

BMJ Open Principal components analysis to identify influences on research communication and engagement during an environmental disaster

Charlene A Winters,¹ Colleen F Moore,² Sandra W Kuntz,³ Clarann Weinert,⁴ Tanis Hernandez,⁵ Brad Black⁵

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For numbered affiliations see end of article.

Correspondence to

Dr Charlene A Winters;
winters@montana.edu

ABSTRACT

Objectives: To discern community attitudes towards research engagement in Libby, Montana, the only Superfund site for which a public health emergency has been declared.

Study design: Survey study of convenience samples of residents near the Libby, Montana Superfund site.

Participants: Residents of the Libby, Montana area were recruited from a local retail establishment (N=120, survey 1) or a community event (N=127, survey 2).

Measures: Two surveys were developed in consultation with a Community Advisory Panel.

Results: Principal components of survey 1 showed four dimensions of community members' attitudes towards research engagement: (1) researcher communication and contributions to the community, (2) identity and affiliation of the researchers requesting participation, (3) potential personal barriers, including data confidentiality, painful or invasive procedures and effects on health insurance and (4) research benefits for the community, oneself or family. The score on the first factor was positively related to desire to participate in research ($r=0.31$, $p=0.01$). Scores on factors 2 and 3 were higher for those with diagnosis of asbestos-related disease (ARD) in the family (Cohen's $d=0.41$, 0.57). Survey 2 also found more positive attitudes towards research when a family member had ARD (Cohen's $d=0.48$).

Conclusions: Principal components analysis shows different dimensions of attitudes towards research engagement. The different dimensions are related to community members' desire to be invited to participate in research, awareness of past research in the community and having been screened or diagnosed with a health condition related to the Superfund contaminant.

INTRODUCTION

At any Superfund contamination site, community engagement in the clean-up process and health research is important. In

Strengths and limitations of this study

- The use of principal components analysis is a strength as it is rarely used in studies of research engagement.
- The identification of dimensions of attitudes towards research and research engagement in a Superfund community is a strength of the study.
- The use of convenience samples is a limitation of the study.
- Survey 2 did not fully replicate the results of survey 1 and is seen as a limitation of the study.

particular, community involvement in research is essential in order to identify the health, psychological and socioeconomic impacts of the toxic exposures as well as the effectiveness of the clean-up. In this paper, we address how a rural community views research and research engagement during the clean-up of an ongoing environmental health disaster. Our study was conducted in Libby, Montana, the only community to date at which the United States Environmental Protection Agency (EPA) has declared a public health emergency due to health effects of an environmental contaminant.¹

Background on Libby and the WR Grace/Zonolite vermiculite mine

Libby and its surrounding county is designated as rural according to the 2010 census (pop. 2628, county pop. 19 687, 5.4 persons/square mile).^{2 3} Historically, the economic mainstays of Libby and the surrounding area have been forestry and natural resource extraction. From the 1920s until 1990, vermiculite ore mined near Libby provided ~80% of the world's supply.⁴ Vermiculite is a naturally occurring fibrous mineral widely used in industry and construction⁵ primarily as an insulating material, and also as a soil

conditioner. The ore was distributed from Libby to more than 200 processing facilities across the United States during the time period when the mine was operating. Vermiculite was freely available for residents of Libby and widely used in the community on unpaved alleys, the baseball field and high school track, as well as in residents' attics, yards and gardens.

It is now known that the vermiculite ore from the WR Grace/Zonolite mine near Libby was contaminated with naturally occurring amphibole asbestos.⁶ Amphibole asbestos is a toxic mineral associated with lung cancer, mesothelioma and non-malignant lung and pleural disorders, including asbestosis, pleural plaques, pleural thickening and pleural effusions^{7–9} in exposed workers, family members of exposed workers and members of the Libby community. Recent research has also shown immune system effects of amphibole asbestos in human and animal research.^{10–12}

EPA investigation of asbestos contamination in Libby began in 1999. In 2002, the EPA listed Libby and the surrounding area on the National Priority List as a Superfund site due to community-wide amphibole asbestos contamination from W.R. Grace's vermiculite mine and operations. This designation came after medical screenings of more than 6668 Libby residents found pleural disease in a substantially higher number of residents than would be expected in the non-asbestos exposed population.¹³ It was 7 years after the Superfund designation when in 2009 the first public health emergency in United States history was declared for the Libby area under the Superfund Act¹ in recognition of the significant and ongoing risk to the public and negative health effects caused by exposure to Libby amphibole asbestos (LAA). At that time, there were 1617 hazardous waste sites nationwide on the National Priority List¹⁴ eligible for long-term remedial action (clean-up) financed under the Federal Superfund Program.

