5
Using the Internet for Surveys and Research

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Introduction

This chapter gives an overview of the use of the Internet in the research process, with emphasis on using the Internet as a source for qualitative research and on using the Web for surveys. The Internet obviously also plays a role in literature research, finding methods, protocols and instruments, communicating with peers, and dissemination of results (i.e., electronic publishing). These topics are beyond the scope of this chapter.

Qualitative Research

The Internet is the most comprehensive archive of written material representing our world and peoples' opinions, concerns, and desires, at least those of the industrialized world. Physicians who surf the Internet for the first time are often stunned by what they learn on websites of patient self-support groups. This illustrates that material published on the Internet may be a valuable resource for researchers desiring to understand people and the social and cultural contexts within which they live, giving due emphasis to the meanings, experiences, and views of people.

With its myriad websites, blogs, chats, mailing lists, and discussion boards, the Internet is a rich source for qualitative research (e.g., identifying research issues, generating hypotheses, or for *needs assessment*). Systematic reviews (content analysis) of information posted by consumers and/or health professionals on the Internet may help to identify health beliefs, common topics, motives, information, and emotional needs of patients and healthcare professionals, and point to areas where research is needed or where information systems can fill an information gap. Log-files of search terms used by consumers or health professionals [1] or questions asked in private e-mail conversations (e.g., between patients and providers) are another potential data source for an information system needs analysis.

In the context of iteratively developing a healthcare information system, developers may integrate discussion boards in the system for users to discuss the system and make suggestions for improvements. Qualitative analysis user postings may be a component of the *formative or summative evaluation* process, and may elicit richer data than (quantitative) surveys.

The ease with which information is accessible for analysis and the anonymity of the Web allows researchers to analyze text and narratives on websites, use newsgroups as global focus groups, and conduct interviews and surveys using e-mail, in chat rooms, on websites, and in newsgroups. Evolving branches of qualitative research include the analysis of interactive communication on the Internet (e-mail), studying Internet communities (virtual self-help groups, newsgroups, mailing lists), investigating communication processes between patients and professionals, reviewing the World Wide Web (www) to study consumer preferences, patient concerns, and information needs, and exploring the "epidemiology of health information" ("infodemiology") on the Web [2–4].

As will be expanded below, the Web population is certainly not representative of the general population, restricting its use for quantitative studies. Qualitative studies, on the other hand, do not necessarily require representative samples, since

> in qualitative research we are not interested in an average view of a patient population, but want to gain an in-depth understanding of the experience of particular individuals or groups; we should therefore deliberately seek out individuals or groups who fit the bill. [5]

Still, even in qualitative studies, one should not forget that the experiences, views, and opinions gathered through the Internet may differ systematically from those of the general population, so that these methods are often ideally complemented by doing face-to-face focus groups and interviews with traditional sampling methods. Although some studies have suggested that there are no systematic differences (i.e., the themes emerging from an online focus group are the same as the themes emerging from an offline focus group [6]), this certainly depends on the research question. For example, a study on access barriers to an information system may elicit totally new themes in an offline group because the online group is too self-selected.

Broadly, three different research methodologies for qualitative research on the Web may be distinguished:

1. *Passive analysis*, for example, studying information patterns on websites or narratives and/or interactions in newsgroups, mailing lists, chat rooms, without researchers actively involving themselves.
2. *Active analysis* (can also be called participant observation), meaning that the researchers participate in the communication process, often without disclosing their identity as researchers.
3. *Interviews and surveys*—see below.

These methods have different ethical implications [2], as will be expanded in the following section.

Some examples of (mostly qualitative) research on the Internet are given in Table 5.1.

Ethical Issues

The ethical issues involved in online research (passive analysis, active analysis, and survey research) should not be ignored [2,31–36]. These include informed consent as a basic ethical tenet of scientific research on human populations [37], protection of privacy, and avoiding psychological harm (e.g., by intruding in virtual communities).

