Staying in Touch:
Two Emerging Issues in Epidemiologic Research

Thomas Koepsell

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I’d like to focus this morning on two challenges that I think we face as epidemiologic researchers over the next few years. The first is gaining and maintaining access to populations. The second is dealing with some of the side effects of increasing specialization in our field. I’ll spend most of my time on the first topic.

Access to populations

The first issue is the growing difficulty that many of us have been encountering in simply getting access to populations to gather epidemiologic data. To be sure, we can often obtain disease data and basic demographic characteristics from pre-existing sources such as vital records, registries, and so forth. But for many important diseases, such as obesity or arthritis, no such pre-existing surveillance system exists. Also, the kinds of exposures of interest in many analytic epidemiologic studies nowadays cannot be assessed satisfactorily from any pre-existing data source. So, modern epidemiologic research often requires primary data collection on members of a defined population, often a geographically defined one.

A very common example is a population-based case-control study. We start with all cases in a certain geographic area, perhaps obtained from vital records or from a population-based registry like the SEER cancer registry, and then we try to sample and recruit controls from the population at risk that generated those cases.

Random digit dialing

Over the last two decades, the telephone has played a key role for this purpose. It’s a mature, almost ubiquitous technology: in the U.S., about 95% of households have a telephone [1].
We epidemiologists have made use of this fact in two ways. First, random digit dialing, or “RDD,” has offered a relatively inexpensive way to obtain a probability sample of the population of a certain area. Second, telephone interviews have often been an efficient means of data collection as well. With RDD, the one-third or so of the population with an unlisted telephone number has the same chance of being sampled as anyone else.

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As a result of these nice features of RDD, its use spread like an epidemic among epidemiologists. Searching MedLine with the keywords “random digit” and “epidemiologic-methods” reveals zero citations for the five years before 1980, but a steadily increasing number per year since then. In a recent review by Sara Olson of response rates in case-control studies [2], RDD was found to be the most commonly used method for identifying population-based controls, either by itself or in combination with other techniques. In short, RDD has become a real workhorse for sampling populations in epidemiologic studies.

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During the 1980s and early 1990s, response rates in the range of 60–75% or more were often reported [3, 4]. We got better and better at it, learning how to distribute calls across different days and times to increase the chance of making contact; by re-contacting “soft refusers” after a period of time and often converting them into study participants; and by using techniques like Mitofsky-Waksberg sampling method or list-assisted sampling to increase the proportion of calls that reached a residential phone number.

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In recent years, though, dark clouds have been gathering. For some time, survey researchers have lamented a general decline in response rates for telephone surveys [5–7]. The view that such a decline is occurring seems to be widespread among survey researchers and epidemiologists [4, 5, 8], although hard evidence is not so easy to come by, and what there is is somewhat mixed [2, 9].
For example, the study by Olson on trends in response rates over time in case-control studies included the figure shown here. In a sample of 69 case-control studies published between the early 1970s and 1999, only a slight overall decline was observed in reported response rates among potential controls. Note that the data collection period in these studies actually extended only through about 1996 because of the time lag between data collection and eventual publication. This analysis also included studies that used methods other than RDD for control identification. Also, these studies used a bewildering variety of methods for calculating response rates, and often it was impossible to recalculate a response rate for each study in a standardized way for comparison. And finally, the calculation methods may have changed over time.

One way to avoid most of those problems is to examine response rate trends in a single large, long-term survey: namely, the CDC Behavioral Risk Factor Surveillance System, which is the largest continuously conducted telephone survey in the world. Since 1994 it has covered all 50 states. CDC coordinates the survey, standardizes the RDD methodology, and calculates response rates in a standard way. This figure shows the trend in the so-called CASRO response rate from 1994 to 2000. Over this six-year period, the median response rate among the participating states declined more than 20 percentage points from 70% to below 50% [10–12].

Note that this graph begins in the mid-1990s, or about where the previous graph ended. In fact, BRFSS response rates in the mid-1990s were about at their high-water mark. Response rates from earlier years of BRFSS are harder to compare because of different numbers of participating states, but they had been roughly in the 65–70% range for some time. Thus it’s quite possible that the main decline in RDD response rates is of more recent vintage than surveys of published epidemiologic studies have yet been able to detect.