Importance of research engagement and communication in rural Superfund sites

To understand the full health and psychosocial effects of any form of disaster requires the engagement of the individuals who are most affected. The importance of community engagement is recognised by the requirement in the Superfund act that the EPA have a formal community involvement plan.¹⁵ A large number of Superfund sites are located in rural areas across the United States, as shown by the EPA interactive map.¹⁴ However, research addressing rural Superfund sites appears to be minimal. A search of the Web of Science using terms 'rural' and 'Superfund' yielded 13 items, and the same search in PubMed yielded 8 papers. In PubMed, the term 'rural' yields more than 140 000 entries, and the solo term 'Superfund' yields 737 entries. That the conjunction of these terms yields such a sparse set of articles suggests to us that there is a true lack of research. Of the eight papers in PubMed, two were coauthored by our team on the pollution in Libby,

two concerned a Superfund site on a Native American reservation in Oklahoma and the others dealt with a range of other pollutant transport issues.

Recruitment and engagement for research of individuals living in rural communities can be challenging given rural dwellers' discomfort with outsiders and persons unfamiliar to them.^{16–17} Indeed, research has shown that rural residents were least likely to be represented in medical research, behind the general public and African-Americans.¹⁸ In addition, conducting research within the context of an environmental disaster has its challenges as people and community efforts are focused on ensuring safety, return of needed services and economic recovery.

Research that has been conducted in Libby and elsewhere following technological disasters, catastrophic natural disaster or terrorist attack has most often focused on the health of the individual and the community^{19–29} while little research has addressed individuals' engagement in research and research communication within the context of an ongoing disaster.³⁰ In 2007, the United States National Institutes of Health (NIH) launched its Partners in Research Program³¹ in recognition of the importance of engaging individuals and communities in research. The programme initially supported 2-year studies designed to improve public understanding of healthcare research and promote collaboration between scientists and community organisations that would lead to increased participation of lay communities in health research. It is not clear to us if the funding programme currently exists; however, the NIH continues to support the engagement of community stakeholders in research.

Although the topic of research participation during environmental disasters has been neglected, there is a broad literature on motivations for and willingness to participate in biomedical research. The majority of the publications focus on specific clinical trials (see Lovato *et al.*³² for a review). A recent systematic review of minority group research participation concluded that members of minority groups in the United States were willing to participate in research for altruistic reasons (such as helping family or community), as well as for access to healthcare resources and knowledge, and for adequate remuneration. Barriers common across ethnic and racial groups included mistrust and lack of access to information about research opportunities.³³ A widely cited study by Trauth *et al.*³⁴ surveyed a random sample of ~500 people in the Pittsburgh area about their attitudes and beliefs pertaining to the research process and asked whether the respondents would participate, in principle, in research about a specific disease that was a concern to themselves or loved ones. Those with a loved one with an illness were more likely to express willingness to participate. Age was inversely associated with willingness to participate, whereas those who had participated in research previously and who did not have children were more likely to express willingness.

Most directly relevant to the present work is a study in a rural setting of attitudes towards research and participation that used principal components analysis to summarise the attitude dimensions.³⁵ Using modifications of the items from Trauth's study, Morgan *et al* conducted a mailed survey of 865 people from rural upstate New York. The principal components analysis yielded seven factors described as: (1) presence of illness, (2) intangible benefits including helping the community, (3) convenience, including low risk, short travel and knowing the doctor involved, (4) tangible rewards such as gifts, (5) trust barriers, such as not knowing the researcher or others involved in the study, (6) timing barriers, such as missing work and (7) logistics, such as lack of transportation, or weather. Those with a non-fatal illness were more willing to participate in research, and those scoring lower on barriers were more likely to report willingness to participate.

Present study

In this paper, we report the findings of a study supported by the NIH Partners in Research Program and conducted in Libby, Montana. During the time of the study, Libby and the surrounding areas had already been listed as a Superfund site and were in various phases of the clean-up, which is still ongoing in 2016. The public health emergency had not yet been declared when survey 1 was administered but had been declared approximately a year prior to survey 2. The overall funded project, a mixed-method case study, was framed by the (1) cardinal rules of risk communication and the risk communication model,^{36 37} (2) community-based participatory research (CBPR) principles³⁸ and (3) rural nursing theory,¹⁶ which describes rural persons as hardy, self-sufficient, independent, work oriented, distrusting of 'outsiders' and 'newcomers' and trustful and respectful of 'old timers' (people who have lived in the community for an extended period of time). A previous publication reported the overall scope and framework of the project, the background of research in Libby, interviews about research and descriptive findings.³⁰

