TITLE: Using environmental health dialogue in a Diné-centered approach for individualized results reporting in an environmental exposure study following the Gold King Mine Spill

RUNNING TITLE: Diné-centered reporting of individualized exposure results

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Conflict of Interest

The authors declare they have no actual or potential competing financial interests.

Abstract

Background: On August 5, 2015, the Gold King Mine Spill (GKMS) resulted in 3 million gallons of acid mine drainage spilling into the San Juan River impacting the Diné Bikeyah (traditional homelands of the Navajo people). The Gold King Mine Spill Diné Exposure Project was formed to understand the impacts of the GKMS on the Diné (Navajo). Reporting individualized household results in an exposure study is becoming more common; however, materials are often developed with limited community input with knowledge flowing in one direction - from researcher to participant. In this study we examined the development, dissemination, and evaluation of individualized results materials.

Methods: In August 2016, Navajo Nation Community Health Representatives (Navajo CHRs) sampled household water, dust, and soil, and resident blood and urine for lead and arsenic, respectively. From May-July 2017, iterative dialogue with a wide range of community partners and a community focus groups guided the development of a culturally-based dissemination process. In August 2017, Navajo CHRs reported individualized results and they surveyed the participants on the report-back process at that time.

Results: All of the 63 Diné adults (100%) who participated in the exposure study received their results by a CHR in person and 42 (67%) completed an evaluation. Most of those participants (83%) were satisfied with the result packets. Respondents ranked the individual and overall household results as the most important information they received (69% and 57%, respectively), while information on metals exposures and their health effects were the least helpful.

Conclusions: Our project illustrates how a model of environmental health dialogue, defined by iterative, multidirectional communication among Indigenous community members, trusted Indigenous leaders, Indigenous researchers, non-Indigenous researchers, can improve reporting individualized study results. Findings can inform future research to encourage multi-directional environmental health dialogue to craft more culturally responsive and effective dissemination and communication materials.

Introduction

On August 5, 2015, the Diné (The Navajo people or the Navajo Nation) experienced a human-caused, technological disaster, when maintenance on the Gold King Mine resulted in 3 million gallons of acid mine drainage accidently releasing into a tributary of the San Juan River, which flows through Diné Bikéyah (the traditional homelands of the Navajo people or the Navajo Nation). The Gold King Mine Spill (GKMS) Diné Exposure Project (GKMS-DEP), a partnership between the Navajo Nation, academic institutions, and grassroots community organizations, used a community-based, culturally-driven research process to understand the impacts of the GKMS on the Diné within a year of the disaster (Teufel-Shone et al., 2021; Van Horne et al., 2021; Van Horne et al., 2022). In this paper, we examine the process to rapidly develop and disseminate individualized environmental exposure result materials for environmental exposures measured one year after the GKMS.

Environmental health literacy (EHL) is a concept that utilizes various tools to help non-researchers or study participants understand links between environment and health. It emerged as a subdiscipline from a combination of various fields, including health literacy, risk communication, environmental health sciences, communications research, and safety culture (Finn & O'Fallon, 2015; Gray, 2018). Multiple studies focused on increasing EHL at individual and community levels, with most efforts documenting how individuals understand the connection between environmental exposures and health (Barrett et al., 2014; Bogar et al., 2017; Chan et al., 2015; Chen et al., 2014; Cohen et al., 2016; Friendship & Furgal, 2012; Perovich et al.,

100 2018; Schure et al., 2013; White & Johnson, 2005), or assessing how individual behaviors
101 changed after learning about environmental exposures (Butterfield et al., 2011; Derrick et al.,
102 2008; Korfmacher & Kuholski, 2008; Mankikar et al., 2016; Paul et al., 2015; Quandt et al., 2013;
103 Zierold et al., 2016).
104
105 There is a paucity of research focused on building EHL by reporting results in environmental
106 exposure studies. While ways to build EHL are well-researched, the literature regarding the
107 relationship between EHL and research dissemination is lacking, let alone individualized
108 results. Only a handful of studies highlight the change in EHL within the context of reporting
109 results to study participants (i.e., research dissemination, risk communication) (Adams et al.,
110 2011; Brody et al., 2021a; Dellinger et al., 2019; Haynes et al., 2016; Hoover, 2016; Madrigal et al.,
111 2016; Perovich et al., 2018; Ramirez-Andreotta et al., 2016; Oksas et al., 2022). As more studies
112 focus on improving EHL through research dissemination, it will be important to understand for
113 various communities how they want results communicated (e.g., on paper, social media), who
114 they want to report results (e.g., study investigator, community member, health professional),
115 and in what setting they want results presented (e.g., home, library).
116
117 One of the 2012-2017 National Institute of Environmental Health Science (NIEHS) Strategic Plan
118 goals was to 'Use knowledge management techniques to create a collaborative environment for
119 the environmental health sciences (EHS) community, to encourage an interdisciplinary
120 approach to investigate, analyze, and disseminate findings' (NIEHS, 2012); a theme that
121 continues in the 2018-2023 strategic plan (National Institute of Environmental Health Sciences

(NIEHS), 2018). Despite NIEHS's call to take a more interdisciplinary and collaborative approach to disseminating EHS results, literature on these topics are lacking especially those related to Indigenous communities (Boyer et al., 2007; Dellinger et al., 2019; Friendship & Furgal, 2012; Hoover, 2016; Jardine et al., 2013; Legaspi & Orr, 2007; Rivkin et al., 2013; Rock et al., 2021). Incorporating Indigenous knowledges and local perspectives and providing opportunities for feedback from community members are critical, considering there are: 574 federally-recognized sovereign tribes with a government-to-government relationship with the United States (Federal Register, 2020); approximately 60 state-recognized tribes; and hundreds of tribes with no federal or state government recognition (National Conference of State Legislatures, 2016). The field of EHL is still evolving and at times can revert back to a "public deficit" model, where researchers teach a supposed scientifically uninformed community (Adams et al., 2011). This is most evident in studies that seek to improve EHL without, at a minimum, understanding the communities' socio-cultural knowledge, priorities, and responsibilities. Incorporating Indigenous knowledges from the community is critical to move from an investigator-centered approach to one that centers environmental health dialogue (EHD) among Indigenous communities (Moll et al., 1992; Tazewell, 2020; Teufel-Shone et al., 2021; Van Horne et al., 2022).

