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# Evaluation Issues in the Drake Chemical Workers Notification and Health Registry Study

**Laura C. Leviton, PhD, Huey T. Chen, PhD, Gary M. Marsh, PhD, and Evelyn O. Talbott, DrPH**

The Drake Chemical Workers' Health Registry combined notification of workers about bladder cancer risk with access to a free program for screening and diagnosis. Evaluation of the project has given rise to several findings and new research questions. Findings in this article illustrate the following evaluation issues: 1) studying the combination of strategies that are most effective and cost effective to notify workers of their disease risks, 2) determining the realistic yield from strategies to gain participation in health screening and other protective services for notified workers, 3) identifying the notification strategies that were most effective for different kinds of participants, 4) using process evaluation to identify key activities for ensuring continued participation of cohort members in screening, and 5) examining the extent to which participants are willing to quit smoking to protect their health. © 1993 Wiley-Liss, Inc.

**Key words: worker notification, occupational health, bladder cancer, risk communication, screening programs, smoking cessation**

## INTRODUCTION

The Drake Chemical Workers' Health Registry and the events surrounding its implementation have been described elsewhere [Leviton et al., 1991; Logue and Fox, 1986; Marsh et al., 1988, 1990, 1991]. Briefly, workers were exposed to β-naphthylamine (BNA), a potent bladder carcinogen. The small, rural plant at which workers were exposed went bankrupt in 1981, and the site became one of the first nominated to the Superfund list. The program was implemented in 1986 under a cooperative agreement between the Pennsylvania Department of Health and NIOSH, with funding from ATSDR. The overall protocol for notification, screening, and registry data is shown in Figure 1.

The project has been underway for 5 years, and workers have been able to receive annual or semiannual screening, depending on eligibility criteria. The study has given rise to several evaluation findings and issues relating to worker notification. The opportunity has not emerged for pursuing all issues in as rigorous a fashion as one

Graduate School of Public Health, University of Pittsburgh, Pittsburgh, PA (L.C.L., G.M.M., E.O.T.).
Department of Sociology, University of Akron, Akron, OH (H.T.C.).
Address reprint requests to Laura C. Leviton, Graduate School of Public Health, University of Pittsburgh, Pittsburgh, PA 15261.
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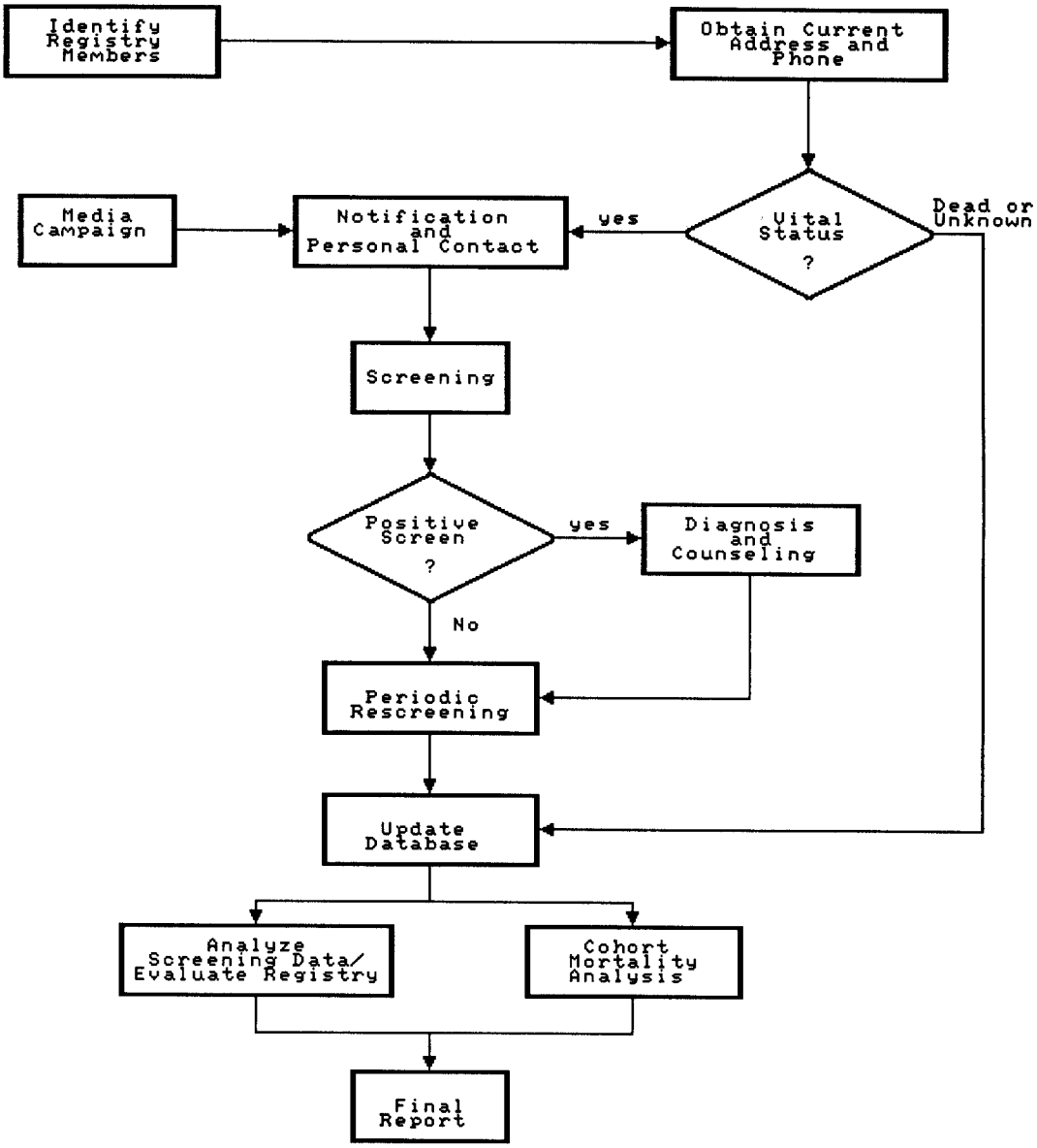