The current report used principal components analysis to identify the empirical dimensions of two surveys of influences on Libby residents' research engagement, and attitudes towards research and researchers. Examining the dimensions of attitudes towards research using either principal components or factor analysis has been rare in the research participation literature. After applying principal components analysis, we tested whether the factors from the survey would be related to (1) past engagement in research and desire to be invited to participate in research, (2) awareness of past research in the community, and awareness of past news communications about research, and (3) past participation in community health screenings for and the presence of asbestos-related disease (ARD) in the respondent or respondent's family.

METHODS

Materials

The questionnaire items in survey 1 were constructed in order to measure sources of communication about research in the community, attitudes towards research and researchers and engagement in research. Items were developed in consultation with a Community Advisory Panel. The items in survey 1 fell into three areas: (1) communications sources about research commonly perceived, effective, preferred and trusted, (2) awareness of research in the community and past participation in research and (3) attitudes towards research and researchers, influences on research participation and willingness to participate. Survey 2 was considerably shorter than survey 1 and contained a subset of items from survey 1, but also included a brief newspaper article about research with questions about awareness of the article. Survey 2 was intended to confirm key results from survey 1, especially regarding attitudes towards research, researchers and research engagement, as well as the most common communication sources. Both surveys included questions about demographic and background variables: gender, race and ethnicity, age, income category, years resident in Lincoln County, years of school completed, ever smoked tobacco products, worked or lived with someone who worked with vermiculite, screened for ARD and whether participant or a family member has been diagnosed with ARD, whether the respondent had respiratory health issues and whether one's home had been cleaned by the EPA. The study was approved by the Montana State University Institutional Review Board.

Sample recruiting, data collection and data management

Data for survey 1 were collected in person using a portable computer kiosk between 28 April and 10 June 2009. A convenience sample was recruited by representatives of the research team at one of the local grocery stores. Data for survey 2 were collected in person between 12 April 2010 and 19 June 2010, using paper surveys at six different community meetings. The data of survey 2 were collected approximately a year after the declaration of the public health emergency by the EPA administrator. Data from both surveys were entered into an electronic database for analysis.

Statistical analyses

Statistical analyses were conducted in R V.3.1.2, SPSS V.22 and BMDP 1990. For survey 1, of the 120 participants who began the survey, 11 were excluded from further analyses because of missing data for more than 15% of the responses (more than 19 answers omitted), leaving 109 whose data are analysed here. For the 109 reported below, missing responses, 'don't know' and 'choose not to answer' responses were excluded pairwise in analyses. 'Don't know' and 'choose not to answer' were options for questions on respiratory health issues, self or family-member diagnosis of ARD, income and having had one's

property cleaned by the EPA. The maximum number of excluded responses on any item was 13 (for property cleaned by EPA, with 10 of those answering 'don't know'). Principal components analysis with varimax rotation was used to summarise the empirical dimensions of the scale. Following principal components analysis, we created factor-based composite scores for the items assessing attitudes towards researchers and influences on research participation. Composite scores were calculated as the average of the existing responses for each participant. A four-factor solution was used based on the eigenvalues and scree plot. The four factors accounted for 63% of the variance. Items with a loading >0.5 uniquely on a single factor were included in the factor-based composite scores, as shown in [table 1](#).

For survey 2, 127 individuals completed all or part of the survey. The total number of missing responses ranged from 0 to 20 (out of 33 items), with a median of 4 responses missing. Questions about the most common, effective, preferred and trusted communication sources showed the pattern of missing data indicating that some participants rated only their top source and omitted rating other sources. These data made up 50.2% of the missing data and are not considered in this paper.

Relationships between the dichotomous variable of past research participation and other dichotomous variables were examined with χ^2 tests of independence (or Fisher's exact test if expected values were insufficient). The strength of association is reported as the ϕ coefficient, and ORs are reported to aid interpretation.