Meanwhile, the level of personnel effort needed to identify each respondent in BRFSS
increased steadily over this period. In 1995, an interviewer needed to call an average of 3.2
telephone numbers to recruit one respondent; in 1999, an average of 6.6 telephone numbers had to
be called to recruit one respondent. Researchers on other epidemiologic studies have noted that
the number of calls and call-backs needed per phone number have also increased [4].

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So what’s going on? My guess is that everyone in this room knows quite well what’s
going on, at least in part, just from the everyday experience of living in a household with a
telephone. My wife and I bought our first answering machine about 7 years ago, thinking that it
would increase the ease with people we wanted to hear from could reach us. Nowadays we hardly
ever answer a ringing telephone in the early evening or on a weekend. We let the answering
machine kick in, and if the call turns out to be from someone we know and want to talk with, we
pick up before they finish leaving their message. So a device that was originally intended to
increase our accessibility to callers has shifted to being used mainly to limit our accessibility to
unwanted callers.

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Telemarketing has grown rapidly in recent years and is now very big business, taking
advantage of many of the same features of RDD that make it attractive to epidemiologists. Nearly
6 million people were employed in telemarketing-related jobs in 2001 [13]. Direct telephone sales
to consumers accounted for about $257 billion in sales in 2000 [13][1]. An estimated 19 billion
telemarketing dials are made each month [15]. It’s not hard to see how a few thousand calls
inviting someone to participate in a fascinating and worthwhile epidemiologic study could be lost
in this hurricane and mistaken for yet another sales pitch from a stranger. Some telemarketers
have undermined our efforts more insidiously by beginning a sales pitch as though it were a
survey—a practice known as “SUGging,” or Selling Under the Guise of research. There’s also
“FRUGging”—Fund Raising Under the Guise of research—when non-profit organizations get

1A subsequently published story in the New York Times [14] cites lower figures for telemarketing employment and
annual sales but still supports the claim that telemarketing is a very large enterprise.
into the act.

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Telemarketing is not necessarily the only culprit. A growing percentage of households contain only a single adult, or all the adults work outside the home [9]. These trends decrease the likelihood that someone will be at home during typical calling hours. Telephone technology has also changed. Consumers have taken back some measure of control with technology of their own. More than 3/4 of U.S. households have an answering machine [16], which is often used for the purpose of screening calls. About 15% of households used caller-ID as an “electronic peephole” to screen out unwanted calls [17].

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Another important recent trend is the explosive proliferation of cell phones. According to an industry trade association, there are no fewer than 135 million wireless phone users in the U.S., about twice as many as just five years ago [18]. Traditionally, cell phones have been avoided under RDD in epidemiologic studies, under the assumption that cell phone users also had a land line at home anyway and might thus be oversampled. Also, cell phone users often had to pay for incoming calls. But as calling plans have come down in price, the practice of using a cell phone as one’s only personal phone is believed to be spreading quickly. So while RDD response rates seem to be falling, the population coverage of the sampling frame seems to be eroding.

Moratorium on access to Medicare enrollees

[Slide 14]

The battle to obtain and maintain access to populations is being fought on other fronts as well. RDD has never been a very efficient way to identify certain subpopulations, such as older adults. Instead, it has been possible, with suitable safeguards, to obtain names and addresses for a sample of Medicare beneficiaries from the federal agency now known as the Center for Medicare and Medicaid Services, or CMS. For several months, the ominous notice shown here has been
posted on the CMS web site, declaring a moratorium on release of names and addresses to researchers. A longer policy statement [19] says that the moratorium is expected to be temporary, but that when it is lifted, access policies will be much more restrictive. Researchers would have to prove that no other way to identify older adults is possible. The actual contacting would be done by a third party, at the research project’s expense, and potential subjects would then have to take the initiative themselves to call the researchers at a toll-free number in order to be included in the study. No follow-up contacts to non-respondents would be allowed. There are, I think, good reasons to be fearful about the cost of such a protocol, the participation rates it would yield, and the representativeness of the resulting sample. SER and the American College of Epidemiology have registered their concern about the potential adverse impacts of these changes on epidemiologic research.

