

Proceedings from a multidisciplinary workshop defining the scope of Resilience Informatics in Public Health

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Submitted to: JMIR Formative Research
on: June 12, 2024

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Table of Contents

Original Manuscript..... 5

Supplementary Files..... 32

 Figures 33

 Figure 1..... 34

Multimedia Appendixes 35

 Multimedia Appendix 0..... 36

 Multimedia Appendix 1..... 36

Proceedings from a multidisciplinary workshop defining the scope of Resilience Informatics in Public Health

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Abstract

Background: In recent years, public health has confronted two formidable challenges: the devastating COVID-19 pandemic and the enduring threat of climate change. The convergence of these crises underscores the urgent need for resilient solutions. Resilience Informatics (RI), an emerging discipline at the intersection of informatics and public health, offers promising avenues for mitigating and adapting to these challenges. Addressing critical questions regarding target audiences, privacy concerns, and scalability is paramount to fostering resilience in the face of evolving health threats.

Objective: The University of Arizona's workshop on Resilience Informatics in Public Health was held in November 2023 to serve as a pivotal forum for advancing these discussions and catalyzing collaborative efforts within the field.

Methods: A purposive sampling strategy was employed to invite 40 experts by email from diverse fields including public health, medicine, weather, informatics, environmental science, and resilience to participate in the workshop. The event featured presentations from key experts followed by group discussions facilitated by experts to ensure diversity in backgrounds. Attendees engaged in collaborative reflection and discussion on predetermined questions. Discussions were systematically recorded by University of Arizona students, and qualitative analysis was conducted. A rapid analysis of workshop notes was initially performed, followed by a more comprehensive qualitative thematic analysis. A codebook was developed iteratively, all transcripts and notes used from the workshop were coded twice using MAXQDA software. Discrepancies in coding were resolved through discussion, leading to a narrative synthesis of findings.

Results: The workshop hosted 27 attendees at the University of Arizona, predominantly from academia, with 21 participants from public health-related fields and 8 experts in resilience. Additionally, participants from governmental agencies, Native American groups, weather services, and mHealth organizations attended. Qualitative analysis identified major themes, including the potential of resilience informatics (RI) tools, threats to resilience (e.g., healthcare access, infrastructure, climate change), challenges with RI tools (e.g., usability, funding, real-time response), and standards for RI tools (e.g., technological, logistical, sociological). Attendees emphasized the importance of equitable access, community engagement, and iterative development in RI projects.

Conclusions: The RI workshop emphasized the necessity for accessible, user-friendly tools bridging technical knowledge and community needs. Future directions include focused discussions to yield concrete outputs like implementation guidelines and tool designs, prioritizing community engagement, cultural sensitivity, and ongoing learning. Clinical Trial: N/A

(JMIR Preprints 12/06/2024:63187)

DOI: <https://doi.org/10.2196/preprints.63187>

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Original Manuscript

Title: Proceedings from a multidisciplinary workshop defining the scope of Resilience Informatics in Public Health

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Keywords: Resilience, Public Health, Informatics

Abbreviations

RI: Resilience Informatics

AI: Artificial Intelligence

Abstract

Introduction

In recent years, public health has confronted two formidable challenges: the devastating COVID-19 pandemic and the enduring threat of climate change. The convergence of these crises underscores the urgent need for resilient solutions. Resilience Informatics (RI), an emerging discipline at the intersection of informatics and public health, offers promising avenues for mitigating and adapting to these challenges. Addressing critical questions regarding target audiences, privacy concerns, and scalability is paramount to fostering resilience in the face of evolving health threats. The University of Arizona's workshop on Resilience Informatics in Public Health was held in November 2023 to serve as a pivotal forum for advancing these discussions and catalyzing collaborative efforts within the field.

Methods

A purposive sampling strategy was employed to invite 40 experts by email from diverse fields including public health, medicine, weather, informatics, environmental science, and resilience to participate in the workshop. The event featured presentations from key experts followed by group discussions facilitated by experts to ensure diversity in backgrounds. Attendees engaged in collaborative reflection and discussion on predetermined questions. Discussions were systematically recorded by University of Arizona students, and qualitative analysis was conducted. A rapid analysis of workshop notes was initially performed, followed by a more comprehensive qualitative thematic analysis. A codebook was developed iteratively, all transcripts and notes used from the workshop were coded twice using MAXQDA software. Discrepancies in coding were resolved through discussion, leading to a narrative synthesis of findings.

Results

The workshop hosted 27 attendees at the University of Arizona, predominantly from academia, with 21 participants from public health-related fields and 8 experts in resilience. Additionally, participants from governmental agencies, Native American groups, weather services, and mHealth organizations attended. Qualitative analysis identified major themes, including the potential of resilience informatics (RI) tools, threats to resilience (e.g., healthcare access, infrastructure, climate change), challenges with RI tools (e.g., usability, funding, real-time response), and standards for RI tools (e.g., technological, logistical, sociological). Attendees emphasized the importance of equitable access, community engagement, and iterative development in RI projects.

Discussion

The RI workshop emphasized the necessity for accessible, user-friendly tools bridging technical knowledge and community needs. Future directions include focused discussions to yield concrete outputs like implementation guidelines and tool designs, prioritizing community engagement, cultural sensitivity, and ongoing learning.

Introduction

Background

Over the past few years two major threats to public health have emerged. The recent COVID-19 pandemic caused an estimated million deaths (1). Long-term effects of COVID-19 are still being identified. Climate change is the long term shift in predicted temperatures and weather behaviors for a given region (2). While COVID-19 emerged within just a few months, making it an acute stressor, climate change's effects have developed gradually, making it a chronic stressor (3). In the long-term, the public health effects of climate change could be even more serious as global warming, infectious disease, air pollution, and other consequences increase in severity(4-7). The effects of climate change threaten the physical and mental health of the public via respiratory disease, infection, stress, malnutrition, heat exhaustion, and a variety of other negative consequences(4-7).

Post-COVID, public health is faced with the growth of misinformation(8, 9), health inequity(10-12), the mental health crisis(13, 14), malnutrition(15, 16), and a myriad of other pressing matters. Following the COVID-19 pandemic, there is now great pressure on the field of public health to be able to prevent a future pandemic and control public response. In navigating a post-COVID world, public health is now faced with challenges of improving communication across disciplines(17, 18), preventing the spread of misinformation and disinformation(19, 20), responding quickly in the face of another public health emergency (21), addressing the mental health crisis(13, 14), and the nutritional crisis within the U.S(15, 16). Overseas, concerns of refugees and displacement of individuals are being seen in relation to political tension and climate change(22, 23).

