



Participation Rates in Epidemiologic Studies

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Participation rates for epidemiologic studies have been declining during the past 30 years with even steeper declines in recent years. This wholesale decrease in participation rate, or at the very least the increase in refusal, has, quite understandably, occasioned some concern among epidemiologists who have long considered a high study participation rate as one of the hallmarks of a “good” epidemiologic study. In this review we synthesize the issues that are central to epidemiologic thinking around declining study participation rates. We consider the reasons why study participation has been declining, summarize what we know about who does participate in epidemiologic studies, and discuss the implications of declining participation rates. We conclude with a discussion of methods that may help improve study participation rates. *Ann Epidemiol* 2007;17:643–653. © 2007 Elsevier Inc. All rights reserved.

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INTRODUCTION

There is little question that participation rates for epidemiologic studies have been declining over the past 30 years (1, 2), with even steeper declines seen in recent years (3). This declining study participation has been documented in studies that are conducted by academic researchers (3, 4), by governmental agencies (5), and by for-profit companies (6) alike.

An examination of changing participation rates in several well-established national surveys illustrates the trends in participation rates over the past few decades, although, as we shall discuss, there is substantial variability in participation rates between studies. The Behavioral Risk Factor Surveillance Survey (BRFSS) has been conducted by the Centers for Disease Control and Prevention (CDC) since 1984 (7). The BRFSS is a nationally representative survey aimed at documenting changes in population-level behavioral risk factors, health screening, and health care access. The overall decrease in BRFSS participation rate is well documented. The BRFSS median participation rate was 71.4% in 1993, 48.9% in 2000, and 51.1% in 2005, the year for which data are most recently available (8). Similar declines in participation rates have been reported by the Survey of Consumer Attitudes (SCA), which has been conducted since the 1950s by the Survey Research Center of the University of Michigan, with surveys taking place monthly

since 1978 (9). The SCA is a random-digit-dial survey assessing consumer attitudes toward spending and expectations about the economy (10). The participation rate for the SCA was 72% in 1979, 60% in 1996, and 48% in 2003 (3). The National Comorbidity Survey (NCS) is the largest, and for many the “gold standard,” cross-sectional study in establishing prevalence of psychiatric disorders. The original NCS, conducted between September 1990 and February 1992, reported an 82.4% participation rate (11). By contrast, the NCS-Replication (NCS-R), conducted approximately a decade after the original survey, between February 2001 and April 2003, reported a participation rate of 70.9% (12). Other epidemiologic studies that report participation rates have also demonstrated a decreasing trend over past decades (13). For example, while the participation rate reported for the original assessment of the Framingham Heart Study, established in 1948, was 69% (14), the participation rate for the Multi-Ethnic Study of Atherosclerosis, initiated in 2000, was 59.8% (15).

Even studies that have reported relatively consistent participation rates over time have shown that refusals to participate have been increasing and that consistent participation rates have been maintained only at the expense of more extensive efforts to ensure participation of hard-to-reach persons who nonetheless do not refuse study participation (16). For example, although participation rates in the National Health Interview Survey (NHIS) remained consistently in the 95%–97% range from the 1960s through the 1980s, refusals made up a greater proportion of all nonrespondents during this time (2). Overall response rates to NHIS surveys have since decreased, with a response rate of 91.8% in 1997 (17) and 86.9% in 2004 (18). Similarly, although participation rates remained consistent between 85% and 97% between 1955 and 1993 (19), refusals have also been increasing for the Current Population Survey

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Selected Abbreviations and Acronyms

AAPOR = American Association for Public Opinion Research
BRFSS = Behavioral Risk Factor Surveillance Survey
CPS = Current Population Survey
HIPAA = Health Insurance Portability and Accountability Act
NCS = National Comorbidity Survey
NCS-R = National Comorbidity Survey-Replication
NHIS = National Health Interview Survey
SCA = Survey of Consumer Attitudes

(CPS) (2), which is conducted by the US Census Bureau for the Bureau of Labor Statistics. Response rate for the General Social Survey decreased to about 70% in 2000, from steady rates between 74% and 82% between 1975 and 1998; the decreases were entirely due to an increase in refusals (3). The International Conference on Survey Nonresponse, held in 1999, convened panels of experts to discuss the roots and the implications of declining study participation rates and to bring greater attention to this growing problem (20), followed by the publication of one of the foremost texts on survey nonresponse (21).