In this paper, we discuss environmental health literacy and past individualized report back of research results efforts, and why report back of research results must be changed in order to be more useful for participants (National Academies of Sciences, 2018). As such, we argue for a new approach: environmental health dialogue, a confluence of ways of knowing among

144 partners such as educational institutions, non-profit organizations, Indigenous communities,
145 funders, and publishers, that is geared toward epistemological equity and community-driven
146 processes. We describe our approaches for fostering environmental health dialogue and how
147 these encouraged multi-partner input and reflection, reshaping researcher-only concepts of
148 content. We report findings from the focus group that evaluated the dissemination and
149 communication methods and the participant evaluation of the individualized report back of
150 research results. We discuss successes, challenges, strategies, and lessons learned.
151
152 **Material and Methods**
153
154 ***Study setting, approvals, and partners***
155
156 The project was initiated within two months of the Gold King Mine Spill. The partnerships
157 began to be developed and the research concept was presented and approved by Shiprock
158 Chapter, San Juan River Farm Board, District 13 Grazing Committee (Chapters under Districts
159 12 and 13 were involved), Nenahazaad Chapter, and Northern Navajo Council with letters of
160 support from Navajo Nation President and Vice President, and community partners. Using a
161 culturally-centered Diné approach over 10 council resolutions supporting the GKMS-DEP were
162 obtained (Teufel-Shone et al., 2021). In addition to these resolutions this project was also
163 approved by the Navajo Nation Human Research Review Board and the University of Arizona
164 Human Subjects Protection Program.
165

166 We conducted the GKMS-DEP on the Navajo Nation in three Chapters, or local tribal
167 governments: Shiprock Chapter, NM; Upper Fruitland Chapter, NM; and Aneth Chapter, UT
168 (Figure 1). The study described in this article is part of a larger Diné-led project, the GKMS-
169 DEP, conducted by a transdisciplinary, collaborative team composed of four academic partners,
170 including the University of Arizona, Northern Arizona University, Fort Lewis College, and
171 Diné College, as well as the Navajo Nation Community Health Representative Program, Tó Bei
172 Nihi Dziil (a grassroots Diné organization focused on water security), and Diné Elders. The
173 study team met weekly to discuss project progress. The Navajo Nation Community Health
174 Representatives (Navajo CHRs) are community health workers, or *promotoras* (Ingram et al.,
175 2008). Based on previous success with individualized environmental exposure study report
176 back of research results (RBRR) (Murphy et al., 2011), the Navajo CHRs worked closely with
177 academic partners to develop materials and then reported back research results to participants.
178
179 ***Exposure sampling***
180
181 From August 8-12, 2016, Navajo CHRs completed environmental (i.e., indoor home surfaces
182 dust wipes, yard soil, and drinking water) and biological (i.e., urine and blood) sampling in
183 households of participating Navajo Nation Chapters. Environmental samples were analyzed for
184 arsenic and led and urine was analyzed for arsenic and lead by the Arizona Laboratory for
185 Emerging Contaminants. Participants' blood lead levels were tested in the home and their levels
186 reported during the visit using the LeadCare II Blood Lead Testing System (Billerica, MA).
187

Many ways of knowing

While other projects have incorporated community advisory boards (CABs) into their research process, our project did not formalize a CAB because it would have not been community-driven and community-centered and would have shifted the project communication from multi- to bi-directional. The community felt the CAB was a settler-colonial western bureaucratic process and was not truly equitable. More practically, community organizations and partners who would have been part of a CAB were already part of the project. Instead, the Navajo CHR Director, Navajo CHRs, Diné principal investigators, Diné student researchers, and the university-based research team members collaboratively developed culturally-appropriate results content and methods with input from the community. It is important to emphasize that these partners worked together on every aspect of the project (i.e., formulating questions, developing protocols, collecting data, analyzing results, dissemination, and writing manuscripts) a process that upholds environmental justice principles and where partners' strengths are recognized as key to improving community health (Van Horne et al, 2022).

For the GKMS-DEP, we sought to develop, and report individualized study results in the most informative way possible for participants. To do this, we promoted continuous environmental health dialogue among many ways of knowing during the results development and dissemination process (Figure 2). As there is no standard reporting of dissemination efforts in environmental health studies, it is difficult to quantify the engagement level utilized by researchers (Jones et al., 2018). It was once common for researchers not to share results with

individual participants. In unidirectional EHL, researchers unilaterally decide how to share results with individual participants without community or participant input on content, process, or methods. In bidirectionally-informed dissemination, the researcher gathers participant and/or community input on results dissemination via survey, focus group, or other approaches. In these cases, the participants and/or their communities may inform the report back of research results, but their engagement in the larger research process is limited. Further, these EHL processes and methods may not consider a community's cultural norms and practices, communication preferences, and existing knowledge banks.

The EHD model utilizes multiple ways of knowing in a multi-directional, iterative dialogue to drive research and inform practices, including report back of research results to individual participants. The study team was comprised of a variety of experts, including but not limited to community organizational partners, cultural advisors, tribal or community programs, students, and youth, Indigenous and allied academic researchers, and individual participants. The partners began a dialogue *during the project conception phase* to include a variety of epistemologies in the design, implementation, and dissemination phases of the research (Gittelsohn et al., 2020; Raphael, 2019). Of note, discussions about report back of research results occurred throughout the research process, not solely at the point of being ready to share with participants. Partners contributed expertise and knowledge throughout the process, shifting and influencing not only methods and processes, but also overall methodologies—or the values and reasons for why and how a research project is run.

232 Sometimes a single way of knowing will influence the selection of a method or process (e.g.,
233 who can(not) report-back certain research results to a participant due to cultural norms), and at
234 other times multiple knowledges will inform method and process selection (e.g., the image to
235 use to indicate the level of contamination). In our EHD model of dissemination, through
236 iterative collaboration beginning with project conceptualization, multiple ways of knowing
237 shape content, methods, and processes for sharing results with individual participants.
238
239 ***Development and evolution of results communication***
240
241 To avoid confusion when reporting research results bilingually, a glossary of pertinent
242 terminology (e.g., acid mine drainage) was created through consensus and guidance by a Diné
243 linguist expert on the study team. As mentioned in the *exposure sampling* section in August 2016
244 we sampled participants' blood lead levels reported their lead levels during the visit. The
245 immediate reporting of the blood lead levels was due to 1) availability of results due to using
246 the LeadCare II Blood Lead Testing System which provides results in 3 minutes (Billerica, MA),
247 2) development of a single-page result of the participants blood lead level in consultation with a
248 pediatrician and 3) recommendation by Navajo CHR director Mae-Gilene Begay to be proactive
249 in case participants had high blood lead levels the study team could properly refer participants
250 to health care facilities.
251
252 In early May 2017 (Figure 3), an initial draft of the individualized report back of research results
253 materials was developed, consisting of a 22-page printed report with detailed figures and

