust and influence of the ICU doctor.

**Table 1. Characteristics of the cohort**

| Characteristic   | Study population<br>(n = 473) | Missing<br>responses<br>(%) |
|--|-------------------------------|-----------------------------|
| Public hospital  | 257 (54.3%)                   | 0%                          |
| Age (years), mean (SD)   | 51 ± 16                       | 2 (0.4%)                    |
| Sex (male)   | 144 (32.8%)                   | 2 (0.4%)                    |
| Relationship to patient*   |                               | 1 (0.2%)                    |
| Parent   | 165 (35.0%)                   |                             |
| Partner  | 167 (35.4%)                   |                             |
| Sibling  | 39 (8.2%)                     |                             |
| Child  | 53 (11.3%)                    |                             |
| Friend   | 23 (4.9%)                     |                             |
| Other  | 25 (5.2%)                     |                             |
| Highest level of education   |                               | 2 (0.4%)                    |
| Did not complete school  | 42 (8.9%)                     |                             |
| Completed school   | 214 (45.5%)                   |                             |
| Undergraduate degree   | 114 (24.3%)                   |                             |
| Postgraduate degree  | 101 (21.4%)                   |                             |
| Duration of ICU stay at time of completing survey (days), median (IQR) | 3 (2–6)                       | 2 (0.4%)                    |
| ICU visits at time of completing survey, median (IQR)                  | 4 (2–7)                       | 2 (0.4%)                    |
| Emergency admission  | 344 (72.9%)                   | 2 (0.4%)                    |
| Post-operative admission   | 234 (49.8%)                   | 4 (0.8%)                    |
| Cause of ICU admission†  |                               | 4 (0.8%)                    |
| Heart problem  | 121 (25.8%)                   |                             |
| Lung problem   | 63 (13.4%)                    |                             |
| Brain problem  | 55 (11.7%)                    |                             |
| Infectious disease problem   | 37 (7.9%)                     |                             |
| Injury or accident   | 36 (7.7%)                     |                             |
| Intestinal problem   | 35 (7.5%)                     |                             |
| Obstetric or gynaecological problem                                    | 34 (7.3%)                     |                             |
| Kidney problem   | 30 (6.4%)                     |                             |
| Cardiac arrest   | 17 (3.6%)                     |                             |
| Orthopaedic surgery  | 10 (2.1%)                     |                             |
| Liver problem  | 10 (2.1%)                     |                             |
| Poisoning  | 5 (1.1%)                      |                             |
| Other  | 17 (3.6%)                     |                             |

ICU = intensive care unit; IQR = interquartile range; SD = standard deviation. \* The listed relationship is that of the patient in relation to the respondent. † Cause of ICU admission as reported by survey respondent.

specific websites visited. A comprehensive list of health information sources was developed from the existing literature, and survey responses were categorised on a five-point Likert scale according to how frequently they were accessed (“very frequent”, “frequent”, “sometimes”, “occasionally”, “never”). The ten sources of health information were the ICU doctor, the ICU nurse, the hospital doctor, the general practitioner, the family, the internet, other people in the waiting room, books and newspapers, television, and other sources. For each source used, respondents were asked to rate their understanding, trust and influence of the source. A draft version of the survey underwent minor amendment after pilot testing by ICU clinicians and NOK for face validity, content validity, structure, and completion time. In order to reduce anchoring bias, eight versions of the survey were produced. These versions contained identical questions, but the order of the sources of health information varied randomly. The quality of health websites visited was evaluated using the eight domains of the Health on the Net Foundation Code of Conduct (HONcode) for medical and health websites ([www.hon.ch](http://www.hon.ch)), with a higher score indicating a higher quality site. The survey tools are provided in the online Appendix (eFigures 1 and 2) ([available at cicm.org.au/Resources/Publications/Journal](http://cicm.org.au/Resources/Publications/Journal)).