This wholesale decrease in participation rate, or at the very least the increase in refusal, has, quite understandably, occasioned some concern among epidemiologists who have long considered a high study participation rate as one of the hallmarks of a “good” epidemiologic study. It is the purpose of this review to synthesize the issues that are central to epidemiologic thinking around declining study participation rates. We will consider what is meant by participation rates, the reasons why study participation has been declining, summarize what we know about who does participate in epidemiologic studies, and discuss the implications of declining participation rates. We conclude with a discussion of methods that may help improve study participation rates.

WHAT IS A PARTICIPATION RATE?

A recent review of peer-reviewed studies published in 10 high-impact journals showed that a substantial number did not report information on study participation (13). This reluctance of investigators to report participation rates is perhaps understandable given the epidemiologic tendency to chide low participation rates as a sign of study inferiority. Perhaps even more prevalent in the epidemiologic literature is a tendency toward dissembling about what exactly is the “response rate” for a study.

The term “response rate” has become freighted with conflicting meaning, much of which is frequently incomprehensible to any but the most careful reader of a particular epidemiologic paper. Unfortunately, there is no such thing as a simple “response rate,” with different modalities of data collection embedding particular, but important, elements, each of which may contribute to the calculation of

several “response rates” that may give us an indication about participation in a particular study. Using just one example, the American Association for Public Opinion Research (AAPOR) (22) suggests that the response rate is the number of completed interviews divided by the number of all possible interviews, the cooperation rate is the number of all cases interviewed divided by all eligible cases, and the refusal rate is the proportion of all cases in which a respondent refuses to be interviewed or cuts off contact before some predetermined point in an interview that represents completeness.

There are several ways to calculate each of these participation rates. AAPOR provides 6 different types of participation rates, depending primarily on how partial interviews are considered. Response rates are the most conservative outcome rates that can be provided, since all possible interviews are included in the denominator in these calculations (including cases of unknown eligibility). Cooperation rates are outcome rates among those eligible and therefore are higher than response rates; there are two cooperation rates that generally can be calculated, depending primarily on assessment of eligibility. There are 3 types of refusal rates that differ primarily on how the disposition of cases of unknown eligibility is treated. In many respects then, the devil of a particular participation rate for a given study is clearly in the details. A study that considers a data collection effort that is a quarter complete to be a numerator case versus a denominator case stands a much better chance of reporting a high participation rate than one that sets its data collection completion bar at 75%.

Given such complexity, it is advisable to report several participation rates, together with careful explanation of how they were calculated, in academic research publications. In addition, as epidemiologic studies become ever more complex, with sampling taking place over multiple stages, there are several participation rate steps along the path to data collection. This then obviates the notion that there is a single, all-meaningful “participation rate” and further recommends instead careful explication of the sample, persons contacted and disposition of all those contacted, and those successfully recruited in the study to partial or full completion of data collection. Unfortunately, detailed presentation of participation rates or the numbers of participants involved in every step of a sample construction are rarely presented in epidemiologic papers (13, 23). We suggest that clear reporting of participation details and of avoidance of overreliance on a single-number “response rate” of dubious or opaque meaning in epidemiologic publications is essential. This can help us move beyond blanket condemnation of low participation rates in epidemiologic studies to a more nuanced appreciation of the biases involved in every step of study recruitment and a study-by-study assessment of the magnitude of the influence of participation rates on study validity.

In many respects, our reluctance to lay bare all steps of study participation is understandable, given the likelihood of peer criticism of perceived “low” participation rates. Unfortunately, not reporting information about study participation rates and unthinkingly criticizing studies for having low participation rates both fail to help us come to terms with the implications of low response rates for the validity of a particular study. Throughout this article we use the term “participation rate,” believing it to be more precise and more carefully reflecting the etiology of the phenomenon under discussion.

WHY HAS NONPARTICIPATION BEEN INCREASING?