254 infographics representing aggregated results of each medium and contaminant adapted from a
255 different community-engaged study by some of the university researchers (Ramirez-Andreotta
256 et al., 2016). An infographic example for drinking water is shown in Figure 4.
257
258 In mid-May, the Navajo CHR Director, Mae-Gilene Begay, provided significant feedback, most
259 importantly to replace a lengthy printed packet with a flipbook (Figure 5-6 and Figure S1),
260 which would act as a conversation guide for CHRs, complete with visuals and limited text
261 (Murphy et al., 2011). The flipbook was designed to prop-up on a table, with one side for the
262 participant and the other side facing the CHR. The participant side had the visuals with
263 minimal text, while the CHR side had detailed talking points, and detailed guiding for
264 frequently asked questions.
265
266 About the same time, the study team held a public, community teach-in in Shiprock to present
267 lead and arsenic concentrations in river, irrigation, canal, and farmland samples, taken in a
268 separate part of the project. While unrelated to samples taken in homes, community members
269 provided valuable feedback. They wanted clear, concise take-away findings to be presented in
270 spoken Diné and printed English before any details about methods. They would ask for more
271 details on research results as needed. In early June 2017, Agnes Attakai (Diné), the Director of
272 Health Disparities Outreach & Prevention Education at University of Arizona College of Public
273 Health, suggested that the flipbook be more concise and have more visual aids for
274 environmental health concepts, such as exposure.
275

In mid-June, CHRs reviewed the flipbook and a draft of a highly-detailed, multi-page printed report of individualized results. They were concerned that the length of the flipbook and the need to explain printed concentration graphs in the report back of research results (RBRR) would require extended home visits, increasing the time burden for participants already stretched by obligations of subsistence practices and multi-generational care giving. Further, including information on the health effects of arsenic and lead exposures greater than those found in the study would distract from the messaging that exposures were generally below standards and guidelines. By focusing on the numerous health effects of these contaminants (e.g., arsenic and lead), we were complicating our message that these exposures were generally low and not of concern.

In response, the study team moved health effects messaging to the end of the flipbook. The format of the flipbook also changed so that the Navajo CHR would have guided talking points for each page of content the participant would view (Figure 4). Initially to represent metals visually we utilized small pyrite stones, however the Navajo CHRs suggested also including visual aids that would be locally-relevant. This led to ensuring that the results packet was place based by including the readily-recognizable image of Shiprock, the Chapter's namesake geological formation associated with oral origin stories, when describing how metals are formed (Figure 5) (Pascua et al., 2017).

In addition, the Navajo CHRs recommended having a halfway point (stopping point) where we would assess if the participant wanted to continue with receiving more detailed information.

Having this halfway point in the flipbook was to ensure participants could receive results without being disrespectful if they were pressed for time. The halfway point came after 17 pages in which the Navajo CHRs discussed the following: background on GKMS; what chemical elements are; where metals come from; a study overview; and the participant's individual research results. If participants wanted to engage past the halfway point the participants received information on the health effects of arsenic and lead and ways to reduce exposure to these metals.

During the report back of research results visit, the Navajo CHR would view the flipbook and then briefly explain and leave a single-page, double-sided printed summary of the participant's biological and environmental results, with arsenic on one side and lead on the other (Figure 6). Each side of the individualized research results sheet consisted of a table with rows indicating the sample type (e.g., blood, drinking water, soil, or dust) and columns displaying the participant's sample contaminant concentration; the mean study concentration; a comparison value and reference; and suggested next steps. We defined comparison values as the legal threshold limit (e.g., United States Environmental Protection Agency [U.S. EPA] Maximum Contaminant Level [MCL]) or a value at which a public health agency would recommend action (e.g., Centers for Disease Control and Prevention [CDC] Blood Lead Reference Value). Information on abbreviations, comparison values, and who to contact with questions related to the results were in the footnotes.

319 The comparison value for lead in blood utilized was the CDC Blood Lead Reference Value. For
320 arsenic in urine, we compared participants values to the National Health and Nutrition
321 Examination Survey 98th percentile. For lead and arsenic in drinking water, we compared the
322 values to the U.S. EPA MCL. For lead and arsenic concentrations in soil, we compared values to
323 the New Mexico Soil Screening Levels. Lastly for contaminants measured in house dust, we
324 relied on the U.S. Department of Housing and Urban Development's lead clearance action level
325 for interior floors and the detectable level of arsenic based on the American Healthy Homes
326 Survey. With Navajo CHR feedback, results were color coded based on a traffic light scheme.
327 Red signified a concentration of concern which could be of concern for potential health effects.
328 Yellow indicated that more information or testing was needed. Green was used for
329 concentrations below the comparison value.
330
331 ***Focus group on report back of research results***
332
333 In early July 2017, a University of Arizona public health doctoral student and a facilitator
334 conducted a focus group in Shiprock, NM to discuss how to report back research results to
335 individual participants and the community. In relation to increasing the efficacy of qualitative
336 research in tribal communities (Teufel-Shone & Williams, 2010), it is important to note both the
337 student and facilitator were Diné, one was female and the other was male, and one was fluent in
338 the Diné language. Studies have shown that local facilitators can establish trust among
339 participants based on mutual culture, language, environment, lived experiences, and kinship

(Makosky Daley et al., 2010; Teufel-Shone & Williams, 2010). The session was audio recorded, and two student interns from Diné College (one of whom was Diné) took written notes.

Recruitment occurred through posted flyers, social media posts, and word-of-mouth referrals. Word-of-mouth referral is typical in these three Diné communities particularly because certain subgroups, such as Elders, may not have access to transportation, electricity, phone, computers, smart phones, or the Internet and may lack social media accounts. Such informal recruitment also helps overcome language barriers, with English speakers translating the event information into Diné and assuring potential participants that there will be a Diné-speaking facilitator at the focus group. Word-of-mouth recruitment also reaches other community members who do not regularly visit locations with posted flyers due to lack of transportation. Two student interns and a staff member from Diné College assisted with word-of-mouth recruitment.

The focus group included 14 participants, and the discussion was facilitated in both Diné and English. Diné facilitators started the focus group with a greeting and identifying their clans and allowing others to establish kinship with one another. Diné kinship, or K'e, is established through the Diné clan system, and positions individuals in society based on four clans: maternal, paternal, maternal grandfather, and paternal grandfather. Facilitators then introduced the larger GKMS-DEP in a manner that acknowledged their personal connection to the GKMS and its collective impact on the Diné.