Fig. 1. The Drake Health Registry Study: Protocols and sequences from initial phase to final report on ongoing study.

**TABLE I. How Participants Learned About the Drake Screening Program***

| | | TV or radio | | Letter | | Phone | |
|---|---|---|---|---|---|---|---|
| | | Yes | No | Yes | No | Yes | No |
| Newspaper | Yes | 48 | 51 | 71 | 28 | 28 | 71 |
| | No | 17 | 148 | 139 | 26 | 77 | 88 |
| TV or radio | Yes | | | 47 | 18 | 13 | 52 |
| | No | | | 163 | 36 | 92 | 107 |
| Letter | Yes | | | | | 98 | 112 |
| | No | | | | | 7 | 47 |

*Missing data differ by item answered. Sample sizes not identical.

would like. Nevertheless, some preliminary information is available, and it may suggest subjects for evaluation in subsequent projects.

## ISSUE 1: WHAT COMBINATION OF STRATEGIES IS MOST EFFICIENT AND COST EFFECTIVE TO NOTIFY WORKERS?

Here the issues are twofold. What combination of message channels will maximize the number of people who are aware of their risk? What is the marginal cost per person notified of adding the most labor-intensive strategies for notification? Asking about the marginal cost of adding notification strategies brings up the issue of whether the cost of a strategy is warranted if it detects, say, only an additional 5%. This study included three basic strategies: a mass media campaign in the 50 mile radius of the Drake site; two notification letters sent to the address to which former workers had been traced; and, if former workers did not contact the program after receiving the letters, personal contact by the screening coordinator. While all notification strategies were helpful, an issue for examination is the expense of personal contact, and the marginal cost of adding time and effort for personally contacting participants who do not respond to other notification methods.

Data on these issues are presented in Table I. Participants responded to an interview that asked them to name the various ways in which they had learned about the bladder cancer screening program. The most useful strategies were media and notification letters. Information via personal telephone contact from the screening coordinator reached a different group than did media but essentially the same group as the letters. Workers were sometimes notified by friends, family members, and other sources, which are not presented in Table I. These methods were essentially a "free" byproduct of other notification methods, the so-called "multiplier effect" of word-of-mouth communication that is so often stimulated by media [McGuire, 1984].

Most people had heard about the screening program through means other than personal phone contact. If notification were the only goal, the marginal cost of personal contact would have been the cost of the screening coordinator's salary, divided by the number of notifications (i.e., seven). Clearly, the additional cost of personal contact would not be justified if notification were the only focus. However, the goal was not simply notification, but to gain a high participation rate in the screening program. Personal contact as a strategy was justified in this context.

These data reflect strategies and logic commonly used in health promotion and

disease prevention efforts, especially community-based efforts. It is argued that the media are a powerful tool for health promotion. Though relatively few people will act solely on the basis of information received through media, a fraction of them will act. In many health promotion campaigns, media are commonly used prior to implementing personal contacts, because the personal contacts will be less labor-intensive once people have been made aware of the health issue through media [Davis and Iversen, 1984; Farquhar, et al., 1985; McAlister, 1991].

## ISSUE 2: WHAT IS THE REALISTIC YIELD FROM STRATEGIES TO GAIN PARTICIPATION IN HEALTH SCREENING AND OTHER PROTECTIVE SERVICES FOR NOTIFIED WORKERS?