To successfully cope with these inevitable threats to public health, people and communities need to develop Resilience, defined as the ability of people, households, communities, countries, and systems to mitigate, adapt to, and recover from shocks and stresses in a manner that reduces chronic vulnerability and facilitates inclusive growth (USAID, 2012). It is recognized that resilience is a necessary precursor to achieving the United Nations' Social Development Goals, including No Poverty, Zero Hunger, and Climate Action (United Nations 2023a-c).

What is resilience informatics?

Informatics has been defined as “the science of information, the practice of information processing, and the engineering of information systems”(24). Informatics tools include data science, artificial intelligence (AI), mobile health, augmented and virtual reality. Resilience Informatics (RI) is an emerging discipline concerned with harnessing informatics to materially improve and promote the ability of people, communities, and organizations, to effectively cope with natural and man-made stressors (3).

While modern informatics technologies can play a major role in helping people and communities develop resilience, much formative research needs to be done to understand the contours of this emerging discipline. Fundamental research and development questions need to be addressed to lay a solid foundation for RI such as: For whom should we develop RI tools? What are the important resilience challenges to be tackled using informatics and what are the priorities? How can we provide privacy, security, and protect sensitive data and account for social determinants of health? How can we safeguard the rights of indigenous populations and help bridge the digital divide? If, as seems necessary, developing resilience entails behavior change in people and communities, how can we develop tailored and personalized tools to help support behavior change? In addition, RI systems need to be scalable and extensible while not consuming excess energy or environmental resources

that could exacerbate climate change. To answer these questions, input from frontline workers from a variety of different fields, areas of expertise, and levels of implementation in public health and resilience- areas is needed.

The workshop and research question

On November 20th, 2023, the University of Arizona hosted a workshop on Resilience Informatics in Public Health with experts in a variety of relevant fields including resilience, public health, climate, informatics, policy, and technology. These experts were primarily based in Arizona but a few purposefully selected experts from outside of the state with relevant areas of expertise were also invited to participate and present relevant information to help set the groundwork for the workshop discussions. The purpose of the gathering was to shape the future directions and applications of the emerging discipline of Resilience Informatics (RI).

A secondary purpose of the workshop was to provide networking opportunities to build connections across this field and inspire new projects in this up-and-coming area of research and development of RI tools and systems. Attendees had the opportunity to meet and network with other experts in the field who they may not have had the chance to meet in other instances.

Methods

Recruitment

A group of 40 experts were purposefully selected and invited to attend the workshop. Attendees who attended the event were from the fields of public health, medicine, weather, informatics, environmental science and resilience. The institutions represented included Weill Cornell Medicine, the University of Colorado, Northern Arizona University, the Arizona Center for Rural Health, the Mel and Enid Zuckerman College of Public Health, the Arizona Institute for Resilience, and the College of Medicine.

Workshop and Data Collection

During the workshop, participants listened to presentations from a few key experts to spark discussion and ideas. In between talks, six groups of three to seven people each were formed by expert facilitators such that the members of said groups contained as much diversity as possible in terms of background (field of work and discipline). Subsequently, attendees reflected and collaboratively discussed answers to the following questions with the help of the facilitators:

Session 1 (~30 min)

- What does resilience mean to me?
- To what do we need to be resilient?

Session 2 (~1 hour)

- What informatics tools are you using?
- What are the barriers to technological solutions and how do we address them?
- What tools do we need?
- How do we ensure equity across these solutions?

During the discussions, participants were asked to write down their ideas independently on sticky notes and compile them on flipcharts to ensure that no one participant dominated the discussion. Data saturation was not discussed since this was a one-time event and additional data collection was not possible post-workshop. The discussions around the key questions mentioned above were systematically audio recorded and notes were taken by students from the University of Arizona who were part of the organizing team. Workshop attendees were made aware of the recording and note-taking and that the findings of the workshop were to be written up into a proceedings report.

Qualitative Analysis

Three students conducted a rapid analysis of the notes taken during the workshop to produce a report for dissemination to the greater community for awareness. The report was also shared to participants via email to solicit feedback to increase the validity of the analysis as a form of participant checking. Participants from the workshop were also asked to participate in the in-depth thematic analysis process. A group of four students and the principal investigator worked with one expert attendee who volunteered to help develop the codebook. The team used a primarily inductive approach in the data analysis with a phenomenological theoretical approach (25). The analysis team iteratively constructed their list of themes based on the transcripts and notes using standard identification techniques (26). The themes were compiled together using a Jamboard and then were grouped to determine the final list of codes and subcodes (see Figure 1).

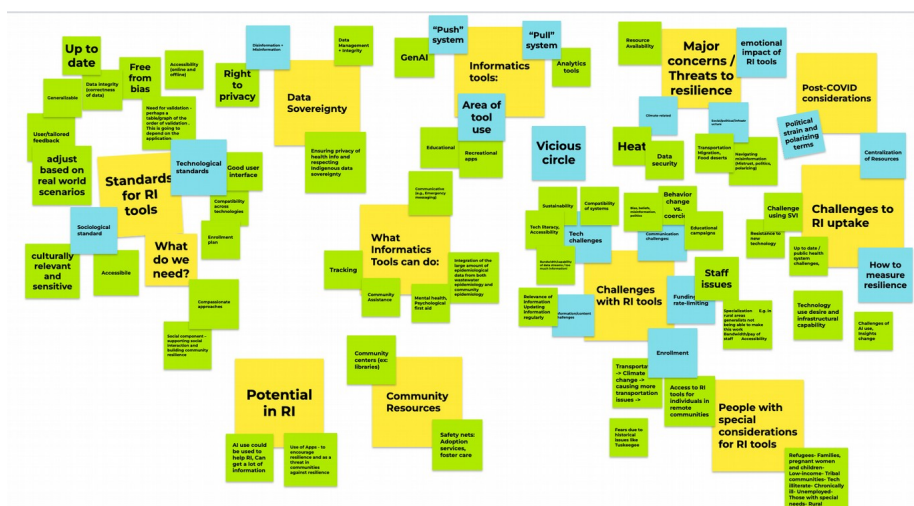


Figure 1. Brainstorming document for codebook development

The four student researchers then coded the transcripts independently. In the case that notetakers forgot to record the discussions, notes were used in place of transcripts. The coding team also coded the notes which were taken on sticky notes by the groups during discussions to ensure no ideas were missed. The team then worked together to finalize the first draft of the codebook with definitions and examples (Figure 1, Appendix 1). The codebook was entered into MAXQDA, and the team began coding. The first transcript was coded by all team members and discrepancies were resolved through discussion and consultation with senior members of the team. The remaining transcripts and notes documents were coded independently by two coders each. Conflicts were again resolved through discussion. The codebook was adjusted through the coding process as themes may have come up inductively. After coding all documents, all documents were reviewed once more by coders to ensure nothing was missed.

