Breaking Barriers: Evaluating Online Education Platforms to Connect Students with Remote Research Opportunities

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Abstract

Community-Engaged Research (CEnR) is a strategy for integrating community needs, priorities, and concerns into the research design, data collection strategies, and subsequent analysis of data. CEnR shares similar properties with both citizen science and community-based participatory research (Woolley et al., 2016). Before the COVID-19 pandemic, CEnR occurred predominantly via face-to-face interactions. However, a review of existing projects revealed that recent students in health-related fields did not receive adequate training in CEnR. Given the need for increased student experiential opportunities that are free of geographic or fiscal constraints, this project investigated online learning platforms as a method for connecting students with research learning opportunities, specifically research that uses CEnR. Data were collected on student perceptions of learning how to use and conduct research via an online platform, as well as their involvement with CEnR. Local CEnR practitioners also reported on their perceptions of participating in online community-engaged research. Finally, this project evaluated the ethical considerations of data safety, participant confidentiality and data sharing/access when conducting online interactive research. We conclude with a recommendation for a future online portal for CEnR.

Background

In a Community-Engaged Research (CEnR) framework, research questions originate from stakeholders (communities, regulators, industry, medical professionals, health professionals, etc.; O'Fallon & Finn, 2015; Khoury, Gwinn, & Ionnidis, 2010; O'Fallon & Dearry, 2002). This framework prioritizes community and stakeholder concerns, questions, and needs and integrates them into a larger research question. Within this framework, the National Center for Advancing Translational Sciences (NCATS) is further driving an emphasis on translational science, defined as “turning observations into interventions to improve health.”

Both CEnR and translational science require repeated interactions with stakeholders to ensure the research question is relevant, the methodologies are appropriate, and the product is useful, actionable and salient (Kowalewski, 2004; Strand, et al., 2003; Ahmed & Palermo, 2010; Rohlman, et al., 2022). The basic structure of CEnR can be laid out linearly, though it is in practice iterative and includes: i) identifying the problem or concern; ii) identifying the research question; iii) performing research with the stakeholder(s); iv) analyzing and reviewing results and v) translating results into clear, concise and actionable information (O'Fallon & Finn, 2015; O'Fallon & Dearry, 2002). Research translation products (e.g., infographics, reports, videos) are best improved via the use of focus groups and/or structured interviews with stakeholder liaisons that are from the community they represent. For example, Silent Spring Institute used comprehensive surveys and focus groups with liaisons and research participants to improve the way they return data to study participants, and have made their evaluation instruments publicly available (Dunagan et al., 2013).

For students, opportunities to engage in local experiential, community-engaged research are essential, but these opportunities are often limited by a number of barriers including geographic, financial, cultural and time-based constraints. While a time-intensive process, the benefits of engaging in community-based research are substantial, both to students (both online and campus based), researchers, and the communities (Kowalewski, 2004; Strand et al., 2003; Ahmed & Palermo, 2010). Specific benefits include: ability to conduct relevant research without a need for costly travel and relocation; ability to gain cultural competence by working with and learning from diverse communities in traditionally difficult to access areas, such as rural and Indigenous communities; and additional time for interacting with communities in a way that benefits the researcher and the community member. For the latter benefit, the ability to conduct virtual

research removes transportation barriers and childcare barriers for participants, giving them the ability to participate from their home, work, or another environment in which they feel safe. Finally, researchers benefit from no longer needing to try to fit all research activities into one short trip itinerary. Given all of these benefits, there is a need to expand opportunities for engagement in experiential learning via research and focus on overcoming these barriers.

The necessary transition to remote work due to the COVID-19 pandemic further magnified the existing barriers associated with experiential, community-based research. There was an immediate need for remote data collection, with many researchers redesigning their projects to avoid in-person data collection and engagement. Through these efforts, online research portals would have enabled remote data collection while facilitating CEnR. Additionally, such platforms could facilitate a broader level of student involvement in CEnR. An online research portal has benefits beyond the ongoing COVID-19 pandemic. Disaster research, such as collecting environmental data during wildfires, has benefitted from CEnR, particularly when study participants are involved in the data collection process themselves. This enables rapid collection of data, and reduces the burdens of researcher travel and geographic constraints (Rohlman et al., 2022). Therefore, there is a clear need for community-engaged research that can be conducted remotely via online research portals, which can be shared by researchers, student trainees and participants.

To date, existing online technologies that can support CEnR research remain limited. Skype, WebEx, Zoom, Facetime or Google Duo allow for individual or group video calls; however, these technologies are not associated with discussion boards, and the platforms require individual software applications. The Amazon mechanical worker (MTurk) platform has been used extensively by researchers to gather anonymous survey data (Hauser & Schwarz, 2016; Huff & Tingley, 2015; Hunt & Scheetz, 2019); participants have the option of directly emailing the researcher with questions, but MTurk is not set up to enable CEnR, which requires a prolonged relationship between the researcher and stakeholders. Community-engaged research has utilized interactive maps through geographic information systems (GIS) software made available by ESRI, called Arc-GIS, allowing participants to interact with research data, yet this is also a uni-directional research interface (Alemy, Hudsick, & Matthews, 2017; Antoniou et al., 2018). Finally, CEnR has recognized the importance of returning data to study participants, as this data can be used to provide actionable information. Existing online interfaces such as the Digital Exposure Report-Back Interface (DERBI) provide a uni-directional platform for the public to use (Boronow et al., 2017); however, it is unable to allow CEnR researchers and participants to interactively engage with each other.