In qualitative research on the Web, informed consent is required (1) when data are collected from research participants through any form of communication, interaction, or intervention; or (2) when behavior of research participants occurs in a private context where an individual can reasonably expect that no observation or reporting is taking place. Informed consent is not required

> when researchers do research in public places or use publicly available information about individuals (e.g., naturalistic observations in public places, analysis of public records, or archival research). [38]

The question therefore arises whether researchers "passively" analyzing newsgroup postings enter a "public place" (in which case obtaining informed consent would not be necessary) or whether the space they invade is perceived as private (in which case obtaining informed consent is necessary). In the context of research, the expectation of the individual (whether he or she can reasonably expect that no observation is taking place) is crucial. Different Internet venues have different levels of perceived privacy (in decreasing order of privacy: private e-mails → chat rooms → mailing lists → Usenet newsgroups → websites). The perceived level of privacy is a function of the number of participants, but also depends on other arrangements such as the group norms established by the community to be studied. For example, in the controversial study of Finn, the authors studied a virtual self-support group where the moderator was actively discouraging interested professionals who were not sexual abuse survivors from joining the group, which should have deterred researchers from joining the group for research purposes [17].

While the group moderator can and should be consulted for any research with a specific virtual community, the consent of the moderator is rarely sufficient and cannot replace informed consent from the subjects studied. Therefore, in practice, obtaining informed consent, especially for passive research methods, is difficult, as researchers usually cannot post an announcement to a mailing list or newsgroup saying that it will be monitored and analyzed for the next few months, as this may greatly bias the

Table 5.1. Framework for and examples of research on the Internet.

	Passive analysis (naturalistic observation)	Active analysis (observation as active participant)	Interviews and surveys
Objectives examples	Identifying research priorities; needs assessments; studying narratives; identifying and studying the "epidemiology" of health beliefs, topics, motives, information and emotional needs etc.; studying gaps between evidence and peoples' experiences	Studying communication processes, e.g., patient–professional interaction, communication processes in virtual self-help groups	Identifying concerns, opinions; generating hypotheses; formative evaluation
Example method	Content analysis of Internet information	Action research; participant observation; ethnography (e.g., participating in a mailing list and studying reactions)	Web-based questionnaires, e-mail questionnaires
IRB/ethical committee approval	Not always necessary, but may be advisable if reporting involves vulnerable online communities	Usually necessary	Usually necessary
Examples of studies on websites	Reviews of Internet information [7]; ethnography on websites [8]; observing usage patterns (log-file analysis) [9]; analyzing search terms.	n/a	Web-based forms: gathering clinical epidemiological data [10]; survey among peers [11]; health status assessment [12]; quality of life research [13]
Examples of studies on newsgroups/ mailing lists	Analyzing messages on newsgroups [14–17] or mailing lists [18,19]	Asking questions on a newsgroup and analyzing feedback [20,21]	Posting questionnaires on a newsgroup [22]
Examples of studies on chat rooms	Using case stories from a chat room and other venues [23]	No study published yet	Online focus groups [6]
Examples of studies on e-mail interaction	Analyzing unsolicited e-mails to identify motives and information needs [24] or improving information systems [25]	Posing as a patient and sending a fictitious case to physicians [21,26–29]	E-mail surveys [30]

results. Subjects who know that they are being monitored may behave differently than under normal circumstances (*Hawthorne effect*). Apart from this threat to validity of the research, postings of researchers may in extreme cases disrupt or even destroy a virtual community.

A much better alternative would be to analyze the communication retrospectively and write individual e-mails to all participants whose comments are to be analyzed or quoted, asking for permission to use them; this technique has been used, for example, by Sharf [39].

Informed consent may also play a role when researchers report aggregate data on usage patterns, such as a log-file analysis (reporting data on what websites have been accessed by a population). Crucial here seems to be an appropriate privacy statement to be brought to the awareness of all users, saying that these data may be analyzed and reported in aggregate [33]. For survey research, researchers may obtain informed consent by declaring the purpose of the study, disclosing which institutions are behind the study, and explaining how privacy will be assured, with whom data will be shared, and how data will be reported before participants complete the questionnaire.