RESULTS

Sample descriptive statistics

The demographics and other characteristics of the samples from Surveys 1 and 2 are given in [table 2](#). The two samples were highly similar, with the exception of length of residence, which was approximately a decade longer for the sample in survey 2 than in survey 1. In survey 1, approximately one-quarter of the sample was ARD diagnosed, and across the two surveys ~41% had a family member or self with an ARD diagnosis. These results punctuate the extent of the impact of the asbestos contamination in the community but are not surprising given other estimates of ARD in the Libby area. For example, the results of the 2000–2001 public health screening found pleural abnormalities in 18% of Libby residents, 26% of residents who had a family member who worked at the mine and 51% of former WR Grace (mine and vermiculite processing plant) workers.³⁹

Attitudes towards research, researchers and influences on research engagement

[Table 1](#) includes the results of the principal components analyses of Surveys 1 and 2, the mean responses and Cronbach's α for each factor-based composite score. The mean responses to the eight items included in survey 2 are given in the far right column of [table 1](#). In survey 1,

the first factor contained the items pertaining to attitudes towards research and researchers, whereas the potential influences on research participation fell into three additional factors. We call the second factor who and what because it contained items pertaining to who conducts the study, who requests participation in the study (the researchers or healthcare provider), the topic of the research and study length. The third factor pertained mainly to potential barriers to research participation: whether one's data would be protected, effects on insurance or one's healthcare and whether a study would involve invasive or painful procedures. While these items were worded positively (as lack of barriers) in our survey, we use the term potential barriers because much of the literature on research participation has studied barriers. We named the fourth factor research benefits because it included items about whether the research was believed to be worthwhile, helpful to the community and helpful to the person or his/her family. Cronbach's α was good for all four factor-based scores, as shown in the bottom row in [table 1](#). As in some other studies,⁴⁰ monetary reward was not rated to be very important and did not load uniquely on any factor. Time and effort for participation also did not load uniquely on a single factor, although the length of the study did load on the who and what factor. Very few items showed strong cross-loadings on more than one factor. An exception is the item "If I think the research will positively affect my healthcare", which loaded somewhat strongly on factor 4 (research benefits) as well as on factor 3 (potential barriers), indicating that a personal outcome can be important. However, it is interesting that a similar item in factor 1, "Their research makes a significant contribution to me personally" did not cross load onto factor 4 (research benefits). These two items were not included in survey 2, and so the distinctiveness of the factors on this issue is preliminary.

A separate principal components analysis of the eight items included in survey 2 showed two factors that accounted for 87% of the variance. The four questions about characteristics of the researchers loaded strongly on one factor, and the four questions about influences on research participation loaded strongly on another factor. Factor-based composite scores had good reliability, with Cronbach's α exceeding 0.90. The two factors from survey 2 align most closely with the attitudes towards research and researchers (factor 1 survey 1) and research benefits (factor 4 survey 1) factors of survey 1.

One approach to a partial cross-validation of the factors across the two surveys is to apply the factor loadings from one survey to the other survey and then correlate the factor scores within a survey.⁴¹ We applied the factor loadings from survey 2 (which had only eight items) to the same eight items in survey 1 and also created factor scores from a separate principal components analysis of only those eight items in survey 1. The correlations of the two factors within survey 1 were 0.99 and 0.98, respectively. We also carried out this process by

Table 1 Principal components factor loadings of attitudes towards researchers and influences on research participation

Item	Survey 1, mean (SD)	Factor 1: attitudes towards research and researchers	Factor 2: who and what	Factor 3: potential barriers	Factor 4: research benefits	Survey 2, mean (SD)	Survey 2 factor 1: attitudes towards research and researchers	Survey 2 factor 2: research benefits
Attitudes towards researchers and research								
Their research makes a significant contribution to community	6.57 (2.69)	0.86				7.0 (2.62)	0.77	
Report their results to community	6.19 (2.48)	0.85				5.70* (2.59)	0.93	
Announce their studies to the community	6.16 (2.41)	0.84				6.62 (2.60)	0.90	
Are available to community	6.45 (2.26)	0.78				6.03 (2.82)	0.88	
Their research makes a significant contribution to me personally	5.65 (2.93)	0.76						
Are friendly	7.40 (2.08)	0.63			0.51			
Use understandable language	6.66 (2.34)	0.57			0.44			
Potential influences on research participation								
Group/person conducting study	6.85 (2.67)		0.87					
The researcher asked me to participate	6.44 (2.80)		0.71					
My healthcare provider asked me to participate	6.90 (2.80)		0.68					
Research topic	8.02 (2.30)		0.67		0.44	8.10 (2.44)		0.96
Length of study	6.57 (2.30)		0.61	0.31				
Not invasive or painful	6.92 (2.91)			0.75				
Information legally protected from release	7.51 (2.93)			0.71				
Release of information will affect my insurance coverage	6.85 (3.35)			0.72				
Positively affect my healthcare	7.92 (2.53)			0.70	0.50			
Research will help my family and me	7.97 (2.77)			0.33	0.67	8.36* (2.54)		0.93
Research is worthwhile	8.73 (2.07)		0.33		0.67	8.18 (2.38)		0.92
Research will help the community	8.59 (2.12)		0.43		0.67	8.27 (2.30)		0.92
Monetary reward offered	3.39 (2.86)			0.49	-0.45			
Time and effort for participation	6.86 (2.55)		0.46	0.40				
Factor, means (SD)		6.52 (1.90)	7.04 (2.02)	7.42 (2.30)	8.47 (1.91)		6.49 (2.47)	8.23 (2.30)
Cronbach's α		0.90	0.81	0.80	0.82		0.92	0.95