The team then wrote a narrative analysis of findings, summarizing major points that came up to help answer the research questions. The analysis write-up process was aided in part by ChatGPT for certain sections in the synthesis of the summary of information gathered from the text; said syntheses were subsequently reviewed by hand to ensure accuracy, validity and appropriate language usage in the narrative. The research team used the consolidated criteria for reporting qualitative research (COREQ) checklist to guide the reporting of the workshop findings and qualitative analysis (27).

Facilitator reflexivity

The facilitators of the workshop were three female professors and researchers with PhD degrees and experience in the fields of epidemiology, environmental health, climate and resilience. One of the facilitators is a widely recognized infectious disease epidemiologist with practical experience in public health practice at a health department level and a focus on the environmental determinants of vector-borne disease transmission and control. Another facilitator is an assistant professor at the college of public health with a focus on building the public health capacity to address "wicked" public health challenges through the development of decision-support tools, enhancing science communication and translation, and integrating a health and equity lens to adaptation planning. At the time of the workshop, she was leading the Arizona Department of Health Services-Center for Disease Control and Prevention COVID Disparities Initiative at the Arizona Center for Rural Health aimed at mobilizing partnerships to advance health equity & address social determinants of health-related to COVID-19 health disparities among higher risk and underserved populations. Finally, the last facilitator is an experienced Research Professor with the Lyda Hill Institute for Human

Resilience, adjunct faculty at the University of Colorado Denver, School of Public Health, a Guest Researcher with the U.S. Centers for Disease Control and Prevention, and an affiliate scientist at the National Center for Atmospheric Research in Boulder, Colorado. She focuses on the intersection of weather, climate and health with an emphasis on vector-borne diseases.

Participants were primarily invited because they had a relationship with at least one of the facilitators in their line of work related to public health and resilience. The participants were familiar with the researchers and their public health interventions which have benefited the state, especially in relation to the COVID-19 pandemic.

Results

Attendees of workshop

Twenty seven attendees participated in the workshop. The organizing team present included the three facilitators, one principal investigator and eight students from relevant fields who helped with logistics, note taking and audio recording of conversations. The largest number of participants were from academia, mostly affiliated with the University of Arizona (n=19), followed by Arizona State University (n=3), and two specially invited attendees from academic institutions outside of Arizona (University of Colorado and Weill Cornell Medicine). Two attendees came from the Arizona Department of Health Services while three others were from county-level health departments (Pima, Coconino, Maricopa). Three participants came from organizations representing Native American groups (Salt River Pima-Maricopa Indian Community and Arizona Advisory Council on Indian Health Care). Two participants were from NOAA / National Weather Service, one participant was the CEO and founder of an mHealth organization (Wehealth), and one participant was from a statewide community health worker organization (AzCHOW). In terms of areas of expertise represented at the workshop, most participants were from a public health-related field (n=21), with at least five with a concentration in epidemiology, five with a concentration in community outreach, and three with a concentration in medicine. Eight expert attendees worked in the field of resilience and seven had a concentration in a field of technology such as data science (n=4). Finally, three experts had extensive experience in emergency management or preparedness and one in environmental science and two in meteorology.

Codes

Codes which were identified during the qualitative analysis included the Potential in resilience informatics, Threats to resilience, People with special considerations, Challenges with resilience informatics, Standards for resilience informatics tools (technological, sociological and logistical), and data sovereignty among others (see Appendices 1 and 2). Major findings associated with the codes are included below.

Potential in Resilience Informatics

Resilience informatics tools were mentioned in many of the conversations. Examples of existing tools that were mentioned included the three tools from the expert presentations during the event, Pilas, AZCOVIDTXT, AZX, and Wehealth, as well as 200+ essential tools for public health data monitoring including:

- Organization assessments,
- Quality assurance tools,
- Heat maps,
- Tele-mapping tools,

- Mental health screening,
- The 988 system for mental health,
- And more.

RI tools were also used for educational purposes such as:

- Community education,
- Healthcare worker training, and
- Simulation tools.

Such tools were also mentioned as having a multitude of different purposes and functions, such as:

- Create clinical guidelines with community perspective and provider perspective,
- Record membership sign-ups,
- List contact information for outreach in emergencies,
- Take raw data and put it into a usable format,
- Digest complex information and summarize relevant information, then push to the relevant audience,
- Record how many people have enrolled in a course,
- Evaluate a course or intervention,
- Measure the intensity of reactions from the public,
- Survey the prevalence of infectious diseases or chronic illnesses,
- Act as a decision tool for gauging/assessing data, and
- Project the impact of an intervention.

Finally, there are new technologies out there such as generative artificial intelligence which may have the potential to make a huge difference in the potential for RI to make a big difference. As one participant said:

“So this is actually a really hot area of research for generative AI. And you have to look at it a little bit differently than what you see on the surface. But what generative AI is, you can feed it a corpus of knowledge. And it builds a giant tree out of that knowledge. And so when you ask a specific question, it'll try to navigate that part of the tree and find those things.

I mean, there's reasons to be skeptical because basically the ChatGPT systems that we know have gotten their information from all over the internet. There's some really bad information. But there are other ways where, for example, Maricopa County could put all of your policies, plans, procedures and every...

Build your own corpus of knowledge and use the same generative AI algorithms so that you could ask a question like, "How do I answer this question?" And so then it's taking your internal information, sort of trying to like capture your brain and everyone else's brain and all of the documents and you can produce stuff.” (Participant from Arizona State University's Knowledge Enterprise)

In summary, RI tools have the potential to span a wide range of functions. Many RI tools are already available, but there remain many possible areas where RI may be able to expand.

Threats to Resilience

Resilience faces challenges in a variety of sectors of health which are often intersecting and complex. Protecting the resilience of communities and ensuring their health and well-being begins with understanding these threats and how given communities are impacted.