There are two central reasons why nonparticipation in scientific studies has been declining over the past 50 years: potential participants have been increasingly refusing to take part in scientific studies, and it has become harder to find persons who might be eligible study participants. We discuss each reason in turn.

Refusing Participation

At the core of any discussion about nonparticipation in epidemiologic and other scientific inquiry is a growing proportion of persons who are contacted and invited to participate in research who simply refuse to participate. There are probably 4 reasons for this growing refusal to participate.

First, there has been a proliferation of research studies during the past few decades. Thus potential participants (and by potential participants we are considering both persons in the general population and persons in particular subgroups of interest, such as persons with a particular disease) are faced with an increasing number of requests to participate in studies, including health-related research and other academic and government-sponsored research. This increasing number of requests to participate in research studies may well have the effect of having persons refuse to participate in all studies, which cumulatively are becoming an intrusion on personal lives (24). In addition, as the number of potential research studies in which persons may participate increases, people may view their participation in studies as less and less worthwhile, and they may invest much less effort in making an attempt at participating than they might have when opportunity for study participation was more unusual (2, 25). Coincident with the increase in research studies in the United States, there has been a proliferation in marketing surveys and political polls that to participants are often indistinguishable from scientific inquiry. It has been suggested that we have created an “oversurveyed” society (2, 24, 25). It is worth noting that the rise in telemarketing in particular may be a particular threat to epidemiologic study

participation (3, 26–28). Telemarketing, or the practice of calling persons on the telephone at home to sell products or services, has dramatically increased in prominence throughout the last two decades (28). Although telemarketing has a clear goal of selling a product or soliciting support for particular causes, the distinction between telemarketing efforts and genuine research efforts may well be blurred in the minds of a substantial proportion of the population (29), often because of efforts to disguise marketing efforts as surveys (28, 30). Recent efforts, including a federal Do-Not-Call Registry, have been made to minimize telemarketing intrusions in the general US population (31). The federal Do-Not-Call Registry was implemented in 2003 (32). It is illegal for telemarketing companies to contact persons who voluntarily place their name on this “do not call” list, unless contact has been initiated by the consumer; violations of this policy may result in fines up to \$11,000 per call (32). No such prohibition applies to research efforts. However, although the Do-Not-Call Registry may indeed, in the long term, reduce telemarketing, it may also increase skepticism about research efforts that contact participants by telephone. In addition to the customary hurdle of discussing with potential respondents that the purpose for a particular contact is research, not marketing, research efforts now may well have to overcome the hurdle of explaining why persons were contacted, despite their being on a “do not call” list.

A second factor likely contributing to increasing participation refusal rates in epidemiologic studies is a general decrease in volunteerism in the United States and in other western countries. Evidence has long suggested that willingness to participate in scientific research parallels participation in community organizations and other activities (29, 33). Several studies have shown that participation in organizations and social activities has declined dramatically in the last few decades (34). Therefore the overall decline in willingness to participate in scientific studies, which may hold little immediate benefit to the participant her/himself, likely coincides, at least in part, with the overall decline in social participation.

Third, there is abundant evidence that potential participants are much more likely to take part in a study that is concerned with an issue which is particularly salient to the participants’ lives. For example, studies of the relation between cellular phone use and cancer (35) and between fried potato consumption and cancer (36) have reported participation rates of 90% or higher. Conversely, people are often reluctant to participate in studies that do not have a personal salience (2, 37). Similarly, participation rates among cases in case-control studies are consistently higher than those among controls (38–40). While the different salience of study topics to participants’ lives may be associated with differential participation rates across studies, it also likely contributes to the overall decline in participation rates over the

past few decades. There is growing popular disillusionment with science worldwide (41–44). Contradictory messages about the benefits of health screening (45–48) and conflicting results of disease prevention trials (49–51), as well as changing recommendations for nutrition and health standards (52, 53), may leave the public confused and wary of the validity of research claims. A number of studies regarding willingness to participate in clinical trials and other studies have identified distrust of the medical profession and fear of exploitation or being “experimented on” as a hindrance to participation, especially among minority groups in general, and among African Americans specifically (54–59). In some contexts, particularly in the United States and concerning certain topics (e.g., stem cell research), popular debate has cast science in contrast to religious belief, further complicating public perceptions of the scientific enterprise. These broader forces then contribute to diminishing enthusiasm for science in general, and, operationally for participation in scientific studies.