**HIPAA**

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Lastly, there is the Health Insurance Portability and Accountability Act—HIPAA. One of the most positive things to say about its impact on epidemiologic research so far is that it could have been worse. Some of the most draconian requirements in early drafts of the HIPAA regulations were later softened. Now there should not be too many studies that were possible before HIPAA that are impossible after HIPAA. But there will certainly be added costs, effort, and time required. Study subjects will have to plow through, and consent to, more conditions of participation than ever before. And some health care organizations are thinking twice about whether they want to collaborate on epidemiologic research in the era of HIPAA.

A worrisome aspect of these developments is that they may signal an underlying hardening of attitudes about privacy in the U.S. Most people may be willing in principle to do their bit for medical research, but faced with the task of having to distinguish between legitimate invitations to do so amidst a barrage of sales pitches and requests for money, they would rather
just be left alone. Reportedly the main motivation for the moratorium on access to names and addresses of Medicare enrollees was not that there had been any misuses of such data by researchers, but that CMS had received complaints from Medicare beneficiaries about their having been contacted for research recruitment purposes at all [20].

Coping strategies

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So what can we do? I’ll start with some more cynical options, just to get them out of the way. Just like everyone else, we epidemiologists respond to the incentives and disincentives presented to us. A rational response might be to turn to other kinds of research without all these headaches—use only pre-existing data, use just populations of convenience, or even look for greener pastures abroad. Who among us has not envied our colleagues in Scandinavia, with uniform personal identifiers and a generally more relaxed privacy climate? Maybe they need more collaborators.

General

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But for those of us still committed to trying to do good population-based epidemiology with primary data collection here in the U.S., there are some general measures we might consider. First, one factor that actually is under our control is how we track the problem of study participation. The literature about response rates in epidemiologic studies has been a confused literature for a long time for lack of consensus on how response rates are calculated and reported. We need to know where we stand and to be able to determine what factors, including alternative recruitment strategies, are associated with different levels of participation across studies. A useful analogy might be the CONSORT guidelines for reporting of randomized trials. A recent proposal to standardize the categories in which the final dispositions of potential study subjects are
reported seems like a good first step [21].

Second, we need to do what we can to promote the public image of epidemiologic research. As Patricia Hartge has noted, participants often value getting back information about themselves, or about the results of research in which they took part [8]. We should also be mindful of respondent burden issues and minimize discomfort whenever possible.

Third, we need to be scrupulous in protecting privacy and confidentiality. Even one widely publicized breach of confidentiality in an epidemiologic study could be quite damaging to our field.

Specific

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A few more specific coping strategies may also be worth noting. One option is to be more selective in worrying about response rates. Low participation does not always lead to bias. Bias due to non-response depends on two things: (a) the participation level, and (b) the extent of the difference between participants and non-participants on the factor of interest. When comparisons have been possible, some health-related characteristics have been found not to differ very much in relation to respondent status, which is reassuring [22–25]. But a clear pattern has yet to emerge as to when differences between respondents and non-respondents can be expected to be large or small, which is not reassuring. So the safest strategy is still to maximize study participation.

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Another coping strategy is to keep trying to make incremental improvements to RDD. It may be ailing, but it’s not dead yet. For example, leaving messages on answering machines seems to increase the chance that follow-up contact attempts will get through [16]. The number of callbacks can be increased. Once contact has been made, some interviewers are better than others at gaining participation [8]. Money also talks: cash incentives seem to increase participation and may be a small price to pay in the context of overall recruitment costs [7].
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A ray of hope for the future is the planned implementation next month of a national “Do Not Call” registry by the Federal Trade Commission. Consumers will soon be able to put their telephone numbers on a single national list and be protected from receiving a lot of unwanted telemarketing calls. Calls related to epidemiologic research will still be permitted. This new registry may help clear the air and help us get through to people in the future. Nonetheless, other kinds of calls that will also still be permitted include political solicitations, charity fund-raising, and telemarketing within the same state unless prohibited by state law. So we will have to wait and see how much help the registry offers for our kind of research.