Healthcare access was one of the threats to resilience mentioned during our workshop. The cost of healthcare alone makes it inaccessible to many groups of people, or at the very least a burden to individuals who are barely able to afford healthcare. Threats to healthcare accessibility extend beyond cost, however, as the location of health services bears a great weight as well. Within the services themselves, our participants mentioned that the presence of healthcare workforce strain can pose a threat to public health. Health practitioners' mental health was also mentioned as having a direct impact on the quality of treatment that patients will receive. Overworked healthcare professionals introduce the potential for practitioner mistakes or a shortage of healthcare professionals in the community. As one participant mentioned:

“But then you take into account that 30% of the public health workforce left the profession during Covid. And one of the biggest challenges in health departments right now is retention, not just retention of people, retention of historical knowledge and community understanding. I mean, of this idea. And I'm like, "Yes." But it really sucks when you have a room full of people who don't really know, understand and haven't worked, been on the ground during the pandemic, haven't done these things, don't know the community.” (Participant from Arizona Advisory Council on Indian Health Care)

Infrastructure was mentioned by our participants to be a large threat with respect to the centralization of resources and transportation accessibility, as previously discussed with healthcare access. However, the threat of infrastructure continues to be seen in the housing crisis, internet access, and utilities. Centralization of resources and transportation services is necessary to protect the health of communities, as discussed before, in the ability to reach health services. Beyond healthcare, however, a lack of transportation services and decentralized resources continue to threaten resilience as transportation proves a great necessity for individuals in food deserts to be able to reach grocery stores and for those in areas of job shortages to reach work. Housing accessibility and affordability were also mentioned during the workshop, as housing prices have increased in the past few years in Arizona.

In the case of water, communities rely on their running water being present and safe for consumption and bathing. This important resource, especially in the desert environment of Arizona, has not always been protected in cases of droughts and contaminated water supplies. As one participant mentioned:

“So, what has happened in a lot of the orchards, like the nut orchards, have moved from California to the Willcox area to pump the water out because they don't have any restrictions. And so basically, they're sucking it dry. So, the concern is, there won't be any water in the future, 50 years from now, in that area.” (Participant in environmental science field at the University of Arizona)

Internet access was mentioned as being of great importance for protecting health as well, as many health services and information are found on the Internet. Being able to view this health information or find health services through web searches is important for individuals to be able to protect their health.

Large-scale events such as the ongoing climate crisis were mentioned during our workshop as one of the greatest threats to resilience. Climate change has negatively impacted water resources, raised temperatures, and increased the prevalence of infectious diseases. Furthermore, modern infrastructure is not able to weather the challenges that extreme weather events pose, leaving communities more at risk of being devastated by such an event. One participant stated:

“How, for me, is its emergency response, but it's also how to prevent and mitigate issues with

climate change. And we're getting into it with the hottest heat on record in the city of Phoenix. I'm trying to get more involved with getting areas that don't have cooling centers, doesn't have things like that, like the tribal machines... Outlying areas of, even in the Phoenix area, doesn't have cooling centers.

So, we see a big phase for central Phoenix and getting in some rural areas, but when you start going outside the Phoenix area or into tribal nations, there's nothing to help them recover or even get supplies. So, to me, that's a big issue. I live in Queen Creek, so even looking at my own town, they have a station. Yeah, it's the fire station. You drop off the water, but you have no cooling stations for the homeless or individuals or even the reservations.” (Participant from the Arizona Coalition for Emergency Response)

The climate crisis is made even more difficult to address as the concern has become politicized.

Political strain was another threat to the resilience of communities in working against the polarization of health concerns mentioned during the workshop. Our participants mentioned that during the COVID-19 pandemic, communication of information proved difficult as the public was exposed to mass amounts of misinformation and disinformation. As one participant mentioned,

“Politics can modify how we approach public health disasters.” (Participant from a county health department).

Communication proved to be an individual threat to the resilience of communities as approaches to addressing the pandemic were disjointed and limited as a result, according to our workshop participants. There were disparities in information between clinicians and public health practitioners who did not have the means to properly hold discussions with each other. The inability to properly communicate exacerbated the issue of trust in information and misinformation prevalence. Creating adaptable communication systems can pose difficulty in the field of public health, as one workshop participant said:

“I think uncertainty too. There's a lot of the things we're talking about happening in the future. I think especially when we talk about extreme heat and things like that, or even other things like how AI is going to come into play. There's just a lot of uncertainty of what's going to happen. I think that really heavily influences the way people respond to information. How do you communicate something that, things that are changing, things that are uncertain, and how do you make decisions in an uncertain environment, the burden that puts on a household person trying to plan financially or somebody just mentally the load, or even a city planner trying to figure out what's the best decision?” (Participant from Arizona State University's Knowledge Enterprise)

Issues related to access to resources was another theme which emerged as a potential threat to resilience for the communities our participants serve. A lack of financial resources limits what the community can afford to support its health. As one participant said:

“And it's for our community organizations so that they can leverage that piece to apply funding, to ensure there's more programs within the services, within the communities they serve. Because we can't do everything. We don't have the capacity.” (Participant from a county health department)

Other resource-related issues mentioned by participants included water, food supply, air, and housing.

Several social issues were mentioned during the workshop that directly work as threats to resilience as public health professionals face concerns surrounding food insecurity, the housing crisis, transportation, migration, racism, gentrification, war and politics, cultural sensitivity, cost of living, employment security, and the education system. As one participant mentioned:

“Yeah. I think distrust is more just the fact that if we need to be resilient, we need to trust each other and we don't anymore. And so that's a thing we need to be aware of. How do we build trust in communities? And the disinformation is more about are we just getting the right information or not? That's why I meant trust between communities.” (Participant in software development and CEO of an mHealth intervention)

Mental health was a concern raised by several participants. For instance, aging populations were mentioned as being vulnerable to empty nest syndrome and isolation issues. Additionally, substance misuse was directly related to mental health, such as the growing prevalence of drugs such as fentanyl. Concerns surrounding the lack of empathy and social capacity were discussed in depth in one group at the workshop. The lack of empathy in American culture was mentioned as possibly branching from the colonial mindset to care for oneself. Social capacity, on the other hand, was raised as an issue due to the ever-growing role of phones and social media today, especially for younger generations. Mindful interventions were mentioned as having potential to address this and ensure that populations will continue to be socially capable. One participant stated:

“It's compassion fatigue or something. You get so much information because you're connected to the internet, you just get bombarded every day.” (Participant from county health department)

People with special considerations

A recurrent theme which emerged during the discussions in the workshop was that certain communities may face greater challenges to resilience than others. As one participant mentioned from a local county health department, *“No one would choose not to have running water.”* It was apparent in many of the discussions at the workshop that some communities simply do not have basic resources such as consistent access to water. Indigenous communities, asylum seekers, the aging and elderly population, people with disabilities, non-English speaking language communities, and other marginalized individuals often face unique challenges to resilience that merit special considerations when considering the use of resiliency informatics tools.