A fourth reason for declining participation in studies is more endemic to the nature of scientific studies themselves. Particularly during the past decade, scientific studies in general, and epidemiologic studies in particular, have become increasingly demanding of participants on multiple fronts. Epidemiologic research has grown increasingly complicated, involving survey assessments, biologic sampling, and frequently requests for ongoing follow-up that is burdensome for participants. Therefore participants may be rightly wary of committing their involvement to an endeavor that is likely to take up a substantial amount of their time. Compounding this increasing respondent burden, institutional review board requirements have also become increasingly burdensome for respondents, with often lengthy consent forms written at inappropriately high reading levels (60–62). One early study in the area assessing the impact of informed consent procedures on survey response found that requiring a signature before the start of a survey reduced the response rate (63). More recent studies have suggested that more complex consent procedures discourage study participation (54, 57, 64).

In summary, overall, persons eligible for research participation are being asked to participate in increasingly complex and demanding research protocols within a climate of more requests for study participation, declining volunteerism and trust in science. It is then little wonder that participation rates have declined over the past several decades, and it is perhaps remarkable that they have not declined even more than the evidence suggests they have.

Difficulties Finding Potential Participants

Increasingly during the past few decades, challenges in actually finding and talking to persons who may be study

participants have compounded the circumstances, discussed above, that contribute to refusal to participate. Although mobility has actually decreased in recent decades in the United States (34, 65), people have become harder to contact as unlisted phone numbers are more common (66), cell phones are more commonly used (67, 68), and telephone screening has increased (3). All these contribute to more barriers between potential study participants and research efforts to approach these potential participants.

Lifestyle factors have also contributed to increasing challenges in finding, and contacting, potential study participants. Although the average number of hours worked per week has remained fairly steady in the United States during the past several decades (69), the proportion of men and women working more than 50 hours per week has increased between 1970 (21.0% of men, 5.2% of women) and 1999 (25.2% of men, 10.8% of women) (70). Longer working hours keep Americans out of their homes more (70, 71) and reduce free time that may potentially be dedicated to study participation. The increased movement of women into the workforce (69, 70) over the past 3 decades also makes it less likely to successfully reach someone at home, even with multiple attempted contacts at varied times of day. For example, the percentage of women in the workforce increased from about 30% in 1960 to 60% by the year 2000 (72). Of particular relevance to studies that are concerned with contacting primary respondents as well as household members, the average household size in the United States has decreased from 3.37 in 1950 to 2.61 in 1999 (69, 73). This limits the number of persons who are eligible for potential study participation as household members and also reduces the number of household members available to serve as informants for the purpose of participant tracking.

Finally, congruent with the issues of oversurveying and greater reach of aggressive marketing efforts noted earlier, increases in unsolicited mail and phone calls have also made it more difficult for study communications to successfully reach potential respondents (28, 30). It is increasingly challenging for materials related to scientific studies, be that material conveyed through the mail or by phone, to reach participants, who are routinely sorting through numerous items of unsolicited mail or phone messages, all of which end up being categorized as “junk” by the intended participants.

WHO PARTICIPATES IN EPIDEMIOLOGIC STUDIES TODAY?

Recognizing that study participation rates are declining, it is then of particular concern to epidemiologists planning studies to identify who is likely to participate in studies. Such

awareness ahead of study implementation may help plan targeted recruitment.

Most systematic efforts to characterize who does, and who does not, participate in studies have focused on the demographic characteristics of study participants. There is clear evidence that women are more likely to participate in scientific studies than men (37, 74–77). Evidence with regard to study participation and age is much less consistent. While some studies have found that older persons are more likely to participate in studies (37, 74, 75, 78), others find higher participation rates among younger persons (33). The evidence about participation rates by race/ethnicity is similarly inconsistent. While some studies have documented higher participation rates among whites (79), others have found higher participation rates among blacks and minority groups (33, 80). The burden of evidence suggests that persons with higher socioeconomic status are more likely to participate in scientific studies (74, 76, 78, 79, 81, 82). Consistent with this observation, it has been shown that more educated persons are more likely to participate in studies, regardless of type of study or mode of data collection (33, 79). Also consistent with these latter two observations, employed persons are, by and large, more likely to participate in studies (75, 79, 82). Finally, it has been shown that married persons are more likely to participate in studies than are unmarried persons (79, 82).