362 ***Focus group analysis***

363

364 The co-facilitators and one notetaker debriefed immediately after the focus group to: synthesize
365 preliminary themes for immediate feedback to the broader GKMS-DEP team within the week;
366 discuss any conflicting interpretations; and create a qualitative foundation for further analyses.
367 Preliminary themes and recommendations were related to content and presentation and
368 confirmed or were compatible with input from Navajo CHRs and the community. In early
369 August 2017, the doctoral student analyzed the transcript using structural coding techniques
370 (Saldańa & Mallette, 2017), and these results validated preliminary themes and findings.

371

372 Focus group participants agreed that study results should use clear, concise messaging to
373 inform community members' decision-making processes. One participant responded, "I'd like
374 to know where it [lead/arsenic] becomes harmful. What are the side effects of those." Focus
375 group participants also echoed the Navajo CHRs' suggestion that the results flipbook include
376 more detailed information about potential health impacts of arsenic and lead exposures, which
377 was added to the end of the flipbook. Focus group participants reiterated their preference for
378 clear, concise statements on whether it is safe to irrigate, plant, and interact with the water.
379 Participants also strongly preferred messaging to be in both Diné and English, with Diné being
380 the stronger preference, and for results to be delivered by a bilingual speaker knowledgeable in
381 environmental science and Diné cultural protocol. Participants cited Dr. Karletta Chief, a Diné
382 environmental scientist and former Miss Navajo Nation (tribal ambassador), as an exemplar.

Unlike western pageants where contestants are judged solely on their outward appearance, the focus of the Miss Navajo Nation is in the beaty found within (Yazzie, 2018). Contestants are judged on both traditional and contemporary skills. For example, contestants are expected to butcher a sheep, and be knowledgeable on Diné culture and traditions (Richards et al., 2022). Women who are in the role of Miss Navajo Nation are representatives of the Diné people and highly respected goodwill ambassadors of the community. Focus group participants also commented that, regardless of age, most farmers are comfortable speaking in Diné. Participants preferred traditional in-person verbal and visual presentation of results.

When discussing how to visually present results, participants had no interest in infographics and 'academic' data visuals (i.e., pie charts and bar charts). When provided with sample infographics (Supplementary Figure 2), a participant commented, "You've got too much up there. It needs to be simplified." Pie charts and bar charts were acceptable only if they were explained in person in both Diné and English. These findings echoed Navajo CHR suggestions to replace graphs or infographics in the report back of research results (RBRR) materials with a simple table (Figure 6). The focus group also confirmed the decision to use the traffic light color coding, stating that red means "bad" and green means "good." There were mixed feelings on yellow as "caution" – some people felt it should be grey to indicate a "grey area."

Navajo CHR training of individual report back of research results

405 In order to reach consensus on messaging we held a one-day training prior to individual home
406 visits with the Navajo CHRs and a facilitator in August 2017. Many of the Navajo CHRs are
407 fluent in Diné, and thus reaching consensus on terminology was key to achieving a uniform
408 message. During this training we had the Navajo CHRs role play and practice hypothetical
409 scenarios where they would take turns being the Navajo CHR disseminating the information
410 and the other would be the participant asking questions in Diné. With the assistance of the
411 facilitator the Navajo CHRs mutually agreed in a consensus on the best way to orally
412 communicate the results presented in the flipbook (Figure 6).
413
414 ***Individual report back of research results and follow up questionnaire***
415
416 Following the training, Navajo CHRs were provided the packets for participants. Over the
417 remainder of the week, Navajo CHRs reported back research results to 92% (58/63) of the
418 participants. Within two weeks, the Navajo CHRs reached the rest of the participants that were
419 not available during the initial week of report back of research results. The dedication of the
420 Navajo CHRs and their commitment to their clients resulted in 100% of participants receiving
421 their results.
422
423 After the Navajo CHRs had completed the report back of research results with individuals,
424 adult participants (≥18 years of age) were asked to evaluate the materials and process with a
425 short questionnaire. Individuals who agreed to participate in the questionnaire provided

written informed consent. Participants were compensated an additional $25 for completing the evaluation questionnaire. The entire visit took 45-60 minutes.

The report back of research results evaluation questionnaire was developed collaboratively by Navajo CHRs and academic investigators. The original questionnaire was a pre/post survey focused on knowledge gained from the report back of research results. The format was changed to solely evaluate how well the research team communicated research results and the usefulness of different report-back components. Additionally, Navajo CHRs were concerned a pre/post knowledge test would not be accepted well by some participants, because they would view the visit as an academic test and some participants were not afforded a western education. The survey was shortened to seven questions, so Navajo CHRs could be respectful of the participant, especially if they were an Elder or, through the Diné clan system, a figure of authority in relation to the Navajo CHR.

Analysis of individual report back of research results evaluation

Differences in report back of research results satisfaction by Chapter (Upper Fruitland, Shiprock, and Aneth), gender (male, female), presence of child in the study (child participated vs no child), and age group (young adult [18 to 25 years], adult [26 to 54 years], elder [≥55 years]) were assessed using an ANOVA test. All statistical analyses were completed using R 3.1 (R, Vienna, Austria).

448 **Results**

449

450 *Demographics*

451

452 A total of 63 Diné adults participated in the household environmental and biological sampling
453 portion of the study. Their mean age was 51 years, and 42 (67%) participants identified as
454 female. From August 21-24, 2017, one year after initially collecting samples, Navajo CHRs
455 returned to participant homes and presented individualized results to 100% of study
456 participants. Of the 63 eligible adult participants, 42 (67%) completed the evaluation
457 questionnaire (mean age = 50 years; 28 (67%) identified as females). Of the 42 participants who
458 completed the questionnaire, 11 (26%) resided in Aneth; 14 (33%) in Shiprock; and 17 (41%) in
459 Upper Fruitland (Table 1).

460

461 *Evaluation of individualized report back of research results*

462

463 About half (52%) of participants completed the questionnaire in only English; 38%, in both Diné
464 and English; and 10%, in only Diné. When ranking the two most important pieces of
465 information they received, participants most often chose "their personal results" (69%) and "the
466 summary of the overall findings of the study" (57%) (Table 2). Alternatively, respondents said
467 the two least helpful pieces of information were "additional information on the health effects of
468 lead and arsenic" (29%) followed by "background on the GKMS" (19%) and "nothing" (19%).
469 Most participants (75%) wanted to receive the information in a different format, by a different

person, or in a different setting (Table 3). When asked, 'On a scale of 1 to 5, how satisfied are you with how this results packet showed your results?', most participants (83%) marked a 4 or higher. There were no differences by Chapter, gender, or age.