Because of the limitations of available interfaces, this study investigated the possibility of developing a multi-directional online research platform wherein all study materials (training videos, fact sheets, maps, etc.) would be easily available to research participants and stakeholders. For example, discussion boards would allow stakeholders to interact with the research team and the use of embedded video-conferencing programs and chat rooms would allow for confidential focus groups to be held online. If successful, such an approach would allow for greater involvement in learning through research, while simultaneously improving CEnR and translational science research efforts. In addition, this approach would benefit online students who can participate as research assistants as well as research participants. These students face two-fold geographic challenges, as they are often not located at the institution conducting the research and may also be distanced from the area being researched. Secondarily, such a platform would be responsive to the increased

interest in public participation in science, thereby strengthening connections between Oregon State University research and impacted stakeholders (Bonney et al., 2009; Bonney et al., 2014).

As a first step, this project examined perceptions of such a platform for promoting experiential learning, as well as perceptions of virtual research amongst stakeholders, including student researchers and community members. First, existing online research portals and products were identified and assessed using a gap analysis to better understand the functional components of a virtual research portal. Next, we assessed data security that was informed by requirements for safeguarding participant information. Then, we developed a survey guide for individual conversations with student researchers and communities to understand their needs, concerns, and perceptions, around online research. Finally, the existing best practices in CEnR and translational science were evaluated for adaptation to an online medium.

Methods

Identification of exiting online research portals and products

Before making recommendations for the design of a future CEnR portal online, we first identified existing online research platforms found through Google search, personal knowledge, and those referenced by other online research projects. Search terms were generated and reviewed by the team of researchers for this project. Search terms included “Online research” “Citizen science projects” “Community-engaged research online”. There were 21 online research platforms and products identified in the review. Of those, 12 were specifically online research platforms (see Table 1).

Gap analysis

Prior research projects conducted by the research team identified important limitations to conducting research that required face-to-face interaction with community members (See Table 2). These limitations and requirements for an online research portal informed a gap analysis using the identified portals and products. Specifically, the online research platforms and products were assessed and coded in a data dictionary, with each potential platform or product evaluated for the following: i) research field (e.g. biology, chemistry, etc.); ii) direction of communication (unidirectional, bidirectional); iii) accessibility (designed for low/no vision, color blindness, hard of hearing, responsive web design); iv) communication capacity (video chat, discussion board); v) training for citizen scientists and; vi) data storage and security capabilities. The research team reviewed each entry and discussed it to ensure consensus.

Individual Guided discussions

Based on the results of the gap analysis, structured interview questions were developed and used for interviews with community members and graduate student researchers (Appendix A-B). Questions included the following: i) concerns regarding confidentiality when participating in an online research study; ii) willingness to join an online team-learning platform and; iii) suggestions to improve online integration between students, researchers and stakeholders. The questionnaires and study activities were reviewed and approved by the Oregon State University Human Research Protection Program (IRB-2020-0657).

Interviews were conducted in February 2021 using the Zoom video-conferencing platform. Interviews were audio-recorded with permission and transcribed. A moderator introduced the project goals and led the participant through the questions. A second researcher was present to take notes.

Table 1. Existing Online Research Portals Reviewed

Online Research Platform	Required elements (out of 13)	Participant Base				Minimum Education Level			
		K-6	7-12	Gen	Spec	8th	HS	Coll	>Coll
All of Us	9	■	■	■	■				■
23andMe.com	9	■	■	■	■		■		
NHANES	8	■	■	■	■				■
Detox Me: Action Kit	8			■		■			
The Global ECT-MRI Research Collaborative	7				■				■
ADNI	6				■				■
American Gut Project	6	■	■	■			■		
Ancestry.com	5	■	■	■	■	■			
Microsoft Research Open Data	4				■			■	
The Zooniverse	4	■	■	■		■			
NIH Human Microbiome Project	3	■	■	■	■				■
EMBL-EBI	3				■				■

The 12 examples identified in the literature review were assessed for 13 capabilities: i) adapt to colorblindness; ii) adapt to deaf or hard of hearing; iii) adapt to dyslexia; iv) responsive web design; v) video chat capacity; vi) discussion board capacity; vii) availability of training materials; viii) develop a user profile; ix) track user progress; x) restrict access; xi) messaging capacity; xii) dissemination of results and xiii) use of technology to collect data. The participant base (individuals that are encouraged to participate) was identified, and the estimated minimum education levels needed to utilize the site are shown in black.