When reporting results, it is obvious that the total anonymity of research participants needs to be maintained. Researchers must keep in mind that, by the very process of quoting the exact words of a newsgroup participant, the confidentiality of the participant may already be broken. This is because powerful search engines such as AltaVista or DejaNews can retrieve the original message, including the e-mail address of the sender if a direct quote is entered into the query. Therefore, it is essential to ask newsgroup participants whether they agree to be quoted, pointing out the risk that they may be identifiable.

Problems can also potentially arise from just citing the name of the community (e.g., of a newsgroup), which may damage the community studied. For example, King [35] quotes the complaint of a group participant that he feels uncomfortable being observed and retreats from a group with the remark that "When I joined this, I thought it would be a support group, not a fishbowl for a bunch of guinea pigs. I certainly don't feel at this point that it is a safe environment, as a support group is supposed to be, and I will not open myself up to be dissected by students or scientists."

Internet Surveys

Taxonomy of Internet Surveys

Interviews versus Questionnaires

In general, surveys may be conducted by means of interactive (one-to-one, in the case of individual interviews, or one-to-many, in the case of focus groups) interviews or by questionnaires designed for self-completion. Both

methods can be used on the Internet: electronic interviews can be conducted via e-mail or in chat-rooms [6]; survey questionnaires can be administered either by e-mail (e.g., using mailing lists), posted in newsgroups or discussion forums, or on the Web using HTML forms.

Email versus Web Questionnaires

Surveys distributed by e-mail or posted in discussion forums are usually simple plain text (ASCII) versions and usually instruct participants to e-mail the completed questionnaire back to the researcher, who then needs to enter the responses into a database. In contrast, Web-based surveys allow for survey elements such as radio buttons, checkboxes, drop-down lists, and text fields, and store the responses directly in a database, where they are immediately accessible for real-time analysis.

Web-based surveys have the advantage (or disadvantage, depending on the context and objective) that the respondent can stay anonymous (as opposed to e-mail-based surveys, where the e-mail address of the responder is revealed).

If e-mails are used to administer (and reply to) questionnaires, they are usually sent to a selected group with a known number of participants, so that the response rate can be calculated. Server-side software used to administer mailing lists (e.g., listserv or majordomo) often have commands that allow users of mailing lists to view the list of subscribers or at least determine their number (e.g., WHO for majordomo), so that the researcher can determine the denominator when sending an e-mail to a mailing list. However, the list owner can also disable this command, meaning that the number of subscribers of a mailing list may also be unknown.

Surveys posted on a discussion forum such as a Usenet newsgroup are even more problematic since it is usually impossible to determine who and how many people read the questionnaire. Thus, a response rate (which serves as indicator of how representative the responses are) cannot be calculated. In the continuum between highly controlled survey administration for rigorous research on one hand and uncontrolled surveys for explorative purposes, this method is more on the right hand of this spectrum (see Figure 5.1). However, there are "tricks" allowing the researcher to determine how many people have read a posting on a Web-based forum. If the forum allows HTML postings, the researcher can include an IMG-tag in the body of the message that loads a 1×1 pixel invisible image from a remote server, to which the researcher has access. A simple log-file analysis may then determine how often the image has been served, as an approximation for how often the message has been opened.