**Participants**

NOK of patients admitted to the ICU of study sites were eligible to participate if they identified themselves as the primary surrogate decision maker for a patient currently admitted to the ICU for a period of more than one day. NOK were excluded from participation if they were aware that the survey had previously been completed by another surrogate decision maker of the same patient. As an approximation of the total number of potential survey respondents, each site was asked to provide the number of ICU patients with an ICU length of stay of more than 2 days during the study period.

### Survey administration

Study sites were supplied with electronic blank copies of all versions of the survey and asked to print out equal numbers of each version. Paper copies of blank surveys were made available in the ICU waiting room of participating sites along with a poster explaining the study. At some study sites, blank surveys were made available at the bedside of eligible participants. A box to return completed surveys was provided. Data were stored on a central spreadsheet, transcribed from hard copies of the returned surveys. The St John of God Health Care Human Research Ethics Committee provided approval for the study before initiation (ethics approval No. 1175). Completing and returning the survey was considered as indicative of consent to participate.

### Statistical analysis

Categorical data were reported as count and percentage, continuous data as mean and standard deviation (SD) or median and interquartile range (IQR), as appropriate. Univariate analysis was undertaken to assess the variables associated with internet use and the association of internet use with the frequency, understanding, trust, and influence of the ICU doctors and nurses. Multivariable logistic regression was undertaken to investigate the independent predictors of high or very high internet use, with stepwise removal of non-predictive variables. A  $P < 0.05$  was considered significant. To increase the generalisability of our findings, we aimed to include sites from public and private hospitals, a range of jurisdictions and ICU sizes, and permitted a maximum of 50 responses from each participating site. Analyses were carried out using Stata SE version 13 (StataCorp).

### Results

Between December 2017 and December 2018, 476 survey responses were received from 13 study sites, of which 473 included sufficient data for analysis. The survey sample represents 6.1% of the 7722 total patients with an ICU length of stay of more than 2 days over the study period at each site. The fewest surveys returned by a site were 12, and seven sites (53.8%) returned the study target of 50 surveys.

### Characteristics of the cohort

The relationship of the patient to the NOK was most commonly partner (35.4%) or parent (35.0%). The median ICU admission days and number of ICU visits by the NOK at the time of completing the survey was 3 (IQR, 2–6 days) and 4 (IQR, 2–7), respectively. The characteristics of the survey cohort are provided in Table 1.

### Frequency, understanding, trust and influence of using health information sources

NOK used a median of 3 (IQR, 2–4) sources frequently or very frequently. The most commonly reported source used very frequently for health information was the ICU nurse (55.6%), followed by the ICU doctor (38.7%), the family (23.3%), the hospital doctor (21.4%) and the internet (11.3%), (Table 2). The majority of NOK reported that all sources of health information used were understood easily or with little difficulty (online Appendix, eTable 1). The sources most frequently completely or mostly trusted were the ICU doctor (98.3%), the ICU nurse (98.2%), the hospital doctor (92.7%) and the GP (86.3%) (online Appendix, eTable 2). The internet was completely or mostly trusted by 37% of NOK. The influence of each source is described in the online Appendix (eTable 3).

### Internet use

Using the internet for health information was reported by 230 NOK (48.5%). Univariate analyses of factors predicting frequent or very frequent internet use are provided in the online Appendix (eTable 4). On multivariable analysis, factors independently associated with frequent or very frequent internet use were age (odds ratio [OR], 0.97; 95% CI, 0.95–0.98;  $P < 0.001$ ) and the number of other sources of health information used frequently or very frequently (OR, 1.21; 95% CI, 1.01–1.46;  $P = 0.37$ ). Compared with those aged 50 years or older, younger respondents had significantly higher odds of reporting frequent or very frequent internet use (OR, 2.7; 95% CI, 1.7–4.4;  $P < 0.001$ ).

Compared with NOK not using the internet, those using the internet reported a significantly higher frequency of using the ICU doctor as a source of health information. NOK using the internet had significantly lower understanding of, trust in, and were less influenced by the ICU doctor (Table 3).

Specific websites visited were recorded by 121 NOK (25.6%). The inter-rater reliability of the HONcode domains, assessed independently by two investigators, was high ( $\kappa = 0.93$ ;  $P < 0.001$ ). Overall, the quality of the 40 different reported websites accessed was moderately high, with 25 (62.5%) scoring 8/8 on the HONcode domains (median score, 8; IQR, 6–8) (online Appendix, eTable 5).