Table 2. Previous Research Conducted by the Authors, and Observed Limitations and Potential Solutions

Study Title	Study Description	Limitations Identified	Recommendations
Hurricane Florence Personal Chemical Exposures	Conducted virtually, participants consented online and were mailed a personal passive sampler at no cost to them. The sampler was then mailed back for analysis.	There were limited opportunities to interact with a researcher or ask questions during the consent process (telephone and email for a researcher provided).	Offer video chat 'office hours' to obtain additional information.
Exposure, Location, and lung Function (ELF) study	Conducted in-person, participants measured their chemical exposure, carried a smart phone to gather location data, and took twice daily lung function measurements. All data was reported back to participants.	The online portal for returning data was based off data portals for researchers and was not intuitive for participants. While redesigned, the portal was only able to handle individual return of data, so participants did not see aggregate data.	Incorporate reporting systems into online research hubs. Example: Digital Exposure Report-Back Interface, developed by Silent Spring Institute.
Hurricane Harvey Personal Chemical Exposures	Conducted in-person, researchers held focus groups with study participants to improve the way data was reported back.	The focus groups required a physical meeting place which created timing and transportation challenges for researchers and participants. Research participants cited difficulty in finding childcare, scheduling time for the meeting between school events, work and family meals.	Conduct focus groups online using video conferencing; hold individual online interviews.
Unconventional Natural Gas Drilling (UNGD) Study	Following community concerns, researchers flew to Ohio to set up environmental and personal samplers at residences located near UNGD sites. Participants later mailed the samplers back (hybrid research design).	Training materials were mailed, requiring participants to manually enter a URL into their computer to view the videos. In addition, compliance with study protocol was less than ideal (labels incomplete, samplers improperly stored, samplers deployed for an incorrect length of time).	Develop training modules; participants must demonstrate understanding of the study and their activities (>80% score) before continuing to the data collection phase.

Graduate student interviews. We selected graduate students in environmental science degrees with prior experience or interest in conducting community-engaged research. Emails were sent to graduate students that had previously been involved in environmental science research projects through Oregon State University and expressed an interest in doing research via an online research portal. Five students were contacted and three agreed to participate. Given the small sample size, and limited number of students doing this type of work, no demographic information is provided, to protect participant confidentiality.

Community member interviews. We reached out to community members and community groups that had previously been involved in research with Oregon State University. They had been involved in recruiting for other studies or helping collect data with researchers. Community members were asked to participate and share their views regarding potential participation in online research. Nine people were contacted, and one agreed to participate. Notably, community members cited interest in the study but were at capacity given the ongoing COVID-19 pandemic.

Data Security

Data security capabilities were informed via the Human Research Protection Program, which identifies 3 levels of data security (see Appendix C). Applications and resources are rated to a specific data security level. We utilized the Data Security Level decision tree (Appendix C) and cross-referenced the type of data we would conceivably collect based on prior studies (Table 2) to determine the appropriate data security level we would need to achieve for a future multi-directional online research platform.

Results

Results of the Gap Analysis

Based on previous experiences with virtual and in-person research (Table 2), the following considerations for an online research portal were identified:

1. Ability to recruit and enroll participants
2. Ability to host confidential focus groups or individual interviews
3. Opportunities to conduct synchronous and asynchronous training with participants;
4. Ability to provide personalized data visualization

Along with these requirements, the nature of the online portal has associated concerns regarding data security and privacy. There were 12 examples identified as shown in Table 1. Of the 12 portals, none contained all the accessibility and communication capabilities. However, the portals had very different participant bases and differing educational levels needed to utilize the portal. For example, the All of Us and 23andMe.com portals targeted all individuals as research participants to include children and specialists. However, while the All of Us portal was written to be interpreted and used by individuals with a high level of education, 23andMe.com is accessible to those with a high school education.

Each portal was further assessed to determine how they integrated interactive and communication components. As shown in Table 3, nine components were assessed. Half of the portals had the ability to set up a user profile (50%), a majority included training materials (58.3%), and communication methods (66.7%). Interestingly, 41.7% of the portals included a report back of the data they collected to study participants and/or the general public. For example, *NHANES* publishes de-identified data to their website for anyone to review and work with. However, the way portals interacted with study participants varied, with 25% having no interactivity, and seven portals having minimal to extensive interactivity. Finally, only two portals (16.7%) had elements of data security that would allow study participants to view confidential information.

Table 3. Frequency of Interactive and Communication Components Across the 12 Online Research Portals

	# portals	%
Interactivity		
No interactivity	3	25.0
Unidirectional (users can only receive information)	4	33.3
Bidirectional/multidirectional	3	25.0
Unable to determine	2	16.7
Video	3	25.0
Discussion boards	2	16.7
Training materials (print, video)	7	58.3
Ability to set up a user profile	6	50.0
Tracking training progress of users	1	8.3
Data security	2	16.7
Communication (email, internal messaging app)	8	66.7
Dissemination of results (community-level, individual)	5	41.7

Interview Results

The goal of an online research portal would be to connect student researchers with community members to facilitate community-engaged research. However, these are two different user bases, with differing goals and needs. To better understand the way in which each user base would want to interact with the portal, we held individual guided interviews with graduate students (n = 3) and a community liaison. A summary of the interviews is shown in Appendix D.

Student interviews. Three graduate students in environmental science fields were interviewed following a script (see Appendix A). All students had prior experience conducting community-engaged research, and two had experience with online research (see Appendix D). The students were presented a list of potential barriers to conducting online research and asked to identify those they felt were most pertinent. All three identified requirements for obtaining written consent and the logistics of how to return individual data to be potential barriers . Two students also cited Internet literacy and accessibility as concerns. Two of the students cited additional concerns not captured by the question - cultural barriers to engaging a community, underlying distrust of research, and the inability of the research team to see if samplers are properly set up.