Invitation-Only versus Open Web Surveys

If HTML forms are used, they can be either "invitation-only surveys" or "open surveys." In invitation-only surveys, researchers usually publish the survey on a password-protected area of a website and invite only a defined

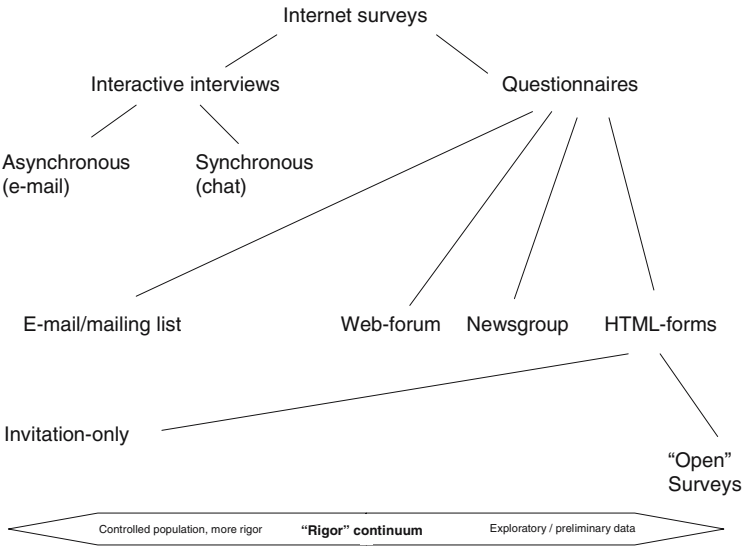

Figure 5.1. Taxonomy of Internet surveys.

group of people to participate, for example, by sending the invitation to participate with a password to a select group. In "open (public) surveys," a survey is simply published on a website and is open to the public (e.g., anybody who visits the site can fill in the survey). These two methods are fundamentally different, and the latter ("open" survey) is often regarded as an "unscientific" poll, because the sample usually will be highly self-selected, the response rate is often unknown, and it is not clear who filled in the questionnaire. On the other hand, open surveys may also generate interesting data (even if they are not necessarily generalizable), in particular if qualitative analysis and/or hypothesis generation is the aim, or if the objective is to study trends over time. Also, as outlined below, while more difficult, it is not impossible to calculate response rates for open surveys (if cookies are used), and multiple completions by the same individual usually can be detected using log-files and cookies.

Survey Tools

A number of commercial "survey construction kits" exist, for example, www.surveywriter.com, SurveyShare.com, www.websurveyor.com, www.quask.com, or www.researchexec.com, to name a few. These products allow researchers to set up a Web questionnaire within minutes. Often, however, these "turnkey" solutions have some limitations in respect to the more sophisticated features such as setting cookies to prevent or identify multiple entries from the same person, or creating more complex multipage surveys with multiple branching options.

Internet Surveys in Health Research

Communication scientists, sociologists, and psychologists were among the first to use the Internet for survey research, while its use for *health* research is still emerging [40–46]. Soetikno [13] used the Internet for quality-of-life research. Eysenbach [10] reported the collection of clinical data from atopy patients. Bethell and collegues explored the use of online consumer surveys as a methodology for assessing the quality of the U.S. healthcare system [47]. Hilsden et al. report a Web-based survey among 263 patients with inflammatory bowel disease [48], Potts and Wyatt surveyed general practitioners on the Web [49], and Schleyer used the Web to conduct a survey among 314 dentists [11,50]. A recent systematic review identified 17 Internet-based surveys of health professionals [51].

In addition to gathering data, the Internet may also be used in the course of developing the questionnaire itself, as it allows rapid prototyping and iterative testing of instruments, for example, to quickly evaluate the effect of framing the questions differently [52].

Several studies have checked the validity of Web-based surveys by comparing the results of studies conducted on the Web with identical studies in the real world. Some seem to suggest that data obtained through the Web are comparable to classical methods [6,40,41,53–55], but issues of limited external validity (questionable generalizability mainly due to selection bias, discussed in detail below) remain important concerns [56], and the researcher should carefully select his or her research question and interpret the results within the limits of the methodology. The benefits and problems of Web-based surveys and some draft guidelines for when they may be appropriate have been summarized by Wyatt [57].

Selection Bias

Selection bias is a systematic error in a research project that occurs because of the nonrepresentative way participants were selected or assigned. Selection bias is a major factor limiting the generalizability ("external validity") of results of Internet surveys. Selection bias in Internet surveys occurs for two reasons: (1) due to the nonrepresentativeness of the Internet population and (2) due to the self-selection of participants (i.e., nonrepresentativeness of respondents, also called the *volunteer effect*) [58].