Items were rated on a 1–10 scale with 1 labelled 'strongly disagree' and 10 labelled 'strongly agree'. Loadings below 0.30 are omitted from the table. Factor-based scales were constructed by averaging item scores loading 0.50 or higher uniquely on a factor. Blanks in the survey 2, mean column indicate item not asked.

*Item is worded slightly differently in survey 2.

Table 2 Sample characteristics for surveys 1 and 2

	Survey 1 (N=109)	Survey 2 (N=127)
Gender	66% F (N=72)	60% F (N=75)
Age	56 (median), 54 (mean), range 21–88	Not asked
Income category	US\$25 001–US\$40 000 median	US\$25 001–US\$40 000 median
Years school completed	14.0 median, 14.1 mean, range 2–22	14.0 median, 13.8 mean, range 1–22
Employed as vermiculite worker	7% (N=8)	6% (N=8)
Lived with employee WR Grace or Sawmill	25% (N=27)	Not asked
ARD screened	57% (N=62)	58% (N=74)
ARD diagnosed	25% (N=25)	Not asked
Family member ARD diagnosed (survey 2: self or family member)	38% (N=38)	41% (N=51)
Respiratory health issues	35% (N=35)	Not asked
Ever smoked	49% (N=53)	Not asked
Years residence Southern Lincoln Co.	20 (median), 23.6 (mean), range 0–66	30 (median), 33.1 (mean), range 1–81
Property cleaned by EPA	26% (N=25)	32% (N=38)
Participated in research (survey 1: in Libby/Lincoln Co.)	48% (N=52)	47% (N=60)
Participated in research outside Libby/Lincoln Co.	76% (N=75)	Not asked
Race/ethnicity	Not asked	92% White non-Hispanic (N=77)

ARD, asbestos-related disease; EPA, Environmental Protection Agency.

applying survey 1 factor loadings (for the eight items only) to survey 2, and the results were similar (r 's=0.99 and 0.97). This indicates that principal components of the eight items common to surveys 1 and 2 yield the same factors. Of course, it does not address wider generality of the results.

Relationships of factor scores to demographics

In survey 1, scores on the who and what factor were positively related to age ($r=0.27$, $p<0.01$) and length of residence in the area ($r=0.27$, $p<0.01$). In survey 2, length of residence was related significantly to the attitudes towards research factor ($r=0.32$, $p<0.01$) (participant age was not asked in survey 2). Gender was not associated with factor scores in either survey.

Research engagement: desire to be invited for research, past research participation and research awareness

In survey 1, participants rated their desire to be invited to participate in research (1–10, 1=definitely not, 10=definitely yes). Answers to this question were positively related to the attitudes towards research/researchers (survey 1—factor 1) in both a regression with all four factor scores included, and as a bivariate correlation; attitudes factor, $b=0.417$, $p=0.01$, full model $R^2=0.077$, $p=0.085$, $r=0.31$, $p<0.01$. The three other factors were not related to desire to be invited for research ($p>0.65$). Desire to be invited to participate in research was not significantly related to past research participation ($p=0.85$, means=5.83, 5.93 for previous non-participants and participants, respectively).

Previous research participants also showed slightly higher scores on the attitudes factor in survey 1 compared to non-participants, but the difference did not

reach significance (survey 1 M s=6.82, 6.18, SD s=2.0338, 1.8281, respectively, $p<0.09$; survey 2 M s=7.05, 6.29, SD s=2.50, 2.61). Previously having participated in research was not significantly related to the other factor scores in either survey 1 (smallest p value=0.32) or survey 2 (smallest p value=0.12).