The students identified multiple logistical additions to a research portal, such as a calendar for participants to note their availability to participate in a sampling campaign, a registry for participants to log in and confirm receipt of their samplers, the ability to send reminders to participants, and the ability for participants to upload photographs or 360° videos of the location they were sampling. Overall, the students highlighted the role of a portal to encourage and facilitate engagement amongst study participants, as the portal could potentially decrease the burden on a participant and could highlight community-specific needs.

Community member interview. Given the myriad demands on community liaisons, only one community member was able to complete the interview. The interview script is provided in Appendix B. The individual has a rich history of working with communities and researchers through community-engaged research and participating in research through an online forum. While overall supportive of a research portal that could expand research opportunities to the public, the liaison listed concerns about a shift away from in-person to virtual. Specifically, the liaison raised the concern that research initiated online may not be reflective of, or situated within, community history, context, and culture (see Appendix D). Similar to the students, the liaison also identified Internet accessibility as a potential barrier, specifically stating that some populations do not have reliable access to the Internet.

Recommendations

Data security and privacy considerations

Many CEnR studies collect the following types of information: i) name; ii) location data (GPS data rounded to the nearest 1.0 mile); iii) demographic data; iv) general health information (excludes collection of health information that could cause harm to an individual if disclosed, i.e. HIV status, sexual orientation); v) data from a Community Assessment for a Public Health Emergency Response; vi) exposure history (use of pesticides, proximity to oil refinery, etc.) and; vii) occupational exposure history. This type of data is typically designated as minimal risk (see Appendix C).

Following the COVID-19 pandemic, the authors, like many other researchers, rapidly transitioned their research online. This sparked a conversation about the collection and storage of data online, and the potential additional privacy considerations. Related to the online portal, there would be a need for collecting personal identifiable information from participants. To ensure privacy is protected when conducting online research, there are several steps that can be incorporated to facilitate data collection while mitigating breaches in security and privacy. These resources described below were collated by the authors as they transitioned their research online. While they represent the manner in which the authors applied privacy concerns to their research, they do not represent the totality of all privacy concerns around virtual research.

Protecting privacy in remote focus groups or interview settings

Video-conferencing services have several options available to increase security. Recommendations include: i) send out meeting invitations in advance and include guidelines for participation; ii) set each meeting with a required password; iii) utilize a waiting room to ensure participation by consented individuals; iv) set the meeting so only the host or co-host(s) can share the screen; v) only the host can record the conversation (the service will require consent from all participants and; vi) once all attendees are in place, lock the virtual room. If necessary, should a participant violate the guidelines for participation, the host or co-host can turn off their video, mute them, or remove them from the meeting or into the waiting room.

Additionally, consider strengthening privacy considerations by including a message to participants that requests they participate from a private location, where others (family, friends, roommates) cannot overhear. Below is a sample message.

> When we are doing focus groups, you may not mind sharing your information with a friend, but other people in the group may not want their information shared with uninvited participants. That is why we are requesting that ONLY invited participants view and listen to this meeting. Go into a room where you have privacy, and you won't be interrupted. Consider using headphones.

To further protect privacy, while participants are in the waiting room, ask them to change their name to just that of their first name, or first name plus last initial. In the waiting room, only the host and co-hosts can see participants, so this prevents other participants from seeing full names or other information that may be present in an individual's Zoom account name.

Lessons learned during the COVID-19 pandemic

In March 2020, research shifted dramatically to accommodate the ongoing COVID-19 pandemic, with activities once conducted in person shifted to video conferencing and online workspaces. Creating guidelines for conducting research virtually becomes critically urgent. Here, we share lessons learned from transitioning research into an online space.

Recruitment, enrollment, and informed consent

During the COVID-19 pandemic, recruitment was conducted in several studies entirely virtually,

using social media (Facebook, Twitter, Instagram), email list-servs, and attendance at virtual community forums. Eligibility testing can be conducted using survey tools such as Qualtrics, with branching and display logic used to collect the necessary information and to allow the participant to opt out at any time. Additionally, survey tools can also be used to collect informed consent. Briefly, participants are shown one or two simple questions, asking which activities they are being asked to participate in. If they answer the question(s) incorrectly, they are redirected to the study description to review the study goals and activities, before being given a second chance to answer the questions. If the question(s) are answered correctly, this is indicative of informed consent; if answered incorrectly, branching logic will transition the participant to a different screen, thanking them for their interest yet notifying them they are not eligible to participate.

Conducting virtual focus groups

Focus groups can be a useful strategy for collecting data from a target population. Traditionally held in person, methods for virtual focus groups have been explored (Murray, 1997; Browne et al., 2022). While video conferencing software such as Zoom or Webex are excellent for connecting video and audio feeds of researchers and participants, they are limited in their ability to collect data. For example, researchers often ask participants to write down short answer responses, or rank options on a Likert scale. Existing platforms provide simple, multiple choice, anonymous polls which were often insufficient for research purposes. Platforms like Google Jamboard are effective tools for mitigating this issue, as they allow participants to view materials and write comments.