### Discussion

In our survey of 473 ICU NOK identifying as surrogate decision makers, we found that the internet was the fourth most common source of health information, used by nearly half of all respondents. Internet use was more common in younger NOK and those who used multiple

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**Table 2. Frequency of use of sources of health information**

| Source                 | Very frequent | Frequent    | Sometimes  | Infrequent | Never       | Missing* responses |
|------------------------|---------------|-------------|------------|------------|-------------|--------------------|
| ICU nurse              | 263 (55.6%)   | 138 (29.2%) | 34 (7.2%)  | 14 (3.0%)  | 24 (5.1%)   | 0                  |
| ICU doctor             | 183 (38.7%)   | 167 (35.3%) | 61 (12.9%) | 12 (2.5%)  | 50 (10.6%)  | 0                  |
| Family                 | 110 (23.3%)   | 69 (14.6%)  | 94 (19.9%) | 51 (10.8%) | 149 (31.5%) | 0                  |
| Hospital doctor        | 101 (21.4%)   | 109 (23.0%) | 89 (18.9%) | 33 (7.0%)  | 140 (29.7%) | 0                  |
| Internet               | 53 (11.3%)    | 37 (7.9%)   | 85 (18.1%) | 53 (11.3%) | 243 (51.6%) | 2                  |
| General practitioner   | 36 (7.6%)     | 31 (6.6%)   | 52 (11.0%) | 38 (8.1%)  | 314 (66.7%) | 2                  |
| Others in waiting room | 11 (2.3%)     | 13 (2.8%)   | 30 (6.4%)  | 31 (6.6%)  | 386 (82.0%) | 2                  |
| Books and newspapers   | 6 (1.3%)      | 11 (2.3%)   | 17 (3.6%)  | 28 (5.9%)  | 409 (86.8%) | 2                  |
| Television             | 5 (1.1%)      | 2 (0.4%)    | 12 (2.6%)  | 27 (5.7%)  | 425 (90.2%) | 2                  |
| Other                  | 5 (1.1%)      | 4 (0.9%)    | 5 (1.1%)   | 1 (0.2%)   | 457 (96.8%) | 1                  |

ICU = intensive care unit. \* Total of 473 survey responses.

**Table 3. Internet use and the associated frequency, understanding, trust and influence of intensive care unit (ICU) clinicians**

|                       | Internet use<br>(n = 228) | No internet use<br>(n = 243) | Odds ratio<br>(95% CI) | P       |
|-----------------------|---------------------------|------------------------------|------------------------|---------|
| ICU doctor            |                           |                              |                        |         |
| Very frequent         | 103/228 (45.2%)           | 79/243 (32.5%)               | 1.71 (1.18–2.49)       | 0.005   |
| Completely understand | 134/209 (64.1%)           | 159/210 (75.7%)              | 0.57 (0.38–0.88)       | 0.01    |
| Completely trust      | 159/210 (75.7%)           | 185/205 (90.2%)              | 0.34 (0.19–0.59)       | < 0.001 |
| Completely influenced | 129/208 (62.0%)           | 154/209 (73.7%)              | 0.58 (0.34–0.88)       | 0.011   |
| ICU nurse             |                           |                              |                        |         |
| Very frequent         | 129/228 (56.6%)           | 133/243 (54.7%)              | 1.08 (0.75–1.55)       | 0.687   |
| Completely understand | 169/222 (76.1%)           | 174/224 (77.7%)              | 0.92 (0.59–1.42)       | 0.697   |
| Completely trust      | 160/220 (72.7%)           | 186/222 (83.8%)              | 0.52 (0.32–0.82)       | 0.005   |
| Completely influenced | 128/219 (58.4%)           | 153/224 (68.3%)              | 0.65 (0.44–0.96)       | 0.032   |

other sources. The ICU doctor and nurse were the most frequently used source of information and had the highest levels of associated trust and influence. Compared with those who did not use the internet, NOK who used the internet reported significantly higher frequency of obtaining information from the ICU doctor, but reported significantly lower understanding, trust and influence associated with health information received from the ICU doctor.