It is worth noting that the demographic characteristics of persons who are more likely to participate in studies speak clearly to the complex forces that may shape likelihood of study participation. For example, while persons who are employed and with higher socioeconomic status may be harder to reach because of their schedules (2), these persons may be more likely to participate, likely reflecting greater trust in science (83) and greater rates of volunteerism in these demographic groups (34) contrasted with persons with lower socioeconomic status and lower education.

Of particular concern to epidemiologists is the relation between exposures and outcomes of interest and likelihood of study participation. Starting with typical epidemiologic exposures of interest, it has been shown in several studies concerned with the influence of risk behaviors, such as smoking, alcohol, or drug use, that those who engage in the risk behavior are often underrepresented among respondents (74, 77, 78, 84). In contrast, however, in studies of environmental or occupational exposures, it is likely that those with the exposure may be more likely to participate in studies than those who are not exposed (85–87). This difference pertains directly to the issue of study salience, discussed earlier as a reason for declining study participation rates during the past decades. Studies that are perceived by potential respondents to be concerned with a behavior that is marginalized, or stigmatized, are likely to face difficulties enrolling participants who partake in the particular marginalized

behavior. Conversely, studies that are concerned with enrolling persons faced with an exogenous exposure, who may hence be interested in documenting the consequences of their exposure, may have an easier time enrolling such persons than they do persons who have not faced the exposure and who are uninterested in studies concerned with studying the consequences of such exposures.

Patterns of study participation based on health status reflect the competing influences of demographic characteristics and study salience on differential nonparticipation. The association between lower socioeconomic status and poorer health is one of the most robust findings in epidemiology (88–91). Commensurate then with the observation that persons with lower socioeconomic status are less likely to participate in epidemiologic studies, study nonparticipants have higher disease and mortality rates, poorer health status, and lower levels of functioning than study participants (76, 82, 84, 92–95). In contrast, persons with a particular symptom or condition may be more likely to participate in studies related to that symptom or condition because of the relevance of the study to their lives (27, 37). Congruent to the observations about persons with exposures that are socially unacceptable being less likely to participate in studies, it has been shown that persons with socially undesirable health conditions may also be less likely to participate in studies. For example, studies concerned with eating disorders or sexually transmitted diseases have been shown to underrepresent persons with these disorders (96, 97).

IMPLICATIONS OF STUDY NONPARTICIPATION

Although, as noted earlier, study participation rates are often considered a cardinal feature of good epidemiologic study execution, in light of the growing challenges faced by researchers in obtaining high participation rates, it is worth revisiting the fundamental reasons for our concern with study participation rates. There are two key considerations in this regard.

The central concern about study nonparticipation is the issue of nonparticipation bias (or, as it is more commonly termed, nonresponse bias). Nonparticipation bias refers to the systematic errors introduced in the study when reasons for study participation are associated with the epidemiologic area of interest. Although there is little doubt that nonparticipation bias should be of concern for all epidemiologic studies, the empiric evidence about the magnitude of the effect of nonparticipation bias is somewhat more reassuring than the theoretic concerns might lead us to suspect.

Best available evidence suggests that participation rate alone does not determine the extent of bias present in any particular study and low participation rates do not