Additionally, when asked 'From what we have presented to you here today, have your feelings regarding the Gold King Mine Spill changed?', 31% said yes, while 55% said no. One participant who marked yes, and said "Yes, it gives me a better idea of how to make a change in my environment - both at home and community. I feel more informed about the Spill and I feel empowered to help the environment." Only four people said they would talk about their results with other people (e.g., their family). Of those interested in receiving additional information in the future, most wanted to receive updates about the study either via social media (24%) or at a Chapter house meeting (63%). It is important to note that, Chapter houses are official political units within the Navajo Nation government (Powell & Curley, 2008). In addition to the physical Chapter houses holding regularly scheduled monthly meetings they are also used as spaces for festivities, hosting of various other meetings, outreach, and educational events, and are key for research dissemination (Ornelas et al., 2017; Yazzie et al., 2020).

Discussion

This paper illustrates how our EHD model helped shape and guide the dissemination of results of individual participants in the GKMS-DEP. In this study, we proposed and utilized a new model of EHD (Figure 2), in which a wide array of partners collaboratively create

492 environmental health study decisions by promoting a continuous dialogue among many ways
493 of knowing throughout the results development and dissemination process (Figure 2). We
494 focused on how a Diné-centered process driven by Navajo CHRs and their director, community
495 members, and project team members developed culturally and linguistically appropriate
496 individualized report back of research results methods and materials. As a sign of this
497 effectiveness, the majority of participants (35/42) were satisfied with how the results packet
498 showed their individual results. Participants ranked the 'their personal results' and the 'overall
499 findings of the study' as the top two most important pieces of information they received during
500 the visit (Table 2).
501
502
503 The logistics on how, when, and where for report back of research results is an evolving process
504 that is best determined by local knowledge. This is most evident in community-academic
505 groups who have invested in developing their own resources to support the dissemination
506 process (Brody et al., 2021b; Nolan et al., 2021; Schollaert et al., 2021). Participants enrolled in
507 the study preferred to receive results from the person in charge of the study in a verbal format
508 at a Chapter house meeting. Additionally, participants noted that the least helpful information
509 they received was the additional information and background on the GKMS (i.e., health effects
510 of arsenic and lead, and how they could be exposed). We also asked participants if what we had
511 shown during the report back of research results changed their feelings about the GKMS. Only
512 31% of the participants said that their feelings regarding the GKMS had changed after having
513 the research results reported back to them. Given that this occurred two years after the Spill,

514 these results may have been because these participants no longer had concerns about the
515 GKMS, their feelings about the GKMS had already changed, or the report back of research
516 results did not change their feelings. We have previously documented in these Diné
517 communities' perceptions of short-term impacts of the disaster, as well as past and present
518 injustices, communication related to the Spill, and concerns of persistent threats to Diné
519 lifeways through focus groups within the first year (Teufel-Shone et al., 2021). Thus, a 31%
520 change in how participants felt about the GKMS after receiving their results could be significant
521 in this context.
522
523 When asked "Would you want to get this information in a different way?", a majority of the
524 participants (75%) said yes to all three choices. However, we did not ask the participants which
525 they preferred, including the current option. The wording of this question might have caused
526 the participants to feel like they had to provide an answer. Identifying the preferred location to
527 deliver results as well as the preferred person to present the results or allowing participants to
528 decide where and how to receive their results might improve people's feelings about the
529 outcomes of the study. Future studies would benefit from piloting of evaluation questionnaires
530 with relevant constituencies.
531
532 After reporting individual research results to participants, aggregated sampling results were
533 presented in public community meetings at the Chapter houses in December 2017 by "the
534 people in charge of the study" (Principal Investigators Chief and Beamer). These events were
535 advertised through the radio, flyers, social media, newspaper, email, and word of mouth. The

Aneth and Upper Fruitland community sessions received the least turnout (<10 people at each session). A poll conducted at the Shiprock Chapter session where there was the largest attendance (n=24), indicated that 50% (12/24) heard of the event by the radio, 25% (6/24) by newspaper, and 25% by flyer (6/24). The majority (17/24) of those attended were older than 60 years of age. Attendees indicated they use the San Juan River for cultural and traditional purposes (9/24), ranching (6/24), swimming (3/24), farming (3/24), and ceremonial and religious use (3/24). Despite the low attendance (n=24), 75% (18/24) of attendees at the Shiprock session found it useful. Learning from other community members (7/24), connecting with other community members (7/24), and sharing concerns about the GKMS (4/24) were the most useful. When asked if they felt more informed about the project, 35% (8/24) agreed, 14% (3/24) were neutral, and 43% (10/24) disagreed. While there were few respondents, these responses indicate that community meetings on report back of research results are a community function first, and an opportunity to hear results second. Future studies should also evaluate the efficacy of having "the people in charge of the study" present aggregate study results in a public community meeting.

While report back of research results is required by the Navajo Nation Human Research Review Board, there are no rules or guidance on the process or materials. This allowed a wide array of partners to inform and guide development of report back of research results. Recently, there has been five factors identified that influence successful environmental health risk communication strategies with Indigenous Peoples (Boyd & Furgal, 2018). As we conducted our work before Boyd & Furgal (2018), we did not initially set out to incorporate these factors. However, our

guiding community-engaged principles successfully included these factors in our communication strategies (Table 4).

This project embraced the concept of "relational accountability" as it has emerged out of Indigenous Knowledges, rooting epistemologies and methodologies in the relational values of Indigenous communities (Wilson, 2008). Relationships with people; the environment and other living beings; and with the spiritual world are foundational for Indigenous ways of knowing (Absolon, 2011; Kovach, 2009; Lambert, 2014; Smith, 2012; Thomas, 2005). Placing relational accountability at the heart of the research process has implications for both how research is conducted and the resulting research products. As with the dialogue process, relational accountability in this project was multidirectional.