Asylum seekers and refugees were mentioned as having challenges related to privacy and access to resilience tools as they are vulnerable to exploitation and often face barriers to legal recourse. The aging and elderly, people with disabilities, non-English speaking communities, and other marginalized groups were also mentioned as needing special consideration when designing RI tools, for example considering translation, accessibility, and other tailoring to fit their needs.

Challenges with Resilience Informatics tools

Some workshop participants mentioned that RI tools face challenges of usability which must be understood and addressed to maximize the positive impact of the tools in improving community resilience while also preventing possible adverse effects.

Accessibility is the first of these. RI tools can be limited in impact based on the size of the audience they can reach and effectively assist. Tools should be tailored to the community being served and designed with end-users in mind. Elasticity and scalability were mentioned as being issues which should be at the forefront of the RI tool design considerations so that the tools may serve the greatest

number of communities which can vary in size, geography, etc. Accessibility concerns further include issues of resource centralization, language barriers, technology literacy, and all related considerations. As one participant remarked:

“So, one thing too, I would say the integration of social determinants of health in city planning. So general plans as well as emergency response plans. One of the things we learned during Covid is a lot of our emergency response plans really weren't built to address supporting diverse populations, multi-language speakers, all of these other things. And so being able to go in and make those the norm now.” (Participant from a county health department)

Real-time response was mentioned as being especially desirable in RI tools. Between collecting data, analyzing it, and publishing results, the process can be all too slow to be able to properly respond to fast-moving issues which may threaten resilience, such as a pandemic. RI tools must be able to quickly respond in times of crisis to be able to limit the amount of people who are affected by the crisis. As one participant said:

“Informatics can assist me in finding what that trigger point is, but it can't assist me in actual response. It's too late. Once it's already happening, now I'm in the door. I'm working with a problem and actually implementing things. Informatics takes a backseat; they don't care anymore. But I want informatics to inform that response. That would be very valuable to tell me, “Hey, you're done. You can stop now. You can turn it off.” That would be nice. But I don't know how informatics can assist in the response phase or the recovery phase.” (Participant from a county health department)

Funding was mentioned as being a particular challenge for existing public health and resilience-building initiatives. RI tools and projects must be able to secure funding, such as through grants to establish the tool itself and to sustain it. An example given by a participant was fitting into grant expectations. If an RI project does not fit expectations, adjustments will need to be made to maintain funding, and the project's efficiency may suffer. Funding is necessary to be able to develop the RI tools, but it is also a potential threat if the tool does not look appealing to funders. One of the workshop participants stated:

“...Make recommendations to other departments and divisions within the health department to say, ‘Hey, we need to allocate resources here. Here's what we're hearing.’ And to your point, we're listening to people's individual stories. We're also looking at data as a whole. And the reality is, we've tried to push a lot of these dashboards and a lot of these things to the general public.

They're not really interested in a lot of that unless it's very easy to use and speaks directly to them. So again, my job is that, ‘Okay, that's not working. And how can I frame it in a way that's really going to focus on that individual so they can make an important decision themselves?’ So a lot of what we've done is really just change the way we present data.” (Participant from a county health department)

RI tools are also tasked with the challenge of measuring resilience, especially across the many fields which may work within the field of resilience. For instance, resilience must be defined in a standard way and units of measurement may need to be standardized to definitions of resilience. A group of participants had the following discussion:

“Speaker 6:

Do you guys think that's a problem, the way that we measure their resilience, and solve problems in this case? So the thing that we should think about how we are measuring this resilience about other things right here, I don't know if we have the right tools right now to do that. The resilience measurement tools.

Speaker 9:

And then the definition of resilience, which alters person to person, agency to agency.

Speaker 6:

Yeah, that's true.

Speaker 9:

Race, ethnicity, there's so many implications, things that affect that. So I always look at it as you have to define what the meaning is first in order to measure it. Otherwise, it's positive outcomes, just how you go about it. What do you define as success in the situation? Again, that's always going to alter and shift.

Speaker 8:

Or how do you weigh different? If you can agree that resilience is sort of a combination of metrics that we already account for, okay, so we're counting. We're trying to measure things like food security and vulnerability, heat and different mental health metrics. But then you try to combine that into some sort of measurement of resilience. It's like, 'Well, how do I weigh in some sort of statistical way, the weight of my mental health versus my heat resilience, which are all...,'"

Later in the same group a participant stated:

"We spent all this time trying to measure the wrong things, like risk. Risk is great. Let's take probability times consequence and its risk. And then we've got everything solved and we're measuring the wrong things. So at least now that we can talk about resiliency and all of the constructs that come with it, you package it up and you've got to talk about social cohesion and adaptivity and vulnerability, and then you sprinkle in some of that probability and consequence stuff. But that's so reductive that you miss the point of what resilience is, which it's an intended positive outcome about how we can work together and have shared goals that are different than individual goals. But you have to have all of that. So, I think it's a really positive thing for results is hard to measure, and you have to roll around in the mud with a pig for a while in order to put some thoughts together. Yeah, it is refreshing." (Participant from Arizona State University's Knowledge Enterprise)

Technological Challenges with RI Tools

Several challenges that are more technological were also mentioned by many participants. For instance, infrastructure issues such as broadband access are problematic if an RI intervention is to be effective in many cases since these types of projects often rely heavily on the presence, functioning, and quality of technological tools. At times, government intervention may aid in increasing said infrastructure. For example, some programs provided by the government could help to provide free WIFI or expand hotspots. Rural communities were mentioned as being especially vulnerable to such issues, where there may be higher turnover in technology. In this case, low-cost smartphones may be

needed to support these communities, or perhaps a community-operated mobile phone provider could be enlisted to help increase cell-phone coverage and access.

Communication

Resilience in informatics communication faces a spectrum of barriers and facilitators, prominently highlighted by the necessity for two-way communication. This involves ensuring a cohesive message and fostering a shared understanding among stakeholders. However, intergenerational disparities present challenges, as differing communication preferences and styles may hinder effective dialogue. Establishing rapport amidst these differences can prove arduous, as illustrated by the struggle to navigate technological nuances and preferences, such as the preference for traditional email over newer communication methods.