Awareness of research and research news communications

Research awareness was measured in survey 1 by a 'true-false-don't know' question: "Over the past several years, a variety of health research studies have been conducted in Libby." Those who answered true had significantly higher scores on attitudes towards research (factor 1) compared to those answering false or don't know (M s=6.93, 5.55, $t=3.61$, $p<0.01$). None of the other factor scores differed significantly by research awareness (smallest $p=0.20$). Those who answered true to the research awareness question were also more likely to have previously participated in research in Libby or Lincoln County, $\chi^2=5.89$, $p<0.02$.

Research communication awareness was measured in survey 2 by two yes–no questions. One asked whether participants usually read articles about health research in Libby, and another asked whether the respondent remembered either of two specific newspaper articles about health research. A large majority (85%) reported that they usually read news about health research, but fewer remembered either of the example articles (38%). These questions were significantly associated such that those who usually read news were more likely to say they remembered one of the articles, $\chi^2=4.15$, $\phi=0.19$, $p<0.05$. However, the research awareness questions were not associated with the survey 2 factor scores (smallest $p=0.21$).

Table 3 Associations between past research participation* and other characteristics

	p value less than	ϕ	OR
Survey 1			
ARD screened	0.0001	0.504	4.18/0.44=9.50
ARD diagnosed (self)	0.0050	0.274	3.17/0.49=6.47
EPA cleaned property	0.43	0.082	1.50/1.03=1.46
Survey 2			
ARD screened	0.0001	0.545	2.36/0.18=13.28
ARD diagnosed (self or family)	0.0001	0.399	2.40/0.43=5.56
EPA cleaned property	0.80	0.023	1.00/0.90=1.11
Remembered reading news article	0.0001	0.384	2.67/0.49=5.44

*In survey 1, respondents were asked about research participation in Lincoln County. In survey 2, respondents were asked if they had participated in research in the past. ORs were calculated as ratio of (participated in research/not participated in research) at each category of the second variable.

ARD, asbestos-related disease; EPA, Environmental Protection Agency.

ARD screening and diagnosis

In survey 1, those who reported that either self or family member had an ARD diagnosis scored significantly higher on who and what (factor 2) ($t=2.09$, $p<0.04$, $M_s=6.79$, 7.59 , $SD_s=2.21$, 1.65 , for not-diagnosed and diagnosed, respectively), and on research benefits (factor 4) ($t=2.82$, $p<0.01$, $M_s=8.10$, 9.10 , $SD_s=2.25$, 1.03 , for not-diagnosed and diagnosed, respectively). There were no significant differences in the factor scores between those having been screened for ARD or not, although the difference approached significance in the same direction for ratings of research benefits (factor 4) ($t=1.95$, $p=0.054$, $M_s=8.11$, 8.81 , $SD_s=2.26$, 1.54 , for not-ARD-screened and ARD-screened, respectively). In survey 2, those who reported that either self or a family member had an ARD diagnosis scored significantly higher on factor 1 (attitudes towards research and researchers) ($t=2.49$, $p<0.02$, $M_s=6.06$, 7.26 , $SD_s=2.62$, 2.36 , for not-diagnosed and ARD diagnosed, respectively), but did not differ on factor 2 (research topic and benefits), $p=0.13$. In survey 2, there were no significant differences in the factor scores between those having been screened for ARD or not ($p=0.096$ for factor 1 and 0.99 for factor 2).

In Surveys 1 and 2, past research participation was significantly related to having been screened for ARD (see table 3). This is a striking finding because of the importance of screening for ARD in the community of Libby. In survey 1, past research participation was also related to having been diagnosed with ARD, whereas in survey 2 it was significantly related to having self or a family member diagnosed with ARD and also to remembering having read the example newspaper articles about research in the community.

DISCUSSION

The present study adds three new contributions to the literature. First, our research is one of very few studies to examine empirical dimensions of attitudes towards research participation and researchers, regardless of location or biomedical setting. Second, the present

study is unique in addressing attitudes relevant to community engagement in research at a Superfund location. The factor scores were predictive of some aspects of research engagement and were related to a diagnosis of ARD. As emphasised throughout this paper, engaging contaminated (or exposed) communities in research is important for understanding and addressing the full health and psychosocial effects of environmental disasters and their clean-up. Third, our study addresses research engagement in a rural Superfund setting, thus raising important issues about carrying out research successfully in such situations. We discuss each of these contributions below.

Empirical dimensions of attitudes towards research

The first contribution of our study is in the empirical examination of dimensions of attitudes towards research, researchers and research engagement using principal components analysis. The factors from the principal components analyses echo themes that can be found elsewhere in the research participation literature, including in qualitative studies. Frequently discussed aspects of participant attitudes towards research include helping others or altruism, personal benefits such as better medical care, trust and affinity with the person who requests participation and barriers such as lack of trust, invasive procedures, time, scheduling and transportation. We discuss these aspects of research participant attitudes with respect to the factors from our surveys.

