

# Improving on-line information for potential living kidney donors

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Individuals who consider becoming living kidney donors often search the internet for reliable information before contacting the transplant center. The quality of such information requires due consideration. Using the search engines Google and Yahoo and the WebMD information portal, two reviewers independently abstracted data on the classification, readability, and general quality of websites. The coverage and accuracy of each site's discussion of the risks, benefits, and process of living donation was also assessed against a checklist of recommended information. Eighty-six unique websites on living kidney donation were found. Most were created by transplant programs and transplant organizations. Although the content of most sites was accurate, almost all (98%) were written above the recommended patient reading level (i.e., fifth grade). On average, each site covered 38% of the recommended information on living donation (range 8–76%). Educational topics of potential long-term medical risks, psychological risks, and expected benefits to the donor were often missing. The most visited websites were often not ranked among the best sites to provide information. By better understanding the nature of on-line information, transplant professionals can direct their patients to the best available websites. Local educational efforts, including the effective use of internet resources, will ensure living donation and complete understanding of the risks by potential donors and recipients.

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With growing transplant lists and a relative shortage of available organs from deceased donors, health-care practitioners continue to encourage the practice of living kidney donation. Living donor transplantation has a shorter waiting time and better graft and recipient survival compared with deceased donor transplantation.<sup>1–3</sup>

As many recipients are afraid to ask family or friends to donate because of concerns about pressuring or harming the health of a loved one,<sup>4,5</sup> potential donors often initiate the discussion with the potential recipient.<sup>5,6</sup> Before this discussion, many potential donors may seek out information from the internet or other educational sources to address their concerns about the procedure, including the risks of donation on future health, occupation, and lifestyle.<sup>7</sup> The internet also provides the opportunity for prospective donors to speak to actual living donors by listserve or email. The act of contacting the transplant center for assessment is usually an indication that the potential donor has already resolved their main concerns with the donation process and is ready to proceed.<sup>8</sup>

In general, approximately 5% of internet users, or six million people, go online for health information every day.<sup>9</sup> Unfortunately, despite efforts toward standardization,<sup>10</sup> health information on the Web remains highly unregulated and varies in its quality, accuracy, and readability.<sup>11</sup> As patients also vary in their access and use of the internet as a vehicle for education; frequent users are more likely to be Caucasian and highly educated.<sup>12</sup> For patients with renal disease, about 22% of transplant-eligible dialysis patients reported having access to and using the internet to learn about living and deceased donation.<sup>13</sup> Some analyses of the quality of chronic kidney disease websites have also occurred.<sup>14</sup> Yet, little is known about the quality of internet information on living kidney donation. Thus, we evaluated the quality of websites discussing living donation, identified sites which provided the most comprehensive, accurate and readable information for prospective donors, and described site characteristics which were associated with better information.

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## RESULTS

### Finding websites

The three keyword searches resulted in 6 370 000 hits using Google, 2 226 000 using Yahoo, and 694 100 using WebMD. Of these, the first available 450 English websites were retrieved (i.e., the first 50 from each search), with 55% of the initial websites found to be duplicates, indicating that the search strategies successfully identified the most commonly visited websites. After removing duplicates and excluding ineligible websites (Figure 1), 86 websites were reviewed. These 86 unique sites, ranked by their link popularity, are listed in Table 1.

### Classification of websites

Of the 86 websites, 46% ( $n=40$ ) were affiliated with university or hospital transplant programs, 28% ( $n=24$ ) with provincial/state, national or international transplant organizations, 4% ( $n=3$ ) with government organizations, and none with commercial companies. Six percent ( $n=5$ ) were news articles, 5% ( $n=4$ ) were journal articles, 2% ( $n=2$ ) were personal webpages, and 9% ( $n=8$ ) did not fall under any of these categories.

### Website characteristics

Despite the dynamic nature of information about living donation and health information in general, only 35 sites (41%) provided a date of last revision. Over half of the sites (67%) provided a privacy policy detailing the information, if any, collected by the site and the ability of the site owner to

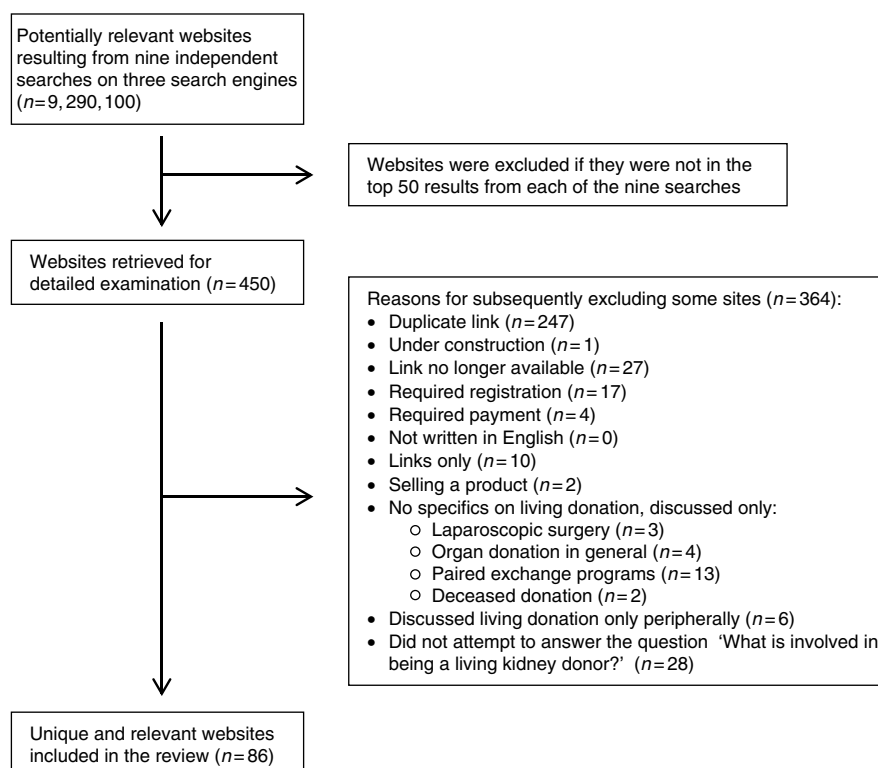
track user access. Most often no personal information was collected from these sites. Access to a message board was available to users at nine sites (11%) and 14% of websites displayed the Health on the Net (HON) seal of approval. Most sites contained disclaimers stating that the information presented by the website was in no way a supplement for physician's opinion. Few sites provided a list of questions for patients to ask their family doctor or transplant team.

### Readability

Based on the Flesch–Kincaid grade level scores, almost all sites (98%) were written above the recommended reading level (i.e. fifth grade) for public comprehension, with 76% written above the tenth grade level. Only three websites contained content written below the sixth grade level. On a scale from 0 (practically unreadable) to 100 (easy for any literate person), results of the Flesch Reading Ease scores ranged from 14 to 72, with only 29% of websites having a Flesch Reading Ease score above 50. The reading level of written information on most of the websites did not differ by website affiliation.

### Quality of websites

The general quality of living donor information provided by websites was moderate; with an overall mean DISCERN score for all sites approximating 3 out of a possible 5. The quality scores of individual websites varied widely, ranging from 1.7 to 4.6. The DISCERN score for each of the 86 websites is presented in Table 1.



**Figure 1 | Selection of websites.**

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