The notification process was aimed at recruiting former workers into medical screening for bladder cancer. Every effort has been made to recruit all participants, across all 5 years of the project. After 5 years, the project has accrued 81% of the potentially notifiable workers, and 90% have returned for at least one annual or semiannual rescreen. The project has reached a point of diminishing returns, and it is unlikely that participation will increase further, although one or two people (e.g., those in the merchant marine) may eventually enroll. The yield has stabilized.

The recruitment is comparable to that of Augusta Chemical Workers' Health Registry, for which resources per person were more limited and for which federal resources were available for only 2 years [Paul Schulte, personal communication, 1986]. Since results are similar, the issue for evaluation becomes one of detecting the point at which recruitment meets with diminishing returns, and whether the marginal cost of additional effort is justified.

## ISSUE 3: WHICH NOTIFICATION STRATEGIES WERE EFFECTIVE WITH WHICH PARTICIPANTS?

Information on a variety of worker characteristics was available from the workers' interviews at the time of initial screening. These included health symptoms, work history, demographics, smoking history, family health history, employment, and access to health care. We had hypothesized that symptoms of bladder cancer, as well as cancer deaths in the family, would lead people to recall media-based notification and announcement about the screening program and would lead them to take greater advantage of the annual screens. However, these hypotheses were not consistently supported.

Several characteristics of participants did differentiate those who learned about screening from media vs. from personal contact. Current smokers (65% of the respondents on whom there are data) had participated in fewer annual screens (mean 2.8) than former and nonsmokers (mean 3.4, t test 3.24, $p < .001$). Fewer current smokers (26.2%) had learned about the screening program through newspaper announcements than did former and nonsmokers (54.4%, $\chi^2 = 14.05$, $p < .0002$), while more current smokers (48.4%) than former or nonsmokers (29.4%) had decided to participate in the program only after a personal phone call ($\chi^2 = 5.80$, $p < .016$).

The relationship between current smoking and participation appears consistently with several dependent variables, leading to the belief that this is not a case of multiple comparisons capitalizing on chance. Also, other researchers have observed

correlations between current smoking and inaction to address other health risks. For example, Settergren et al. [1983], reported a higher rate of smoking among employees who did not participate in a comprehensive work site health screening than among employees who did participate.

Access to medical care also differentiated those who learned about the program through media and those who participated in screening only after a personal contact by the screening coordinator. Workers who had a family doctor recalled the newspaper announcements as well as television and radio news items about the program more often (44.6% and 28.5%, respectively) than did workers who had no doctor (21.1% and 14.5%, $\chi^2 = 11.77$, $p < .0006$; $\chi^2 = 5.01$, $p < .03$, respectively). Workers who had one usual source of medical care were more likely to learn about the program through the newspaper (41.5%) than workers who did not (25.4%, $\chi^2 = 4.83$, $p < .03$). Workers who had no family doctor tended to require personal phone calls from the screening coordinator (48.7%) compared to those who did have a doctor (36.6%, $\chi^2 = 2.82$, $p < .09$). However, those who had some form of health insurance were also more likely to require a phone call (58.3%) than were those without health insurance (35.6%, $\chi^2 = 7.52$, $p < .006$). Those without health insurance tended to hear about the program through the newspaper and to respond without the need for a telephone call (40.3%) compared to those who had health insurance (25.0%, $\chi^2 = 3.29$, $p < .07$). Though two of these findings do not reach conventional significance levels, they are consistent with a pattern.

Those who had a usual source of medical care may be more generally concerned with their health; therefore, they would recall hearing about the screening program through media. Those less concerned with health may require a personal telephone call to be persuaded to come for screening. On the other hand, the pattern with regard to health insurance may imply that some of the workers are relying on the screening program, because it is difficult for them to pay for other sources of care, especially cancer-related care.

These results are based on participant characteristics at the initial screening, and as such, reflect the situation at a single point in time. It would be most interesting to discover whether several years of screening experience altered the relationships. Although these results are post hoc and not hypothesis based, they do provide information for further investigation and for better tailoring of notification and screening efforts.

## ISSUE 4: WHAT CAN WE GAIN FROM EVALUATION OF PROCESS TO IDENTIFY THE KEY INGREDIENTS FOR CONTINUING PARTICIPATION OF COHORT MEMBERS IN SCREENING?