Our finding that internet use by ICU NOK was moderately high across a range of Australian hospitals and ICU admission diagnoses is consistent with a 2017 study conducted in France, in which 55% of NOK of patients with sepsis admitted to the ICU accessed the internet.<sup>4</sup> Similarly, other studies have also demonstrated an association between

more frequent internet use in younger people and lack of association with education level, perhaps reflecting cultural changes and increasing democratisation of internet access over time.<sup>3,4</sup>

In our study, NOK who used the internet reported significantly lower trust in and influence by ICU clinicians than NOK who did not use the internet. It is possible that this relationship is causal and that internet searching yields information that decreases trust and influence associated with ICU clinicians. However, the quality of websites accessed and the reported understanding of internet sites were generally high. Alternatively, there may be a reverse or bidirectional relationship, an explanation that is consistent with the findings of AlGamdi and Moussa,<sup>7</sup> who reported that insufficient information and lower trust

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in physicians may prompt increased internet searching. Trust could also be influenced by the diagnosis and prognosis of the ICU clinicians, with worse prognosis leading to lower trust and more internet searching.

Conflict has been cited as a major stressor for both NOK and ICU clinicians, and NOK of ICU patients frequently report high levels of anxiety.<sup>8,9</sup> Recent evidence suggests that, for patients, seeking additional health information online could improve the patient–physician relationship and may reduce anxiety.<sup>10,11</sup> Importantly, most NOK may not discuss information sourced online with clinicians and this may negate any beneficial effects of using the internet.<sup>2,10</sup> In our study, the internet was the most frequently used information source after clinicians and family. These findings suggest that it may be important to be proactive in providing opportunities for ICU NOK to discuss information sourced online with clinicians. Although specific online resources for ICU NOK exist internationally, Australian resources are limited.<sup>12</sup> Further research should investigate whether educating ICU NOK on how to evaluate the quality of health-related websites and providing specific online resources can help improve surrogate decision making and the quality of the clinician–NOK relationship.

Most of the websites reported by NOK in our study were assessed as high quality using HONcode. Although, health and technology literacy was not assessed directly, internet understanding was reported as high and was not associated with education level. The most common internet site used was Google. In 2017, Google introduced a new feature termed “Google Health Cards”, an information panel generated on the right-hand side of the search screen designed to improve the quality of health information available and provide relevant medical facts and links to further information, based on a user’s search terms. While Google Health Cards rate highly on HONcode, such rating systems have been questioned<sup>13</sup> and the impact of Google Health Cards on the quality of health information accessed and subsequent health information-seeking behaviour by ICU NOK is uncertain.

Our study has several limitations. Our response rate is low, reflective in part of the methodology we chose of passive survey access in the ICU waiting room. The survey was only available to NOK who used the waiting room and our findings may be systematically different to non-responders. As the survey was only available in English, language barriers may have precluded a proportionate representation from non-English speakers. Cultural background was not collected. Respondents were self-selected and it is possible that multiple responses were completed for a single patient. No attempts to access social media sites were reported, but this was not explicitly questioned. This source of health information may raise specific ethical and legal issues that

may benefit from further investigation.<sup>14</sup> Lack of individual patient data precluded analysis of additional factors, such as prognosis, that may affect the association between internet use and understanding, trust and influence. Finally, we hoped to report the quality of other websites visited on the basis of search terms provided by respondents. However, commonly used search engines personalise search results based on geography and the user’s search and browsing history — the so-called “filter bubble”.<sup>15</sup> As a result, there was no reliable method to determine the top hits for a specific respondent and these results are not presented.

### Conclusion

Health care staff are highly trusted and the most frequently used source for information by ICU NOK. However, a substantial proportion of ICU NOK report using the internet as a source of health information, and internet use is associated with lower reported understanding, trust and influence of the ICU doctor.

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### Competing interests

None declared.

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