necessarily indicate a high level of bias inherent in a study (98). Far more important in the assessment of the influence of nonparticipation bias is the extent to which nonparticipation is associated with the exposure, outcome, or relation of interest. It is the difference between participants and nonparticipants that determines the amount of bias present (2, 98, 99). Reassuringly, most studies have found little evidence for substantial bias as a result of nonparticipation (82, 100–102). For example, recent analyses of BRFSS data have shown that for a range of participation rates for telephone surveys between 30% and 70%, the participation rates were at most weakly associated with bias.* In one analysis, it was shown that although a larger difference in participation rates was associated with larger differences in estimates of cigarette smoking prevalence between the BRFSS and the in-person CPS, the effects were small with a 45 percentage point difference in participation rates having a predicted difference in smoking prevalence estimates of 1.5 percentage points.* In another analysis comparing data from two identical surveys with participation rates of 61% and 36%, very few significant differences were found across 91 categories (103). Importantly, in some instances, nonparticipation bias may actually be higher in surveys with higher participation rates than those with lower participation rates (2, 104). In particular, extreme efforts to increase participation rates may introduce more bias into the study if the added respondents are not representative of all nonrespondents, or if they are less conscientious in their survey participation (2, 105, 106). We note that this bias, together with aforementioned selection biases inherent in the differential likelihood of specific groups to participate (or not) in an epidemiologic study, suggests that extreme efforts aimed at enrolling nonrespondents may introduce errors, the effect of which may be difficult to predict in any given study. As a final note, extreme efforts to recruit reluctant participants to improve study participation rates may ultimately be unethical if such efforts border on coercion to enroll persons in epidemiologic studies.

The second concern that arises from declining study participation rates is particular to epidemiologic studies that are concerned with population-based sampling and with attempts to obtain estimates from population-representative samples that are generalizable to whole populations. Declining participation rates and the growing complexity of reasons for study nonparticipation add unpredictability about who is choosing to participate in a study and who is not and challenge the ability of these studies to confidently obtain a population-representative sample. Since population-representative sampling continues, and will continue, to

hold substantial epidemiologic interest, particularly in characterizing population burden of disease for the purposes of guiding public health planning, ever more effort, manifest as an increase in study costs, will likely need to be invested to increase study participation. Typical measures employed to increase participation in this context include advance letters, more extensive follow-up, more generous financial incentives, more interviewer hours to enable repeated contact attempts, and more extensive tracking to locate people, all of which contribute to higher costs associated with population-based surveys (103).

Although a full discussion of the statistical methods that may be employed to adjust for differential study participation is beyond the scope of this review, we note that one measure that is commonly employed to consider the potential bias introduced by study nonparticipation is the collection of minimal data on nonrespondents for comparisons with respondents. Unfortunately, enhanced scrutiny by institutional review boards and regulations, including the Health Insurance Portability and Accountability Act of 1996 (HIPAA), have hampered the collection of these data.

The reader is referred to standard reference works (21, 107) that more fully discuss the role that statistical methods may play in overcoming some of the challenges to study validity imposed by low participation rates.

IMPROVING PARTICIPATION RATES IN EPIDEMIOLOGIC STUDIES

Understanding the study characteristics that may modify the likelihood of study participation may help guide efforts aimed at improving study participation. Although the role of demographic characteristics, including gender, race/ethnicity, and socioeconomic position, has been discussed in the preceding paragraphs as determinants of differential study participation rates, there is very little evidence for measures that can be adopted in epidemiologic studies to specifically tackle demographic heterogeneity in study participation. In contrast, a few study features are thought likely to influence participation rates among all potential participants. Generally, higher participation has been reported in studies that involve face-to-face recruitment and data collection in contrast with studies that rely on telephone or other less personal forms of contact between study recruiter and potential participant (108). Not surprisingly, studies requiring substantial time commitments or involving invasive procedures have lower participation rates than studies with lower participant burden (2, 109). Study conditions that may pose particular challenges or risks for participants decrease likelihood of participation. For example, women living with an abusive partner were less likely to participate in

*Mariolis P. Response rates and data accuracy. Oral presentation. American Association of Public Opinion Research. Nashville, TN; 2002.

a study about domestic violence than women not cohabiting, potentially for safety reasons (27).

Monetary incentives increase study participation; for example, in the National Survey on Drug Use and Health, participation was 69% among those who received no monetary incentive, compared with 79% among those who received \$20 and 83% among those who received \$40 (110). However, evidence about the role of monetary incentives in influencing differential study participation is mixed. It has been suggested that greater monetary incentives may have a greater impact on the decisions of minority, low-education and low-income individuals or households to participate in a study than nonminority, higher education, and higher income individuals and households (111). In contrast, other research suggests that the use of monetary incentives encourages participation among potential respondents with higher income and education (111) who may have a greater demand to be compensated for their valuable time. More recently, several studies have shown that creative administration of incentives may in and of itself improve study participation. For example, enclosing a prepaid incentive with an advance letter requesting survey participation has been found to increase participation rates (10). Similarly, sending incentives with follow-up mailings and between study waves has also been found to be effective in increasing participation rates (112, 113). Offering staggered incentives may be especially helpful in minimizing attrition between study waves, providing motivation as interest in participation begins to decline.