A key to the continuing participation of former workers in this project has been the relationship they have developed with the screening coordinator. Two masters-level students recently interviewed the coordinator about her relationship with 20 of the cohort members (see Acknowledgments). They learned that the coordinator: 1) usually takes a joking tone, once she is sure that the participant will respond well to it; 2) inquires whether the participant jogs, drives a truck, or has had sex in the last 48 hours, because these activities can produce unusual screening results with no cause for concern, and then explains why the questions were asked; 3) learned to talk "labor talk" to relate better to the participants; 4) knows the interview questions by heart,

which helps to keep the screening session informal, allowing conversational topics to be intermixed with interview questions; 5) does not ask participants whether they drink alcohol or smoke marijuana, because most do; 6) explains the purpose of all the tests and repeats her explanations each time; 7) develops into a personal confidante when personal information is offered by the participants; 8) helps participants to get assistance when needed from service organizations such as the Salvation Army and helps participants obtain a Medical Assistance card; 9) clears her calendar for the day whenever a participant is scheduled for cystoscopy (Frequently, the coordinator drives the patient and family to the hospital. Once there, she stays with them the whole day, informing them about the process and taking them out for coffee. She calls them periodically thereafter); 10) has attended funerals of participants' family members and sent sympathy cards; and 11) learns the names of the wives and works with the wives to get the participants to come for repeat screenings. The screening coordinator provided a suggestion: "The secret is to find something about each person that makes the interaction personal. I make notes to myself about what that person likes, and that is what keeps them coming."

## ISSUE 5: WILL PARTICIPANTS FOLLOW MEDICAL ADVICE TO QUIT SMOKING?

A smoking cessation program was made available to workers [Leviton et al., in press]. The program consisted of medical advice to quit smoking, since smoking adds to the risk of bladder cancer. Following a protocol developed by the National Cancer Institute, medical advice and subsequent behavioral counseling were tailored to the participants' stage of quitting smoking. These stages are precontemplation, in which smokers do not think seriously about quitting; contemplation, in which smokers start to think about quitting but have no intention to quit in the immediate future; preparation, in which they are ready to quit; short-term quitting, in which their behavior change is of short duration; and maintenance, in which longer term cessation has been achieved. Relapse may follow upon short-term quitting [DiClemente et al., 1991]. Physician advice helps smokers progress through the stages of change, as long as smokers are willing to expose themselves to this advice.

Of the projected 108 former workers in the 50-mile radius of the site who were current smokers, only 43 chose to listen to what a medical professional had to say about smoking cessation. This intervention made few demands on the smokers, who were not expected to quit smoking immediately. Since the end of the smoking cessation program, an additional 18 workers have asked for assistance in quitting smoking, from which we conclude that this self-protective measure has more to do with being a smoker than with being at risk of bladder cancer. Research indicates that smokers have a "window of opportunity" during which they are willing to consider this major lifestyle change; appeals to their health outside this window are often discounted.

It is notable that the screening coordinator, so trusted and liked by cohort members, simply could not get them to take part in a smoking intervention. A very large proportion of the cohort are likely to be at the precontemplation stage of smoking [DiClemente et al., 1991]. It is unlikely that they would accept advice to quit, even advice received from their own physicians. Relatively low education and the local norms in favor of smoking may offer explanations for their resistance to medical advice.

A lack of interest in smoking cessation has been observed in a similar cohort of workers who live nearby: the Port Allegany asbestos workers [Houts, this issue]. In general, the blue-collar smoker is less interested in quitting than the white-collar smoker [Sorensen and Pechacek, 1986]. On the other hand, other studies of physician advice to asbestos-exposed workers have found interest in quitting and respectable smoking quit rates. In a study conducted at many sites throughout the nation by Kilburn and Warsaw [1990], self-reported quit rates rose from 4.7% in the year before workers received advice to quit to 29.8% of those responding to a mailed questionnaire, and 17% of nonresponders followed-up by phone. The smokers' rate of participation in smoking cessation was not reported. Li et al. [1984] obtained participation in a minimal smoking intervention from 84% of the smokers in their cohort. These authors presented a chemically verified smoking cessation rate of 8.4% at 1 year among smokers who had received behavioral counseling.

These disparate results for participation in smoking cessation and for quit rates require explanation and further study. One possible explanation does present itself. In the studies by Li et al. and by Kilburn and Warshaw, smoking cessation advice was given in the context of the worker's first asbestos screening, and in this context workers might well be motivated to learn all they can about their health in the context of the screening. In contrast, the Drake Chemical Workers project and the Port Allegany program offered smoking advice as a later service, once a health surveillance program had been in place for some time and once the workers had a fairly good idea of their state of health.

## CONCLUSIONS

In evaluation, the investigator must always choose what to measure, and in recent years, evaluators have learned through hard experience the importance of focusing on program planning and implementation [Shadish et al., 1991]. This paper has taken the implementation focus: how to make the process work better and how to link worker notification to specific efforts to protect workers' health. Less well-defined "impact" issues find little consensus on goals and objectives and are left to other investigations. This paper emphasizes a need to assess the effectiveness of alternative strategies in the notification process itself.

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