In our study, participating in research to help the community and to help oneself or one's family loaded together on the same factor in survey 1 (factor 4—benefits) and survey 2 (factor 2 of survey 2—benefits). This is interesting because some of the literature on research participation is caught in arguments over whether true altruistic motivations exist and whether researchers should emphasise potential benefits or altruism⁴² (see Mein *et al*, for a discussion of this issue). Our results, while specific to the Superfund situation in Libby, Montana, empirically ground the suggestion that both motivations coexist and can be equally important.⁴³ Personal benefit and altruism have been cited as

motivations for biomedical research participation in many other studies.^{32 34 35 44} For rural residents in particular, participating to help others or one's community has been found to be an important motivation for research participation.³⁵ More recently, helping others has been shown to be a motivation for research participation in studies on a range of topics including mothers of healthy newborns,⁴⁵ those who have lost someone to suicide,⁴⁶ those who enrol in a registry on dementia research⁴⁰ and enrollees in registry for behavioural research on family members with intellectual disability.⁴⁷

In survey 1, 'the researcher asked' and 'my healthcare provider asked' for participation loaded together on factor 2 with items about the research topic and what group was conducting the research. Results from one recent study showed that 'being asked' to participate was mentioned as a prominent reason for research participation by those with physical injuries,⁴⁸ and recommendations to participate in clinical trials by oncologists or general practitioners have been found to be important in cancer trials.⁴⁹ Of course, there are a number of ethical issues to consider when a primary care health professional makes a recommendation for a patient to consider participation in any research. Patients who have recently received a diagnosis of a serious health condition are in a vulnerable position emotionally, and the primary care provider is a trusted authority figure. Patients may not always understand what a clinical trial is or may think their personal physician should control what experimental treatment the patient ends up receiving.⁵⁰ On the other side, physicians worry that recommending that a patient considers a clinical trial may affect the patient's trust in the physician.⁴⁵ In Libby, healthcare providers from the Center for Asbestos Related Disease are actively engaged in research, believe that research 'is a community project' and routinely provide opportunities for community members to interact with and learn about research from the Center's research partners.

Researchers also found that desire to be connected to the regional university research was a positive influence on enrolment in a research registry,⁴⁷ a finding that emphasises the identity of the researchers. In rural nursing theory, there is an emphasis on rural persons' discomfort with outsiders and persons unfamiliar to them.¹⁶ In this study, regional university researchers partnered with well-known local healthcare providers (community insiders) to design and conduct the study, the second study conducted by the team in Libby. While trust in the researchers was not explicitly assessed in the present research, the identity of the researchers and who requested participation were likely to be connected to trustworthiness for potential participants.

Our review of the literature on perceived barriers to research participation found an emphasis on perceived risks, trust of the researchers and the logistics of participation such as transportation and convenient scheduling. Factor 3 of survey 1 contained items pertaining to

privacy, insurance and procedures that are not painful and invasive. Our survey did not ask directly about research logistics. Other studies have also found that participants feel that invasive or painful procedures and concerns about privacy^{50 51} may be barriers to participation.

Attitude factors, research engagement and research communication awareness

Consistent with previous research on rural groups,¹⁷ we found that attitudes towards the researchers themselves, including seeing them as available, making a significant contribution to the community and communicating well, was a predictor of desire to be invited to participate in research. A potentially important finding is that having an ARD diagnosis for oneself or a family member was related to higher scores on the who and what (factor 2) and research benefits (factor 4) items in survey 1. Trauth *et al*³⁴ found that participants reported more motivation to participate in medical research if it addressed a health condition of a loved one. Interestingly, in our study ARD diagnosis was also related to previous research engagement, although previous research engagement itself did not show significant relationships to the attitude factors. Thus, our findings echo those of Trauth *et al*,³⁴ as well as the work of Morgan *et al*³⁵ who both found that those with a loved one with an illness expressed more willingness to participate in research on that illness. The present results add a slightly deeper texture to the previous results. The factors from survey 1 that showed a significant difference according to ARD diagnosis were related to specifics of who is inviting participation and what the research is, and whether the research will benefit the community and one's family or self. Factor 1 of survey 1, general attitude towards researchers, was not related to having an ARD diagnosis, and neither was factor 3 of survey 1.

Can the present results be used to make recommendations for communicating about research and health screening in Superfund situations?