Moreover, the landscape of informatics communication is marked by silos, where various disciplines converge, including developers, computer scientists, behavioral economists, public health practitioners, and social scientists. This interdisciplinary nature can be both a boon and a barrier. While it offers diverse perspectives, it also necessitates concerted efforts to bridge disciplinary divides. One expert at the workshop asked the question:

“What about in non-emergent situations? Non-emergent public health situations? How can that gap the bridge? And I'm talking about between the academics in between the field of public health and then between the clinical side? That's my question.” (Participant from Arizona Advisory Council on Indian Health Care)

Additionally, the gap between clinical and public health realms underscores the need for enhanced collaboration and communication strategies to align goals and priorities effectively. Overcoming these barriers requires deliberate efforts to foster a culture of inclusivity and open communication across sectors and disciplines.

Components of an RI project

Several different essential components of a successful RI tool or project were mentioned during many of the conversations. Here is a list of some considerations when designing an RI intervention:

- Systems and infrastructure to process data (broadband access)
- Data integration hub and intel sub to pass information along
- Anomaly finder (could be an AI function with data search)
- AI to digest complex information and summarize relevant information, then push to the relevant audience
- Centralized hotline or integration to allow individuals to have a place to call
- Bi-directional flow (receive community input)
- Equity assessment (part of pre-, during, and post-evaluations)
- Human elements and user tests
- Coalition oversight to have a big-picture view and report back
- Communication component to hit all different networks

Standards for RI Tools

A major theme that emerged from the discussions held at the RI workshop was the need for standards, or guidelines, to help guide the design and implementation of RI tools in the future. In the analysis of the conversations held by participants, a list of standards for RI tools were gleaned based on what was presented as ideal characteristics of a tool in any conversation. While it is recognized

that this list may not be comprehensive and that some of the standards may apply to some but not all tools, this may serve as a starting point for others to use in future iterations of RI tool standard development. The standards have been grouped into three categories based on the nature of the characteristics in question: technological, logistical, and sociological.

1. Technological Standards for RI Tools

Technological standards were mentioned in many of the discussions. These standards may be helpful for software developers, statisticians, or other more technical roles on an RI project.

- RI tools should be up to date.

Like other forms of technology, RI tools must be regularly maintained and updated to ensure continued accessibility and usefulness, according to our participants. RI practitioners must also put into place standards for data used by RI tools. This may entail the connection of multiple resources to get a broader scope of data, training artificial intelligence (AI) tools using data from diverse populations to remove bias, standards to ensure the accuracy of data, and the use of validated tools and objective measurements when implementing RI.

- Data must be accessible.

Another concern for RI tools mentioned in the expert discussions at the workshop was accessibility: data should be designed to be accessible (following accessibility guidelines) while still being protected. Tiered access to data, for example, non-public facing and/or anonymized reports to preserve the privacy and security of data, should be implemented. There should also be regulations in place related to the sharing of private corporate data, such as the number of COVID-19 test kits sold.

- RI tools should be interoperable.

Furthermore, RI tools need to be optimized for all major platforms to ensure interoperability across different technologies. This may look like creating versions of RI tools for Apple and Microsoft operating systems, for example.

- Data sovereignty and privacy should be prioritized.

Finally, data sovereignty and privacy must be of utmost importance for RI tool developers and users. This especially applies to the use of RI tools with populations who may be particularly susceptible to abuse or exploitation by bad actors. Data-sharing agreements can be beneficial tools for parties collaborating on resiliency-related public health projects with RI tools, however, these agreements must explicitly be written to protect the sovereignty, ownership, and privacy of the data collected and shared.

2. Logistical Standards for RI tools

Another type of RI tool standard that appeared to emerge from the discussions among workshop attendees included logistical characteristics, that is more related to the planning, organization, design, and nuts and bolts of implementation or roll out of the tool, rather than technological or sociological aspects of the tool or RI project.

- RI tools require thoughtful design.

It was mentioned that when designing RI tools or interventions, it is important to use systematic approaches, following step-by-step procedures. These procedures should include data collection and

performance evaluation to ensure continued monitoring and evaluation of the project, ensuring that objectives are met, and that the necessary information is available to demonstrate the effectiveness of the intervention. Examples of disciplines or approaches from which RI tools could draw best practices include human-centered design, mixed-methods research, and clinical translational science. Acceptability of the desired behavior that the RI tool may be promoting should always be considered as well in the design and implementation of the project. The design could additionally include an implementation model, considering infrastructure, service, providers, users involved, etc.

- The process of RI tool development should be iterative.

The workshop discussions mentioned that there is a need for continual community testing and evaluation. As one workshop participant mentioned,

“We’re always reinventing.” (Moderator from University of Colorado)

- RI tools need to have real-time responses.

RI tools should work in real-time and be able to pivot and adapt quickly to fit the needs of the end-users. Rapid and clear information should be conveyed in a simple report afterward as well.

- RI tools need to have multiple-layer solutions.

RI tools should function at a variety of different levels to meet the needs of the communities they serve. For example, an ideal RI tool should consider all of the channels that the end-users may use: SMS, apps, social media, etc.

- RI tools require funding.

While perhaps evident, RI tools need funding to be most effective, and this was emphasized many times in the workshop. In the planning and design stages, it is important to consider where these funds will be coming from to make sure the tool is most effective and sustainable: grants, sales, etc. Multiple funding streams may be best to consider, should it be possible. Additionally, it is important to consider when budgeting. As one participant said:

"How can I give our community partners something that they can turn around and use as leverage for money, resources, whatever?" (Participant from a county health department)

3. Sociological Standards for RI tools

The following are the sociological standards for the RI tools that were identified during the workshop.

- Focus on community-identified needs first.

Our participants mentioned that RI tools must target prioritized populations first, the needs of those in the communities are being served, who need the intervention the most. To do so, stakeholder engagement in critical conversations about design and intervention implementation is crucial.

- Build trust: *“Partnerships are key!”*

As mentioned above, upfront community engagement is key to RI tool success. Community leaders and partners need to be engaged in the RI tool from the beginning, most especially gatekeepers to those communities. Community members should be additionally involved in decision-making surrounding resource allocation if that is relevant to the RI tool or project. Successful community

engagements are characterized by humility, in other words, our experts mentioned that it is important to be upfront about what you do or do not know. Along the same lines, community values must be recognized early on to have successful community engagement, such as transparency, humility, etc. To identify these values and develop community partnerships, listen to groups (e.g. Tribal communities), understand and learn from others, and recognize that all people have important information, no matter their education level or background. Cultural humility and responsibility and community-based participatory research methods may provide important lessons from which RI tool developers and implementers can learn more about successful community engagement and cultural value identification.