Selection Bias Due to Internet Demography

While it has been argued that the Internet community is "becoming more representative of society as a whole" [59], in reality the Internet community is far from representative of the world's population, or even the population in any given country, and it is unlikely that this fact is going to change in the near future. Household or individual income are important determinants of the presence of personal computers and the extent of Inter-

net access in homes [60]. In higher-income groups, costs of computer equipment and Internet access are less of a barrier than for low-income groups. High income is also associated with better education, which leads to early uptake of information technology. Thus, it is the socially disadvantaged groups who are likely to be underrepresented on the Web. There is also a gender inequality on the Web, with men being overrepresented, but with women being more interested in health issues and generally more likely to complete online surveys.

Another factor to be taken into account is the age distribution—the population above the age of 50 is, while catching up, still underrepresented on the Web.

Considering whether the topic chosen for the survey is suitable for the Internet population is a first and probably the most important step to minimize bias and to increase external validity of the results, but also to make the survey a success in terms of response rates [57]. For example, an online survey targeting elderly homeless alcoholics is unsuitable for an Internet survey and the results are likely to be heavily skewed by hoax responses.

If the demographics of survey respondents are known, results can be weighted and adjusted to extrapolate how the results would look if a representative sample had completed the questionnaire, although whether these methods are sufficient and lead to meaningful data is controversial [56].

Self-Selection Bias

Self-selection bias ("volunteer effect") comes from the fact that people are more likely to respond to questionnaires if they see items that interest them, for example, because they are affected by the items asked or because they are attracted by the incentives offered for participating. As people who respond almost certainly have different characteristics than those who do not, the results are likely to be biased. This kind of selection bias is more serious than the bias arising from the nonrepresentativeness of the population, because the researcher deals with myriad unknown factors and has few chances to adjust his or her results. Such a bias may be exacerbated by providing nonneutral incentives (e.g., typical "male" incentives such as computer equipment as the prize for a lottery). As women are generally more interested in health topics and display more active information-seeking behavior [61], health questionnaires are often more likely to be filled in by females, which may lead to a different self-selection bias effect for men and women.

Response Rate

In surveys, the potential for self-selection bias can be estimated by measuring the response rate, expressed as the number of people who answered

the questionnaire divided by those who have viewed the questionnaire (not to be confused with the participation rate, which can be expressed as the number of website visitors who clicked on the link to the questionnaire divided by the total number of website visitors). A simple way to determine the response rate is to divide the number of unique responses to the questionnaire by the number of accesses to the questionnaire page, counted, for example, by a log-file analysis or with cookies (see below).

A recent systematic review identified 17 Internet-based surveys of health professionals [51] with response rates ranging from 9% to 94%. Sending follow-up reminders resulted in a substantial increase in response rates.

Response rates for online surveys are typically much lower than for traditional surveys. "Open" surveys (i.e., questionnaires on websites offered to anyone) often have a response rate of less than 1%. If the response rates are so low, how can external validity be ascertained? Response *representativeness* is more important than response rate, and if the response rate or participation rate is extremely low, attempts to confirm response representativeness should be undertaken, for example, by

- Comparing the demographics of responders to demographics of nonresponders (if known); if the sample is representative, the likelihood for representative responses increases.
- Comparing the answers/survey results of responders to those of nonresponders (e.g., nonresponders could be called if their telephone numbers are known).
- Inserting questions into the questionnaire that allow comparison with historical data (or data obtained from offline surveys) so that these results can be compared.