While each Superfund site faces its own health, social and economic issues, the issue of research and health screening participation is important to ascertain the effectiveness of the clean-ups. For example, in the area surrounding the Bunker Hill mining complex near Kellogg, Idaho, the rate of blood lead screening of children has fallen dramatically during the 2000s even though blood lead values remain above the national average.⁵² Those authors discussed issues of personal blame and stigma as possible factors in the low rate of screening. In contrast to the Bunker Hill mining Superfund area, the number of children screened for blood lead in the Butte, Montana Superfund area was stable or increased slightly during the 2000s.⁵³

In this study, those who had previously participated in research had more positive attitudes towards research and researchers in survey 1 and were more likely to say

that they were aware of research that had been conducted in the community. In survey 2, those who had participated in research were much more likely to say they remembered reading the example research article. These findings suggest that researchers can have good success communicating with the segment of the population that is willing to volunteer for research participation. It is also encouraging that 85% in survey 2 said that they usually read health articles in the local news source. Less encouraging is the finding that only 35% remembered reading the particular example article about research in Libby. This last finding suggests that repetition in different media outlets is probably very important in order to raise awareness of research opportunities and findings.

Based on our results, as well as other studies of motivations for research participation, it is probably important to emphasise the potential benefits to the community as a whole, rather than only the personal and family benefits of participation in screenings and research. Our results also point to the importance of community perceptions that the research makes a contribution to the community, how the researchers are connected to the community and what the research is about. People in Superfund situations undoubtedly want their participation to be worthwhile. Nurses, followed by physicians and pharmacists, rate highly in national surveys about trusted professions, honesty and ethical standards.⁵⁴ Owing to their familiarity in the rural community, these healthcare professionals have an opportunity to invite persons to participate in research and explain its value.

Limitations

One limitation is the use of convenience samples. Related to this is the fact that we are unable to know whether our two surveys overlapped by including some of the same individuals because responses were anonymous. A second limitation is that because survey 2 was designed to be short and to confirm some of the strongest responses from survey 1, we were unable to test the replicability of the principal components factor structure exactly across the two surveys. However, the eight items that overlapped across the two surveys did show highly similar principal component loadings. With only two factors in survey 2, some of the findings from survey 1 regarding other variables that might be related to the factor scores are somewhat ambiguous.

Finally, a major contingency on the present results is the research context, the Superfund clean-up in Libby, Montana. The research context is important for interpreting any research, but takes on added importance for studies of pollutants and disasters. We think of our findings as an illustrative case study of attitudes towards research and research participation in a Superfund context. As described in the 'Introduction' section, Libby, Montana is the only Superfund site in the United States for which the designation of 'public health disaster' has been used by the EPA. All Superfund clean-ups

involve some controversies, scientific and interpersonal, including community division.⁵⁵ Desire to participate in research, attitudes towards research and researchers and awareness of research communications must be considered in the context of financial controversies over the clean-up, and the economic impacts on the community of the potential stigma of not only Superfund designation but 'public health disaster.' Nevertheless, because our study reveals themes found elsewhere in the literature on research participation, we believe that our study has general relevance to similar situations. Only when other researchers address research participation issues in Superfund or environmental disaster settings will the generalisability of the present results be known.

CONCLUSIONS

Researchers for the present study, conducted in a rural Superfund health disaster site, found that different aspects of attitudes towards research and researchers are related to desire to be invited to participate in research, awareness of past research and research news in the community, and having been screened or diagnosed with a health condition related to the Superfund contaminant. Participation in research at Superfund sites is critical not only for ascertaining the health effects of the toxins in question, but also for determining the perceived effectiveness of clean-up activities. Our study represents a first step and yields information about how Superfund community members think about research and participating in research. Our hope is that this work will begin to help address the research needs of communities impacted by environmental toxins.

Author affiliations

- ¹Montana State University, College of Nursing, Missoula, Montana, USA
- ²Psychology Department, Montana State University, Bozeman, Montana, USA
- ³Montana State University, College of Nursing, Kalispell, Montana, USA
- ⁴Montana State University, College of Nursing, Bozeman, Montana, USA
- ⁵Center for Asbestos Related Disease, Libby, Montana, USA

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Contributors CAW was the principal investigator (PI); SWK and CW were coinvestigators on the study. KR was co-PI and engaged in data collection; TH provided assistance with data collection, data management and communication among team members and community partners and BB served as medical advisor for the study. Each member participated in the development and implementation of the study. CFM analysed the data for this manuscript. CAW and CFM drafted the manuscript, and SWK, CW and TH critically reviewed the paper.

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