- Integrate social determinants of health.

RI workshop participants mentioned how important it is to integrate social determinants of health into the design, implementation, and evaluation of the RI tool, such as income, education level, and healthcare access. These factors are crucial when considering public health outcomes and may confound the impacts of the tool.

- Long-term solutions and sustainability should be the goal.

The RI tool must have a long-term vision in mind, and sustainability as the goal to most effectively build resilience in communities. As one participant said,

“Systemic change takes time, and it builds, and you’ve got to take things and use things to your advantage.” (Participant from the state health department)

Along those lines, the RI project will need a way to follow up with participants over time to continually evaluate and assess the long-term impacts of the RI intervention.

- Tailor the intervention.

Tailoring emerged as a strong theme which was mentioned in many of the conversation’s experts had at the RI workshop. Each RI tool must be tailored to the specific population of interest as one participant said,

“So you know what's dangerous about that idea is that it's measuring urban capability against rural ability, because you're talking to the one of two people in the entire county that is thinking about public health weather. There is no one else” (Participant from a county health department).

RI tool designers must additionally contextualize the problem population-wise, but also for the event as well.

They also mentioned that intergenerational solutions (e.g. physical community spaces) are important when developing RI tool interventions. Language must always be considered, not only in its conventional sense but also in terms of vernacular expressions and subgroup dialects, to increase understanding when communicating with RI tools to different communities. Cultural representation must also be considered when tailoring interventions, considering differences in emergency response language/acronyms and literacy levels. One participant warned against reliance on AI translation, although it appears that AI tools are evolving at a rapid rate and may find ways to improve translation capabilities with time. In the meantime, it may be crucial for most communities to either translate by hand with the help of local community members or at least double-check AI translations by hand. Multimedia and multimodal strategies were suggested as being important to address

language barriers or literacy. Differences in tech accessibility must also be acknowledged and taken into consideration in RI tool design and implementation. To be most inclusive, low-tech or even no-tech alternatives may need to be integrated into the design. As one participant said,

“I always say, ‘It’s the generation of someone who prefers a phone call than a text’” (Participant from the cooperative extension office).

Finally, it was also mentioned that it is important that all tools be inclusive for people with disabilities.

- Equity must be prioritized

During the workshop, participants had to answer a question asking how equity will be prioritized in the RI tools. For instance, it is important to collect data to evaluate equity in the RI intervention, such as documenting equity awareness and feedback. Putting people from the community into roles in the project and paying them equitably may be another way to prioritize equity in the RI project. Assessment of policies and tools (e.g. AI) for discriminatory impact may be an equitable goal or activity of an RI project. Finally, it was recognized in one conversation that Culturally & Linguistically Appropriate Standards (CLAS) are an existing guideline that may be useful for RI tool developers to reference and utilize to increase equitable outcomes.

Issues related to data use

Two main issues emerged regarding data use in the discussions. See the two issues below and illustrative quotes as examples:

- Data is not always presented in an appealing or accessible way for practitioners

“The informatics can inform our response, but we might be just focusing so heavily on the data that the practitioners out in the field start going, yeah, it’s a wildfire, what do you want me to do about it? It’s going to burn. It’s going to burn that long.” (Participant from a county health department)

- The right information must be there for somebody to grab it.

‘I used to develop a lot of software and we used to do pharmacy applications and our user group would say, “We need these 20 data fields.” We go, “Yeah, that makes sense. Okay, we’ll put the 20 data fields in.” Three years later we go back, two of them are used. Now did that mean the other 18 weren’t important or shouldn’t have been used? It probably meant that there was this really subset that needed those data fields to make better decisions. But if you looked at it from utilization of the data field, you would say, “Well just get rid of them, we really don’t need them.”’ (Participant from a county health department)

Data Sovereignty and Decolonization

Indigenous data sovereignty is a key theme that emerged from the guest presentation by Andrew Martinez (Salt River Pima-Maricopa Indian Community) and the discussions among the workshop attendees. Indigenous data sovereignty can be defined as the right of Indigenous Peoples to govern how data from or about them is collected, accessed, used, stored, and disposed of” (Garba et al. 2023). Culturally centered sovereignty requires a conscious effort by public health officials, researchers, policymakers, and RI practitioners alike. Explicit protections and acknowledgments of Indigenous ownership of data and rights surrounding these data must be put into place before RI

tools are deployed in Indigenous communities. This involves an acknowledgment of cultural practices, the political sovereignty of Indigenous nations, collective knowledge and shared wisdom, and the relationship between Indigenous Peoples and the land.

Martinez outlines four principles that must be considered for Indigenous governance known as the 'CARE Principles': Collective benefit, authority to control, responsibility, and ethics. Following these principles is a minimum standard for public health work in Indigenous communities, particularly with respect to sensitive health data collected about Indigenous Peoples (Garba et al. 2023).

Discussion

Principal Results

In summary, the RI workshop experts confirmed the need for tools that allow us to translate technical knowledge into something useful for the community. These tools must be low cost or free, accessible (easy to use), available on any platform (mostly phone), not too complicated in its interface, not require special domain knowledge, connected, bi-directional, responsive in real-time, and respectful of data sovereignty. Technological and multimodal alternatives for different groups with different accessibility are crucial for RI tool success. The end goals of these RI tools are resource sharing, effect behavior change, and health equity.

Comparison to existing literature

Some of the findings from our workshop resonate in other similar studies in the literature. For instance, our attendees confirmed that informatics tools have the potential to help build resilience by improving the capacity for households to respond to and make effective decisions during disasters as well as through improving social capital (Virapongse et al. 2018). Another finding that resonates with the literature is that there is a need for a structured guide for the development of informatics tools (Sijm-Eeken et al., 2022). This paper presents a few initial ideas which could be used to begin the development of a checklist or framework of standards for future resilience informatics tools. Finally, it was demonstrated in this summary from our workshop that resilience informatics, and health informatics in general, encompasses a very wide range of different functions and has the potential to help make healthcare services more resilient in the face of climate change impacts, like other studies on health informatics (Gray, 2022).

Strengths and Limitations

This workshop had a wide range of participants from different fields who were experts in many areas, making the findings validated and wide-reaching. The limitations of this workshop are that the findings may be limited primarily to Arizona since most participants were from regions across the state, but it was recognized that many of the discussions were relevant to contexts outside of Arizona as well. Additionally, since this was not a qualitative study with a systematic approach to data collection, the findings may not be comprehensive and future research should be conducted to ensure that saturation of ideas is reached to get a fuller understanding of the reach and potential of this field.