Collecting environmental and personal data

One of the main goals of this research project was to evaluate how an online research portal could allow student researchers to collect environmental and personal data from research participants. During COVID-19 pandemic, research was made possible by using samplers that can be easily mailed at room temperature and are relatively easy to use, even in disasters, and are used with high compliance by study participants (Rohlman et al., 2022).

Challenges with conducting online research

We were well poised to transition our research to an online space given our ongoing work on this project. However, the abrupt switch to online research, necessitated by the COVID-19 pandemic, also identified unforeseen challenges. Primarily, we identified fatigue amongst participants from spending so much time online or joining multiple video conferencing meetings. 'Zoom fatigue' was a common refrain. Appendix E includes strategies that the research team used to reduce such fatigue for study participants.

Discussion

This project investigated the possibility of developing a multi-directional online research platform wherein all study materials (training videos, fact sheets, maps, etc.) would be easily available to study participants and stakeholders. For example, discussion boards would allow stakeholders to interact with the research team and use of embedded chat rooms would allow for confidential focus groups to be held online. A review of existing online research shows a diversity of platforms with different approaches to researcher-participant interactions, data accessibility, and discrete target audiences and required educational background for participation. None of the identified platforms contained all the elements desired for an online research portal.

To better understand how our anticipated user base may use an online research portal, we interviewed graduate student researchers and community members. Unfortunately, significant limitations apply, as student and community member availability were severely curtailed given the ongoing COVID-19 pandemic. Personal and professional obligations prevented the availability of individuals for interviews. Therefore, the data

we present is preliminary at best, and is not representative of all potential users of an online research portal. Despite this limited sample, the graduate student interviews were surprisingly consistent in their request for logistic support, such as the ability to track when samplers have been mailed, arrived, or are *en route* back to the laboratory. Participant support, such as easily accessible training, calendar alerts, and the ability to track their progress in the study were also highlighted. This is perhaps unsurprising, as much of this support is often conducted by research staff during in-person research events. However, our community interviewee spoke more about the need to ensure that the transition to a virtual space did not create a barrier for researchers understanding the history of the place or people they were sampling. There was a concern that this transition to a remote platform may divorce the research goals from community needs.

In sum, the research, as well as the lessons learned from transitioning research online during the COVID-19 pandemic identified necessary components for an online research portal. More work, specifically around protecting participant information when returning data, is needed. However, the preliminary data from this project indicates that such a portal could allow for greater involvement in learning through research, while simultaneously improving community-engaged research efforts. Secondarily, such a platform would be responsive to the increased interest in public participation in science, thereby strengthening connections between OSU research and impacted stakeholders (Bonney et al., 2009; Bonney et al., 2014).

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Appendix A: Graduate Student Interview Guide

Thank you for participating in this research. I'd like to have a conversation with you regarding your experience conducting community-engaged research and/or translational research. Your participation is voluntary, and you may skip any questions you do not want to answer.
I would like to audio-record this interview. May I record our interview?
[*Interviewer record response here*: _____]

1. Are you a current OSU student? [If no, end interview due to ineligibility]
2. Are you at least 18 years of age? [If no, end interview due to ineligibility]
3. What is your affiliation to Oregon State University? [*prompt*] In other words, who have you worked with at OSU on the topic of community-engaged research and/or translational science?
4. What are barriers to conducting research outside of Oregon? For example, what sorts of things make it difficult for you to do research outside of Oregon? These may be financial, logistic or other barriers.
5. Have you conducted community-engaged research? Community-engaged research is defined as research conducted in collaboration with community members (i.e. community members help design the study, pose the research question, collect and/or analyze data). If no, jump to question 2. If yes, complete these follow-up questions:
    a. What type of research? (Qualitative, quantitative)
    b. Please describe the experience
6. Have you conducted research online or at a distance?
    a. Please describe the experience
    b. What barriers did you run into?
    c. What successes did you have?
7. We are evaluating the effectiveness of creating an online research portal where you could train participants, collect data, hold focus groups, etc. How interested would you be in such a portal? 1 = highly interested, 10 = not interested. Please describe your answer.
8. What sort of elements would you like to see in an online research portal? Examples may include ability to conduct interviews/focus groups, collect survey data, disseminate data, and train participants to collect samples.
9. These are some of the barriers we have identified, specific to conducting research. Please review and rank them based on priority to address (1 = high priority, 5 = low priority). In other words, which barriers are considered to be the most challenging to conducting research online?
    a. Requirement for written consent
    b. Logistics of returning data / communicating data to participants
    c. Developing online data visualizations
    d. Requirement for physical attendance/physical data collection
    e. Requirement for training community participants
10. I'm going to show you two examples of research that is currently being conducted online (https://allofus.nih.gov/, https://www.23andme.com/research/).
    a. Can you tell me some things you like about these sites?
    b. Can you tell me some things you don't like about these sites?
    c. Is there anything that you feel is missing?
    d. Anything that is confusing?
11. Are there any thoughts you would like to share with us, relating to conducting research online?

Thank you for taking the time to chat with us. We appreciate your feedback regarding potential online research portals. Please contact me at 541-357-8577 or by email (diana.rohlman@oregonstate.edu) if you have any further questions.