Further Techniques and Tips for Web-Based Surveys

Maximizing Response Rate

The number of contacts, personalized contacts, and precontacts (contacting the participants before the actual survey) are the factors most associated with higher response rates in Web surveys [62]. Offering incentives, such as presents or entering participants into a lottery, increases participation rates but also the danger of introducing selection bias. This is less of a problem with monetary incentives. However, perhaps the best incentives (and the easiest to deliver via the Internet) are to promise the survey results (either after human analysis or an ad hoc real-time analysis of the database), or to give some personalized answer (e.g., a score) to the respondent.

People are increasingly hesitant to fill in online questionnaires and are wary about market research or even bogus surveys that are just designed to collect their e-mail addresses and personal interests. Thus, one should clearly disclose who is behind the study and a university or research insti-

tute logo may help to distinguish the survey from market research or dubious advertisements coming in the disguise of a survey.

For certain "sensitive" topics (e.g., AIDS), respondents should have the option of filling in the questionnaire anonymously. However, anonymity also increases the risk of hoax answers.

Several studies have shown that postal surveys are superior to e-mail surveys with regard to response rate, but online surveys are much cheaper [30,63]. Schleyer [11] estimated that the cost of their Web-based survey was 38% less than that of an equivalent mail survey and presented a general formula for calculating breakeven points between electronic and hardcopy surveys. Jones gave the figures of 92p per reply for postal surveys, 35p for e-mail, and 41p for the WWW [30].

Cookies

Cookies can be used as unique identifiers assigned to every questionnaire viewer. As mentioned above, cookies can be used to count unique visitors to a questionnaire Web form. The use of cookies is also strongly recommended to filter out multiple responses by the same person in an open survey. People have a habit of double-clicking the "submit" button, which might lead to a double-storing of the same information. Such multiple entries can be prevented or detected by using cookies. The unique participant identifier, read out of the cookie, can then be stored in the database together with each response, so that during analysis multiple responses by the same participant can be easily identified.

The drawback of using cookies is that some people are very suspicious about sites using cookies, and will not accept cookies. Despite (or because of) these concerns, researchers should:

- State up front that cookies will be sent (and the reasons for this).
- Set the cookie to expire on the day that data collection ceases.
- Cover the issue in a published privacy policy.

Measuring Response Time

The response time can be used to exclude respondents who fill in the questionnaire too quickly, as an indication of a possible hoax response where respondents usually don't read the questions. The total time needed to complete a questionnaire can be easily measured by dynamically plugging the time and date a form was created (called-up) into a "HIDDEN" field in the form (see HTML reference books), as well as recording the time and date the questionnaire is submitted. The time needed to fill in the questionnaire can be calculated by subtracting the call-up time from the submit time. Though different transmission times through the network may not allow comparisons exact to the second [57], one may get a good grasp of how long, on average, the completion of a questionnaire takes.

Avoiding Missing Data

A great advantage of computer-administered surveys is that the software can automatically reject incomplete questionnaires and point out missing or contradictory items. To what degree the researcher wants to point out missing or erroneous data immediately (before submission) depends on the research question. In general, one may choose between client-side checking of the responses with JavaScript before they are submitted and stored in the database, or server-side checking (using any server-side script language such as Perl, ASP, etc.), allowing submission and recording of the incomplete results, before any errors are pointed out to the user. The latter method is more suitable if the Web is used to pilot-test questionnaires.

Randomizing Items

Script-languages such as ASP (Active Server Pages) may be used to build up dynamic questionnaires (as opposed to static HTML forms), which look different for certain user groups or which randomize certain aspects of the questionnaire, for example, the order of the items. This can be useful to exclude any possible systematic influences of the order of the items on responses.

Additional Readings

The methodology of Web surveys has become a research topic in itself, with sources such as the "Web Survey Methodology Portal" (http://www.websm.org) offering references and links to conferences and discussion boards. The *Journal of Official Statistics* (www.jos.nu) has announced a Special Issue on methodological aspects of Web surveys for December 2004. Another good introduction is the Rand report, "Conducting Research Surveys via E-mail and the Web," published in 2001 (hence slightly outdated), which can be downloaded from http://www.rand.org/publications/MR/MR1480/ [64].

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