Relational accountability resulted in moving beyond uni- or bi-directional engagements traditionally utilized in EHL to a report back of research results process informed by multiple ways of knowing and created by a diverse team of Diné and allied researchers. The project is Diné-led; 60% of the investigators and 100% of our community research partners are Diné. The academic partners have long-standing relationships with the Diné community: four of seven investigators are Diné and three of those are fluent in Diné, and five of seven investigators have carried out research projects with the Diné community for over 20 years. In addition, one Principal Investigator is Latina and has close to 20 years of experience working with historically marginalized communities. Additionally, over 100 students, a majority of them from historically marginalized populations, and half of them Diné, were involved with the study. This ensured

methods and messages: 1) were congruent with communities' cultural beliefs and understandings of the environment and 2) utilized western scientific knowledge, as needed. For example, based on input from a dozen community meeting attendees, parts per billion was conceptualized as 1 drop of water in 250 55-gallon water barrels, which are commonly used on the Navajo Nation to haul water. When results were delivered to participants, this was done at their homes by the Navajo CHRs. As Navajo CHRs conduct house visits to check on their clients, house visits were deemed an appropriate delivery method of the results. The format and content of the results message was designed and delivered with input from multiple ways of knowing, including Diné, other Indigenous, and allied university, and Diné community research partners.

One of the limitations of this project is the possible lack of input from other community members. A majority of the input received came from Navajo CHRs and their director and attendees at the public rivers, canals, and fields sampling results meeting and the July 2017 focus group in Shiprock. As these two events were completed at the Shiprock Chapter house, attendees may not be representative of the other two participating Navajo Chapters. The Navajo CHRs who provided input in the materials and processes are from some of the participating Chapters but not all. Additionally, while there may be selection bias in those who choose to complete the evaluation, more specific responses showed a wide variety of feelings towards specific parts of the report back of research results. Finally, we neglected to ask results evaluation participants how they felt about their individual results.

One method of community input has been on the reliance of Community Advisory Boards (CABs). While the reliance of CABs in the environmental health literacy processes is one method to assist with the design of research dissemination materials, our project relied on a wide range of multi-faceted approaches. Our project wove together input from a wide range of Diné partners, including community research partners, Indigenous researchers, and other community members to develop and deliver individualized results to exposure study participants. In community-driven research between Indigenous Peoples and other researcher partners, mutually-beneficial dialogue regarding the research goals, methods, and reporting back results increases potential benefits for all involved, improving research. Further, this process leads to epistemological equity, allowing Indigenous and local ways of knowing to guide the research process and use western science, as needed, to address complex questions. Our process for creating and reporting individualized results after the GKMS depended on the relationships and relational accountability among the community-academic research partners. Together, accountability, epistemological equity, and community-driven processes create space for multidirectional dialogue, learning, and development of more effective and appropriate report back of research results processes and materials. Future studies should encourage environmental health dialogues among interested partners early on, in order to craft more useful and appropriate dissemination processes and communication materials and methods.

Role of the funding source

The content is solely the responsibility of the authors and does not necessarily represent the official views of the National Institutes of Health. The sponsor had no role in the study design or in the collection, analysis, and interpretation of the data.

Data availability statement

In accordance with Indigenous Sovereignty and agreements with the Navajo Nation Human Research Review Board any data connected with biological samples from members can only be shared with appropriate Indigenous policies and permissions. Researchers who are interested in accessing these data can submit a request directly to the Navajo Nation Human Research Review Board.

Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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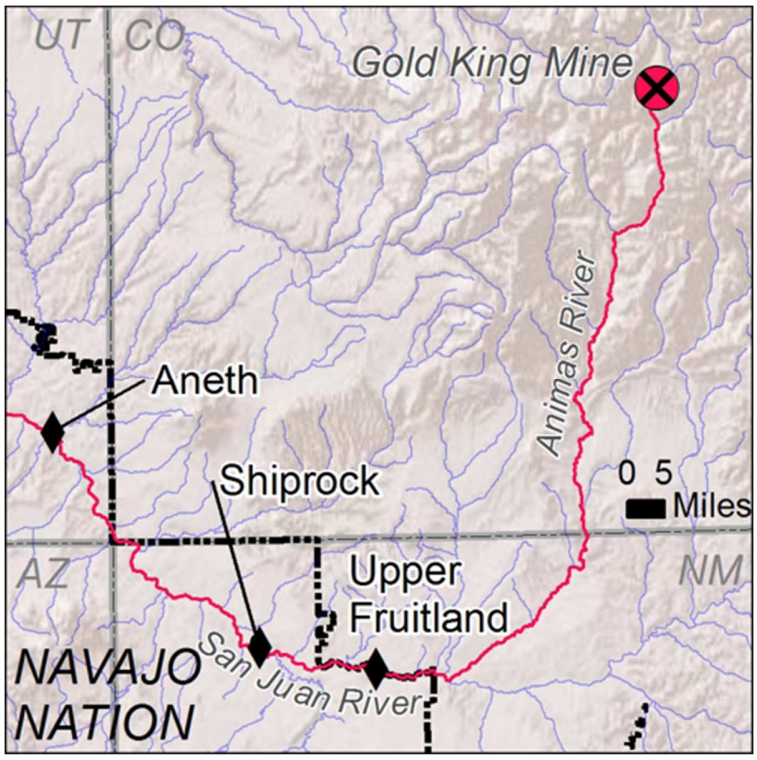
682 **Figures**

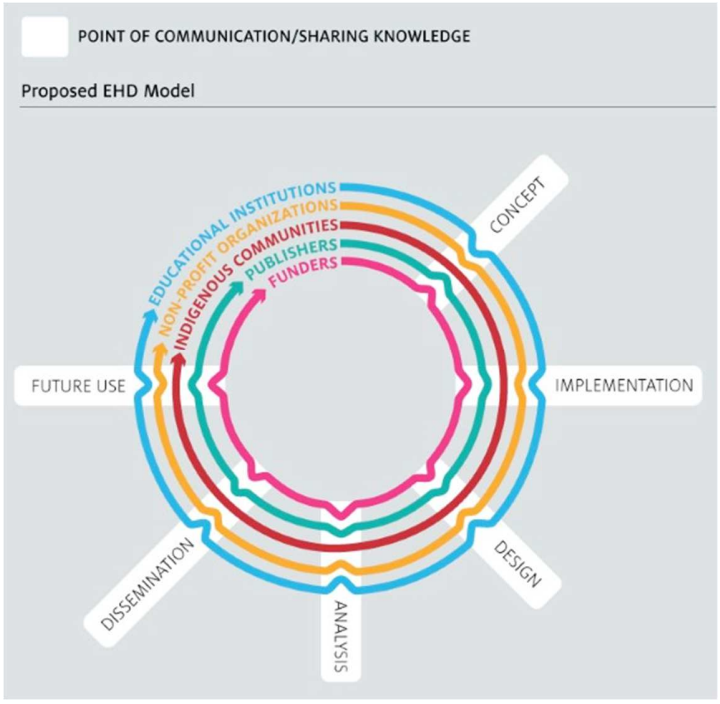


683

684 **Figure 1**. Map of Gold King Mine Spill origin, the affected San Juan River, and participating