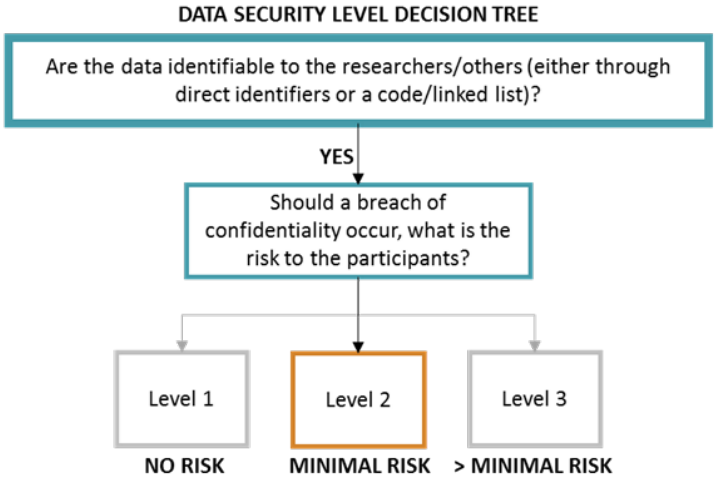
Appendix B. Community Member Interview Guide

Thank you for participating in this research. I'd like to have a conversation with you regarding your experience conducting community-engaged research and/or translational research. Your participation is voluntary, and you may skip any questions you do not want to answer.
I would like to audio-record this interview. May I record our interview?
[*Interviewer record response here*: _____]

1. Are you at least 18 years of age? [If no, end interview due to ineligibility]
2. What community group are you affiliated with? [*prompt*] In other words, how have you worked with OSU on topics of community-engaged research and/or translational research?
3. What are barriers to participating in academic research? (cost, availability, knowing they exist, eligibility, etc.)
4. Have you participated in research before? Research is defined by Oregon State University as "a systematic investigation, including research development, testing and evaluation, designed to develop or contribute to generalizable knowledge" (https://research.oregonstate.edu/irb/does-your-study-require-irb-review). This may include clinical or laboratory research (providing biological samples (urine, saliva, etc.), participating in behavioral studies, collecting environmental samples, wearing research equipment) as well as qualitative research (participating in focus groups, research interviews, surveys, etc.). If your answer is no, jump to question If your answer is yes, complete these follow-up questions:
    a. Please describe the experience
    b. What challenges did you experience?
    c. What benefits did you experience?
5. What are your thoughts about contributing to research online?
6. We are evaluating the effectiveness of creating an online research portal where interested individuals could sign up to participate in studies, or even just to view the data we have collected. How interested would you be in such a portal? 1 = highly interested, 10 = not interested. Please describe your answer.
7. If you participated in a study to evaluate air quality, what resources would you like to be available to you? Examples may include training videos, discussion boards and data visualization.
8. I'm going to show you two examples of research that is currently being conducted online (https://allofus.nih.gov/, https://www.23andme.com/research/).
    a. Can you tell me some things you like about these sites?
    b. Can you tell me some things you don't like about these sites?
    c. Is there anything that you feel is missing?
    d. Anything that is confusing?
9. Are there any thoughts you would like to share with us, related to community participation in academic research?

Thank you for taking the time to chat with us. We appreciate your feedback regarding potential online research portals. Please contact me at 541-357-8577 or by email (diana.rohlman@oregonstate.edu) if you have any further questions.

Appendix C: Data Security Level Decision Tree



Data Types

- Demographic data (DOB, race, ethnicity, income, education)
- Location (address, GPS data rounded to 1 mile)
- Basic health data (smoker, incidence of cough, wheeze, etc.)
- Exposure history
- Occupational exposure history (work with pesticides, etc.)

Data Use

- Individual results – returned using secure email (Exchange)
- Aggregate, de-identified data presented via online interface
- Researcher use only
  - Progress & training completion tracked
  - Correlations between co-variates and exposure
- Authorized researchers – access to identifiable data

DATA SECURITY LEVEL: Level 2, minimal risk

Acceptable Services/Platforms

- Audio & Video Conferencing
- Banner
- Box
- Canvas
- Core
- Data Warehouse
- Docusign
- Exchange email
- Google Drive/Docs
- Office 365
- OSU Network Shares
- Qualtrics

FROM: https://uit.oregonstate.edu/ois/data-management-and-classification-overview

LEVEL 2 REQUIREMENTS – OREGON STATE UNIVERSITY

Information should be shared and stored in a manner that provides access only to authorized individuals. Data may not be disclosed to additional parties without prior IRB approval specifically authorizing the disclosure. If information is stored on a computer, the system should have fully patched operating systems and applications, and current antivirus software with current virus definitions. Information may be stored on approved cloud servers. The data security plan must be reviewed by the information Security Office if the data security category is level 2 and the data is stored in a cloud-based server, unless the server is Qualtrics or OSU Google Drive. A plan for routine back-ups must be in place.