Consistent with the creative administration of participation incentives, it is likely that overall creativity in study design may need to be employed to counter the inexorable forces contributing to declining study participation rates. Several recent studies have demonstrated the utility of studies that use hybrid data collection methods for increasing participation rates and producing samples that are more representative of the targeted study population (105, 114–116). For example, some mixed mode studies give respondents the option of completing data collection in one of multiple ways, usually via mail or via the Internet (115, 117). Other mixed mode study designs may use an alternative data collection method only among nonrespondents to the first method; for example, telephone interviews may be conducted among nonrespondents to a mail survey (105, 114, 116, 118) or an in-person study (119), or Web-based surveys may be used among nonrespondents to mail surveys (120).

One concern about these kinds of studies is the possibility that responses will differ when using different survey modes (118, 121, 122). Most empiric studies have found little evidence for this concern once differences in the characteristics of respondents between modes are taken into account (105, 114, 115, 123–129), even for sensitive topics like alcohol and illicit drug use (130, 131). However, some studies

have found some differences in participation across modes (119), particularly when comparing responses from Web-based surveys to responses from phone and mail surveys (132, 133).

This strategy of using an alternative study method among nonrespondents has limited usefulness among population groups that may be difficult to reach via any mode (e.g., the elderly or people with unstable residence) (105, 114). Some have argued that the increased costs of such mixed mode designs are not justified in epidemiologic studies, where the increased participation rate gained by the strategy may have very little impact on estimates of prevalence and exposure-disease relations (134–136), as discussed above.

As access to and use of the Internet continue to grow worldwide, Web-based modes of data collection are becoming an attractive option for epidemiologists, allowing respondents to complete surveys at a time and in a place that is most convenient for them (137, 138), which has the potential to result in higher participation rates. Younger generations in particular (e.g., college students) demonstrate a clear preference for communicating and conducting financial and other transactions via the Internet, rather than via phone or mail or in person (139–143). This preference may be reflected in greater willingness among these groups to participate in Web-based modes of data collection rather than other modes of data collection. Web-based surveys may be particularly suitable for epidemiologic studies on sensitive topics, including sexual behaviors, since the benefits of interviewer-administered surveys can be preserved (e.g., automatic skips, randomization of questions, logic checks for responses) while maintaining the anonymity of a self-administered survey (26, 137). In contrast, of course, Web-based modes of data collection have very limited utility for studies that are concerned with the collection of biometric information that cannot be collected through self-response.

The evidence for improved participation rates among Web-based surveys is conflicting. For example, some studies have reported higher participation rates among respondents to a Web-based rather than to a mail survey (130), but others have found higher participation rates among mail surveys than Web-based surveys (26, 144). Ultimately, studies conducted exclusively using the Internet have limited usefulness outside of specific groups that have access to and comfort with the Internet (26, 138, 144–146). Concerns about Internet security also impede the use of Web-based data collection (146), but can be overcome by available tools such as user authentication and data encryption (137). Providing respondents with the option to complete surveys via the Internet but preserving other survey mode options in the same study is probably the best strategy for taking advantage of the Internet to increase participation rates.

CONCLUSION

In this review we have highlighted the forces shaping declining study participation rates. We suggest that these forces are, by and large, inexorable and out of the hands of epidemiologists, and that participation rates are likely to decline further in coming decades. In the face of such bad news, the good news is that most empiric work suggests that declines in participation rates are not likely to have substantial influence on exposure-disease associations or point estimates of measures of interest. This is not intended to suggest that we should accept low participation rates. Innovation in epidemiologic studies should involve both the development of creative recruitment and retention techniques that optimize participation as much as possible and the application of statistical methods for adjustment of potential bias introduced by study nonparticipation.

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