685 Chapters: Upper Fruitland, Shiprock, and Aneth.

686



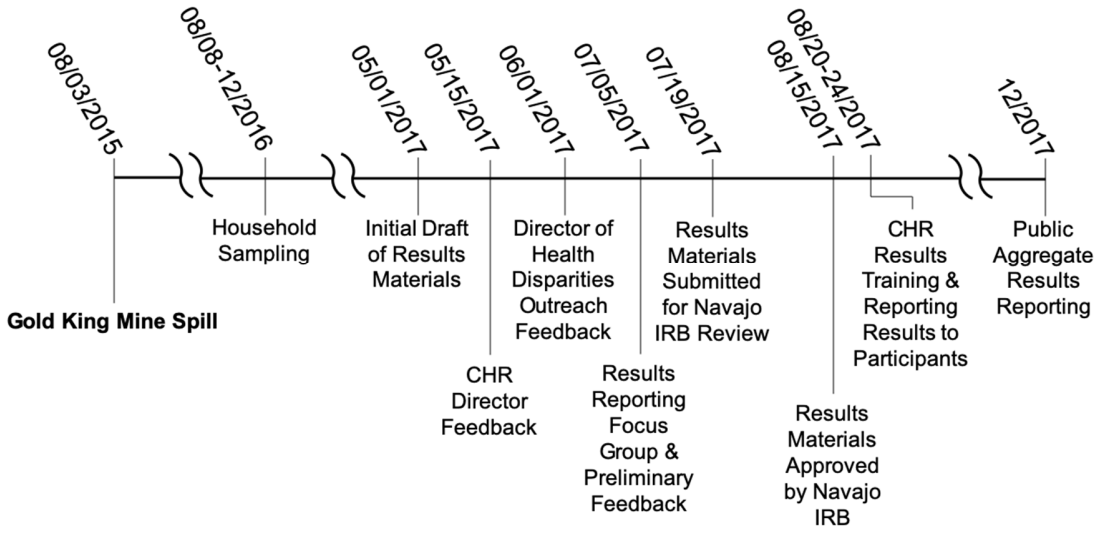
687

688 **Figure 2.** Knowledge relationships over time between partners in our proposed Environmental

689 Health Dialogue model

690

691



692

693 **Figure 3.** Timeline of events for development and report-back of individualized study results.

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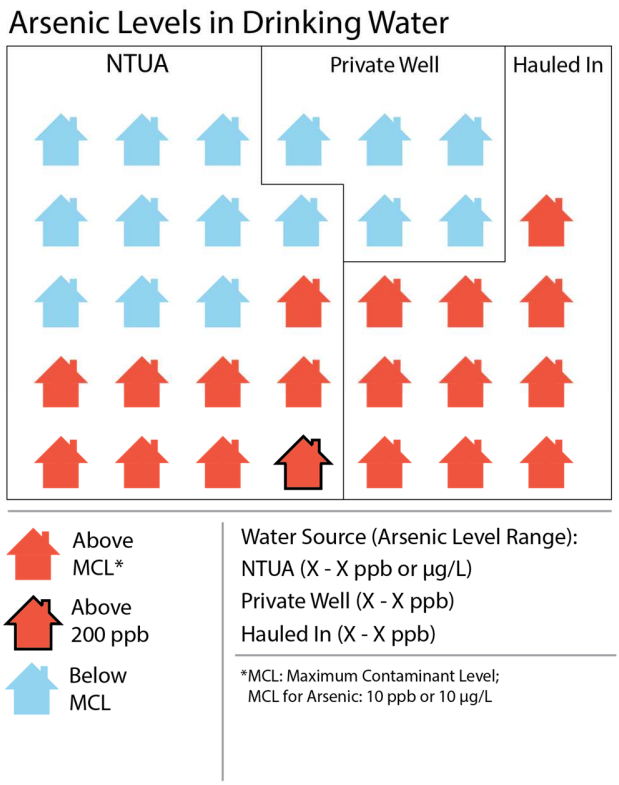
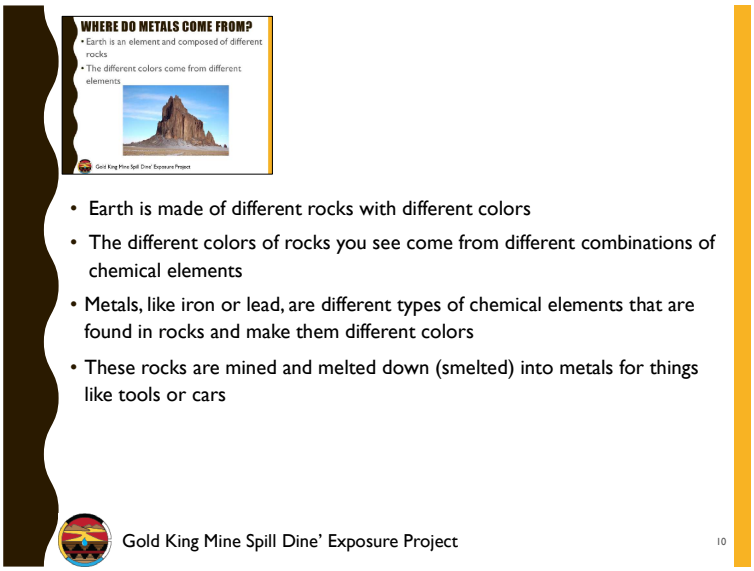


Figure 4. Example of media specific graphic in the original report-back materials version.

699



700

701 **Figure 5**. An example of guided talking points for CHRs from the flipbook. At the same time,

702 the participant would see a full-size version (Figure 6) of the small image in the upper left.

703

Figure 6. An example of locally-relevant imagery (e.g., Shiprock, the readily-recognizable, name-sake geological formation of the Chapter) to more effectively explain environmental health concepts.