Appendix D: Summary of Student (S) and Community (C) interviews

	S1	S2	S3	C1
Prior CEnR experience	Environmental sampling across four states with community members	Personal sampling following hurricane-related flooding	Environmental sampling across the US with community members	Yes – bioremediation study design around a Superfund site
Barriers to CEnR / translational science	Logistics of sampling with participants Timing (when to deploy and aligning all participants) Geography (research sites out of state)	Distrust of research and researchers Appropriate methods of recruitment Ease & equality of participation (consider childcare, transportation)	Logistics (shipped samplers are delayed)	Collecting information from community members Ease & equality of participation (consider childcare, transportation) Understanding community connections
Prior online research experience	Yes	No	Yes	Yes
Components of an online research portal	Calendar for marking availability for sampling, automatic reminders Sampler tracking status Repository for participant photos Use videos and pictures for training and training via Zoom/Skype Simplify language and define all unfamiliar terms	Visibility of the researchers – Have photos and videos of them Registry for sampler status Interactive data analysis options Majority of content written at a 6th grade level with more complex options available	Ability to upload video Registry for sampler status Automated reminder messages Section that presents data from participant's sampler Preferred method of communication Training videos and materials	Each project needs to have a good context in history and ensuring people are being respected, for the benefit of the community. Have a section that puts the research into this context
Methods for facilitating online CEnR	Ensure participants are highly invested in the project Take time to build connections with participants and listen to them.	I see lots of benefits of returning data. It's important to offer the option. Be embedded in a local community. Be in a community group.	Find and integrate publicly available data whenever possible (e.g. use maps to determine if the sampler is near a busy road) – this can reduce the number of questions a participant needs to answer	Community needs should be highlighted first. If there is no benefit to participants people will not participate. The research team needs to do their homework about the community, history of the community – what has been done.

Appendix E: Online Research Portal Design Checklist

A number of recommendations arise during the literature review regarding online research portal design. The following is a list of the main recommendations we felt most pertinent to online research portal design.

1. Defining the user base
   Analysis, especially user analysis, is an important first step in design as illustrated in ADDIE model of instructional design. ADDIE stands for Analysis, Design, Development, Implementation and Evaluation. In reviewing the identified existing research hubs, it became clear that each hub defined their user base differently (see Table 1). It becomes clear to define the user base in the early stages of any online research portal design. And in the first phase of analysis, it is important for any project to identify users, understand user expectations, behaviors, needs, and motivations (Bhowmick, 2017). Similarly, in web design and user experience design, user research is crucial to help designers understand the participants and users of their future product. In research design, it is also important to clearly identify participants of a research as we begin research design (Hodell, 2015).

   Many of the identified research opportunities, while open to a broad range of participants, have a specific user base for the data they produced. For the proposed research, the participant base is considered to include the general public; adults may allow their children to participate as appropriate. The generated data will be made available at an 8th grade level. All data will be fed into a data visualization scheme to allow fast and intuitive conceptualization of the data. All data will be returned to individuals via the portal and aggregate data will be downloaded into a publicly available database. Data can be queried by communities, and users can share and perform their own data analysis (training will be provided).

2. Choice of language, considering the general public with an average literacy level of 8th grade education.
   According to the Literacy Project, the average American reads at the 7th to 8th grade level. In the medical industry, patient education materials are recommended to be no higher than sixth to eighth-grade level (Badarudeen & Sabharwal, 2010) . Therefore, we recommend written language used in the online research portal be around 8th grade literacy level. For more resources:
   - Marchand, L. (2017). *What is readability and why should content editors care about it?* Center for Plain Language. Retrieved from https://centerforplainlanguage.org/what-is-readability/

3. Considerations of a user base with languages other than English:
   Current research conducted by the PI has been predominantly conducted in English. One limitation of English as the only communication language is its inability to accommodate research activities or disseminating research results in a language other than English. Previously, print materials have been translated, and videos have had closed captioning. However, to properly develop an online research portal, it must be accessible to users in different languages. Priority will be given to developing a site in Spanish.

4. Considering web navigation workflow to meet the need of communication between researchers and research participants.
   A review of existing online research interfaces shows that while the majority are largely unidirectional (i.e. participants mail in data and view aggregated data online), these interfaces are designed to facilitate user interaction. Not all are successful, yet this appears to be due to underlying assumptions made for the user base. For example, NHANES is a major data repository which allows individuals to download and analyze data collected from around the United States. However, there is limited training available to help an individual understand how to parse and filter the data, let alone download it and analyze it. In other studies, such as the Human Microbiome Project, it is difficult to navigate through all the various pages of the website. Therefore, an online research portal should have a straightforward workflow, prompting and requiring users to complete all required trainings and certifications before registering for an existing project.

5. Considerations for limiting to 5 items or less in any list of the web portal, such as navigation buttons list (Miller, 1956).
   For more resources:
   - Schenkman, L. (2009). *In the brain, seven is a magic number*. Inside Science. Retrieved from https://www.insidescience.org/news/brain-seven-magic-number

6. Choice of Text font style to be sans-serif.
   Some popular sans-serif fonts are Arial, Futura, and Helvetica. For more resources:
   - https://www.w3schools.com/cssref/css_websafe_fonts.asp
   - https://blog.hubspot.com/website/web-safe-html-css-fonts

7. Recommended text size to be at least 12 or default font size (size 16 for mobile design).
   For more resources:
   - https://learnui.design/blog/mobile-desktop-website-font-size-guidelines.html
   - https://w3-lab.com/website-font-size-guidelines/