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Other emerging technologies may offer new portals of access to populations for epidemiologic studies of the future. As of 2001, about half of U.S. homes reported having Internet access. But population coverage is not yet anywhere close to what it is for telephones, and there are still major sociodemographic disparities in access, as shown here.

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The Internet seems to have most to offer as a data collection method once someone has signed up as a study participant. Unfortunately, there remain serious problems in using it to obtain a probability sample of a geographically defined population. So far the Internet is not promising as a successor to RDD as a sampling method.

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To date, cell phones have been more of a nuisance than an asset for population sampling under RDD, but that could change. An interesting feature of cell phones is that they are linked most closely to individuals, as opposed to residential land lines, which are generally linked to households. Often it really is individuals that we want to sample. As the technology advances and costs come down, cell phones may reach very high levels of population coverage and may obviate the sometimes awkward problems of within-household sampling that we face now. Charging the
subscriber for incoming calls is much less common now than in the past, and this may eventually vanish as a barrier. There may soon be clever ways to use text messaging or other features to make an initial contact without interrupting someone at an annoying time.

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In the meantime, we may need to take another look at older sampling methods as alternatives to RDD. Before telephone sampling, area sampling was a common choice for geographically defined populations. Multi-stage area sampling remains in use on some national health surveys and has been used in localized epidemiologic studies [23–25]. Even in the heyday of RDD, area sampling usually yielded higher response rates [6]—evidently it’s harder to say no to a person physically present on your porch than to a disembodied voice on the telephone. The main barrier is cost. But with lower response rates and more calls now needed per participant recruited under RDD, that differential may well be shrinking. Ralph Frerichs and colleagues [26] in Los Angeles have shown that face-to-face community surveys using area sampling need not always be expensive.

Alternatively, other list-based sampling frames may become more important, although each has its own problems. Commercial mailing lists often have uneven coverage and are skewed toward people of higher income and education [27, 28]. Drivers license files have been reported to have about 85%–90% coverage for adults [3, 29] but do not always have current addresses and usually lack telephone numbers. Voter registration lists omit about a third of the adult population [3] and may be out of date.

In any event, we may be encountering a sea change in the ways we access populations, shifting away from sampling methods like RDD that we have relied on for many years and toward both newer and older alternatives.

**Side effects of specialization**

[Slide 25]
Let me comment briefly on the second challenge that I think faces us as epidemiologic researchers, which also has to do with communication—in this instance, with each other.

This slide shows some of the traditional “cleavage planes” that divide epidemiologists into different camps. We often categorize ourselves as being infectious-disease or chronic-disease epidemiologists; as having a clinical background or straight academic training; according to the setting where we work; and by whether we do basic epidemiologic research or field epidemiology.

As the field grows, epidemiologic researchers are becoming further subdivided according to the disease or exposure area on which they work. We routinely speak of someone as a cardiovascular epidemiologist, or a perinatal epidemiologist, or a nutritional epidemiologist, and often even as a subspecialist within one such area. Junior epidemiologists are encouraged to focus their area of interest early so that they can become an expert in a particular domain and gain command of all the literature and ongoing research in it. For one thing, one can then string together a progression of grants without having to write each new one from scratch. Being a recognized expert is expected when it’s time for promotion review. So specialization is a time-honored and practical strategy for professional development.

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The side effects of specialization, though, are increasing compartmentalization and fragmentation of the field and an increased risk that we become intellectually isolated from each other. We need exposure to each others’ ideas to refresh our own thinking and to identify opportunities for improving our own work.

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Perhaps we should view the factors on this list not just as ways in which we differ from each other but as ways in which we should be interdependent.

One can fight intellectual isolation in many ways—reading, collaborative research, serving on committees, even by being an administrator, as I found out. But organizations like SER play a special role by bringing us together as a large and diverse group of “comrades in arms.” Meetings
like this give us a chance to renew our personal connections, to learn from each other, to
encounter the unexpected, to be stimulated by controversy, and to remind us what epidemiology is
all about and why we were so attracted to this field in the first place.

[Slide 28]

It has been a pleasure and a privilege to serve as president of SER this past year. Thank
you for this opportunity and for your attention this morning.
References


20. Personal communication with Ms. Barbara Frank, 6/2/03.