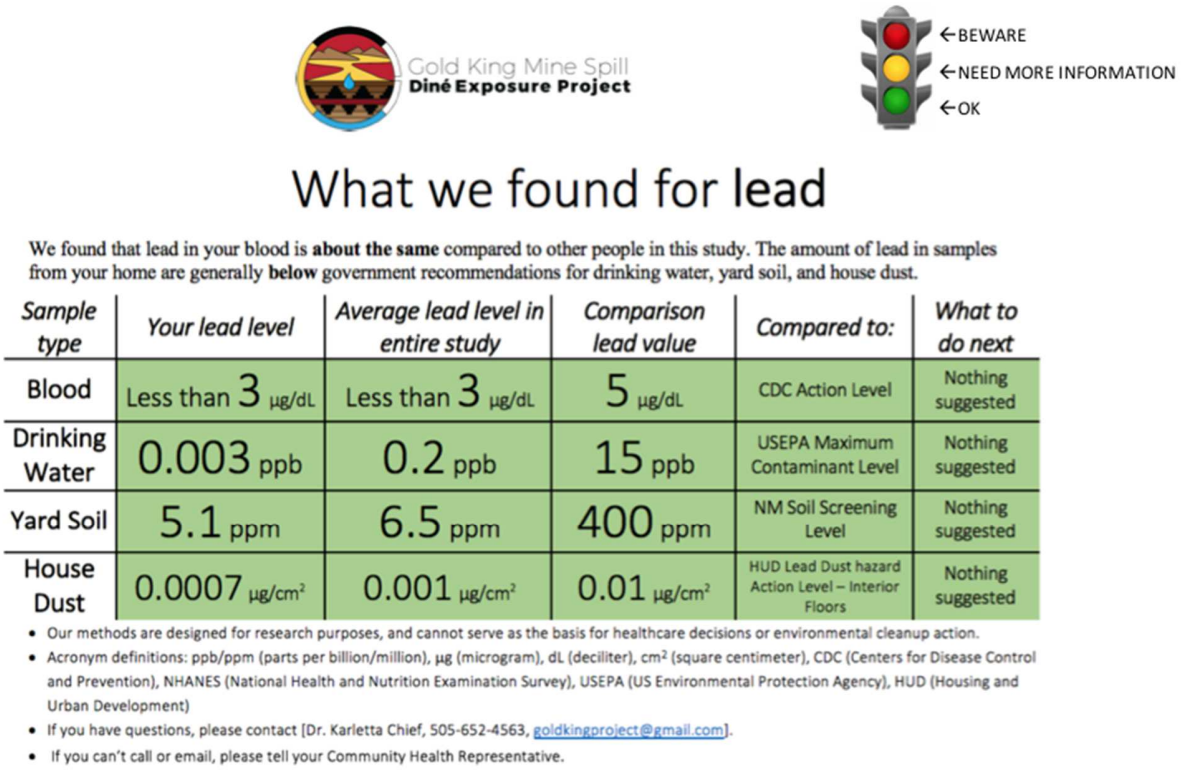


Figure 7: Individualize report back of research results sheet showing lead results side.

715 **Tables**

716

717 **Table 1.** Participant Characteristics, n=42

Characteristic	**Adult**
	n (%)
Gender (female)	
Female	28 (67)
Age (mean ± sd)	50 ± 20
Range	18-84
Race	**n (%)**
American Indian or Alaska Native	42 (100)
Chapter	**n (%)**
Aneth	11 (26)
Shiprock	14 (33)
Upper Fruitland	17 (41)
Education	**n (%)**
No western education	1 (2)
Primary school	3 (7)
Junior high school	2 (5)
High school or GED	14 (33)
Trade or vocational	1 (2)
Some college	13 (31)
2-year college degree	6 (14)
4-year college degree	0 (0)
Graduate degree	1 (2)
Did not want to answer	1 (2)
Household Income	**n (%)**
Less than 20,000	11 (26)
20,000 to 40,000	15 (36)
40,001 to 60,000	3 (7)
60,001 to 80,000	3 (7)
80,001 to 100,00	2 (5)
More than 100,000	1 (2)
Do not know	2 (5)
Did not want to answer	5 (12)
Language Questionnaire Administered	**n (%)**
Diné	4 (10)
English	22 (52)
Both	16 (38)

718 Participant characteristics of those that completed the evaluation

719

720 **Table 2.** Participant views on importance of information, n=42

Question	n (%)
What were the 2 most important pieces of information received today?	
Background on the GKMS	7 (17)
Background on our study	12 (29)
A summary of the overall findings	24 (57)
Personal results	29 (69)
Information on how to reduce contact	7 (17)
Additional information	5 (12)
Nothing circled	0 (0)
What was the least useful piece of information received today?	
Background on the GKMS	8 (19)
Background on our study	5 (12)
A summary of the overall findings	6 (14)
Personal results	1 (2)
Information on how to reduce contact	3 (7)
Additional information	11 (26)
Nothing circled	8 (19)

721

722

723 **Table 3**. Participant preferred method for results dissemination

Question	**n(%)**
Would you want to receive this information in a different way?	**N=42**
Different format	34 (81)
Different setting	32 (76)
Different person	32 (76)
Types of Format	**n=34**
Verbally (e.g., no words or pictures)	17 (50)
A video on the computer (e.g., YouTube)	10 (29)
TV (e.g., KOB)	6 (18)
Radio (e.g., KTNN)	7 (21)
Social media (e.g., Facebook, Instagram, Snapchat)	8 (24)
Nothing circled	1 (3)
Types of Settings	**n=32**
At a chapter house	20 (63)
At another public space	16 (50)
Nothing circled	1 (3)
Types of People	**n=32**
The people in charge of the study	22 (69)
Your healthcare provider	14 (44)
Nothing circled	1 (3)

724

725

726 **Table 4**. Factors for environmental health risk communication and examples from the Gold
727 King Mine Spill Diné Exposure Project

Factors presented by Boyd et al., 2018	**Method incorporated by the Gold King Mine Spill Dine' Exposure Project Individual Report-back**
1. Developing messages that are congruent with peoples' cultural beliefs and understandings of the environment	Report back of research results focus group, Community Health Representatives (CHRs), Diné researchers (e.g., utilization of the street light, English and Diné languages, water barrels)
2. Including Indigenous peoples in message design and delivery	CHRs and Report back of research results focus group participants are Diné and reside in the affected communities; university co-principal investigator and researchers also are Diné
3. Using credible and trustworthy spokespeople in message delivery	CHRs delivered the message
4. Identifying and utilizing effective communication materials and channels	Report back of research results focus group, CHRs, Diné researchers (e.g., CHR home visits as channels, flipbook as material)
5. Ensuring that messages are understandable to the target audience	Report back of research results focus group, CHRs, Diné researchers, evaluation questionnaire

728

729

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