8. Limit the use of text and consider adding appealing visuals.
   Visuals in webpages can "show changes in processes, emphasize the most important information, and draw users' attention". For more resources:
   - Sanduski, J. (2020). Effective Use of Images & Graphics in UX Design. Adobe XD Ideas. https://xd.adobe.com/ideas/process/ui-design/effective-use-images-graphics-ux-design/
   - Wargo, E. (2006). How many seconds to a first impression? Observer. July, 2006. https://www.psychologicalscience.org/observer/how-many-seconds-to-a-first-impression
   - https://www.thecreativemomentum.com/blog/visual-communication-in-web-design

9. Ensuring all text content on the website is accessible.
   This can be done by marking up website content semantically, including article element <article>, section element <section>, paragraph element <p>, and various list elements. https://www.w3.org/WAI/tutorials/page-structure/content/

10. Ensure all video content is accessible by including closed captions for videos or providing a transcript.
    For more resources:
    - Leduc, J. 2019. 3 Reasons why captioning is more important now than ever before. 3 Play Media. https://www.3playmedia.com/blog/importance-of-captioning/
    - Dello Stritto, M.E. and Linder, K. (2017). A rising tide: How closed captions can benefit all students. Educause Review. https://er.educause.edu/articles/2017/8/a-rising-tide-how-closed-captions-can-benefit-all-students

11. Ensuring all audio content is accessible by providing transcripts for audio.

12. Provide "alternative" descriptions for images. Add an "ALT" description for images to help individuals using screen-reading software to be able 'see' or skip images.

13. Create meaningful link names. Avoid using hyperlinks that say "click here" or just placing the URL itself. Instead, label all links with a descriptive title.

14. Make all file types accessible.
    - Do's and Don'ts on designing for accessibility: https://accessibility.blog.gov.uk/2016/09/02/dos-and-donts-on-designing-for-accessibility/

- Utilize files and documents that are largely accessible. If using a PDF, convert the PDF to an accessible PDF file. (OSU Ecampus "Quick Reference – 5 Accessibility Tips").
- WebAIM contrast checker: "WAVE" Web accessibility checker. "WAVE is developed and made available as a free community service by WebAIM at Utah State University. Originally launched in 2001, WAVE has been used to evaluate the accessibility of millions of web pages." (WebAIM, n.d.) You put in a web URL in the web accessibility checker, and the webpage will reveal any accessibility issues that need to be fixed.
- Accessible design tips for screen readers: https://designmodo.com/screen-reader-accessible-design/
- Contrast Ratio of Color: Look for a contrast ratio of at least 4.5:1 for normal text and 3:1 for large text https://webaim.org/resources/contrastchecker/
- Tool to check contrast with a color palette to choose from: http://www.contrastchecker.com#
- 15-Color Palette for color blindness (and low vision): https://www.nceas.ucsb.edu/sites/default/files/2022-06/Colorblind%20Safe%20Color%20Schemes.pdf

15. Use H5P in learning activities and learning assessments for increased and enhanced learner engagement.
    H5P, short for Html-5-Package, is a plugin tool that helps produce and run interactive content and interactive video within your LMS, or other kinds of eLearning browser. It provides interactive content, and it is responsive and accessible. It is open source, free to use, and HTML 5 compatible. (falcon, 2017) (https://h5p.org/blog/h5p-the-superior-format)

16. Limit the length of the page – try to keep it on one screen.
    When long page is unavoidable, use labels such as <nav>, <main>, and <aside> to distinguish two page regions.
    - Mesibov, M. (2018). People don't scroll (and other page length myths). UX Planet. https://uxplanet.org/people-dont-scroll-and-other-page-length-myths-c7ca720a0595

17. Include a navigational menu (Babich, 2019).
    Website & App Navigation Design Best Practices. Adobe XD Ideas.
    https://xd.adobe.com/ideas/process/information-architecture/website-navigation-design-best-practices/

18. Include a status/progress bar so people can see where they are in the site.
    This adds usability to the site. This is especially useful for training modules so people can gauge how far they are into a certain process, such as "Menu > About us > Researchers > Dr. Janeway". You can also show how many pages are in a section and what page the readers are on, as in this example: "page 3 out of 9 pages".

19. Mitigate Zoom fatigue.
    Stanford researchers identified four main causes of zoom fatigue and their simple fixes, listed below (Bailenson, 2021)
    a) To mitigate eye contact via video, exit the full-screen options when needed.
    b) If the 'self' view is difficult, you can use the gallery view mode to see all participants in the call, or use the option to "hide self view"
    c) To ensure ergonomic support, use an external camera farther away from the screen to allow you to sit comfortably.
    d) To reduce the cognitive load posed by using the video feature, consider taking an "audio only" break by turning off your video as appropriate.

About the Research Unit at Oregon State Ecampus

Vision

The Ecampus Research Unit strives to be leaders in the field of online higher education research through contributing new knowledge to the field, advancing research literacy, building researcher communities and guiding national conversations around actionable research in online teaching and learning.

Mission

The Ecampus Research Unit responds to and forecasts the needs and challenges of the online education field through conducting original research; fostering strategic collaborations; and creating evidence-based resources and tools that contribute to effective online teaching, learning and program administration.

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