Future directions:

Future research questions to explore that emerged from the discussions in this workshop included: How do you physically change the environment to protect against infectious disease? How do we leverage community knowledge? What is the compensation for this? How do we teach empathy? And what standards are necessary for resilience informatics tools to be most effective at addressing

public health and climate change-related issues. It is important for future research in this area to be mixed methods, interdisciplinary, human-centered and community based. The research should ensure that equity considerations are at their forefront.

Another follow-up workshop will be held in June 2024 in Tucson, Arizona to present findings and work towards developing solutions to resilience and public health problems together with the same experts from the workshop presented in this paper. For future directions in RI field development, it would be helpful to have more focused discussions with clear outputs such as implementation guidelines or designs of RI tools to put into practice. It is important to continue to build relationships with communities, stay engaged and curious about different cultures, and learn from others.



Acknowledgements

We recognize and thank all the partners who helped us with developing and participating in this workshop including Antonio Hernandez, Charles Gerba, Charles Kmet, Darien Fuller, Jose F Florez-Arango, Kerri Rittschof, Patrick Wightman, Sameer Halai, Sheryl Nelson, Summer Hassan, Sybil Peters, Theresa Cullen, Tim Lant, Yevheniia Varyvoda, Enrique Noriega, Anna Hartman, Ken Komatsu, and the others who participated in this workshop. Special thanks to our organizing team including Rhett Hill, Grace Bohan, Sage Vu, Mary Hayden, Kacey Ernst, and Mona Arora, Zackry Guido, Corrie Hannah.

Conflicts of Interest: None to declare

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Multimedia Appendix of supplementary files

Appendix 1. Codebook with definitions and examples used for qualitative coding and analysis

Theme	Sub theme	Definition	Example
Standards for RI tools		<i>The qualities that all RI tools should ideally have.</i>	<i>Up to date</i>
	Technological standard	<i>A quality of an RI tool that is related to a technological capacity</i>	<i>Validated, accessible on and offline, good user interface</i>
	Logistical standard	<i>A quality of an RI tool that is related to logistics and not to something that is more technological in nature</i>	<i>Accessible, adjusts based on real world scenarios, has enrollment plan</i>
	Sociological standard	<i>A quality of an RI tool that is related to sociological aspects like culture, language, social interactions, etc.</i>	<i>Culturally relevant, generalizable,</i>
What do we need?		<i>What our society needs (that RI tools might be able to help with)</i>	<i>Compassionate approaches,</i>
Challenges with RI Tools		<i>Issues being faced in being able to implement RI in communities</i>	<i>Accessibility, Cultural Differences, Resources</i>
	Accessibility	<i>How to make processes more user-friendly and community-serving</i>	<i>Technology access, Wifi access, interoperability of systems</i>
	Communication	<i>How information is presented and people interpret it</i>	<i>Political beliefs, Educational Campaigns, Behavior and Coercion</i>
	Information	<i>Accuracy of information and data integrity</i>	<i>Timely information, Data Management, Protected Individual Data</i>
Challenges to RI Uptake		<i>Issues in how RI is implemented</i>	<i>SVI, Up-to-Date Data</i>
	Centralization of Resources	<i>Resources which support RI being readily available</i>	<i>Technology, WiFi, community centers</i>
	Measuring Resilience	<i>How resilience can be measured to ensure that it is being practiced</i>	<i>Community surveys and assessments</i>
Data Sovereignty		<i>Data Management and Data Integrity issues</i>	<i>Ensuring privacy of health info and respecting Indigenous data sovereignty</i>
	Disinformation and Misinformation	<i>Issues having to do with the spread of false information and how resilience informatics may exacerbate or help with such issues</i>	
Informatics Tools/ What Informatics tools can do		<i>Examples of informatics tools and its potential</i>	
	Area of tool use	<i>Field in which an RI tool may be used</i>	<i>Recreational apps, Mental health, Psychological first aid</i>
	Potential in RI	<i>What is not being done currently but could be done</i>	<i>AI use could be used to help RI, Can get a lot of information, Use of Apps - to encourage resilience and as a threat in communities against resilience</i>

Community Resources		<i>What resources may exist that may be leveraged or aided by RI</i>	<i>Community centers (ex: libraries), Safety nets: Adoption services, foster care</i>
People with special considerations for RI tools			<i>Refugees- Families, pregnant women and children- Low-income- Tribal communities- Tech illiterate- Chronically ill- Unemployed- Those with special needs- Rural</i>
Major concerns / Threats to resilience		<i>Issues that RI tools need to address that threaten resilience</i>	<i>Resource Availability</i>
	Emotional/Mental Health impact of RI tools	<i>Resilience issues related to emotion and psychology</i>	<i>People not caring, lack of empathy, psychological issues</i>
	Social/political/ infrastructure issues	<i>Resilience issues related to sociological, politics and infrastructure</i>	<i>Data security, Transportation, Food deserts</i>
	Climate-related issues	<i>Resilience issues related to the climate</i>	<i>Heat, Migration</i>
	Post-COVID considerations	<i>Issues that arose due to the COVID-19 pandemic related to resilience</i>	<i>Centralization of Resources, Political strain and polarizing terms</i>
	Interrelated issues	<i>Issues related to resilience that affect different factors, perhaps in an exacerbating and circular way</i>	<i>Transportation, climate change, heat</i>

Appendix 2. Frequency of Codes in transcript and notes documents included in qualitative analysis from MAXQDA

Code System	Grace_Notes for Resili...	Rhett_RI Recording	Maiya_RI Recording	Sage_RI Recording	Andrew_Notes for Re...	Myla_RI Recording	Lidia_RI Recording	TOTAL
Standards for RI Tool	1%		9%	4%	0%		2%	4%
Technological Standard	7%			4%	19%	1%		3%
Logistical Standard	8%	0%	5%	1%	19%			2%
Iterative process	2%			3%	1%			1%
Sociological Standard	13%		1%	24%	38%			13%
Tailoring	12%		7%	7%	2%			5%
What Do We Need?	3%	5%			2%	10%	5%	2%
Communication	12%				1%			0%
long-term solutions	7%			9%	9%			5%
Challenges with RI Tools				1%	0%		15%	2%
Funding-related issues	2%		7%		11%			2%
Accessibility	10%	1%		1%	14%	8%	2%	2%
Communication	3%	1%	11%	4%	3%		5%	4%
Information			11%		1%			2%
Centralization of Resources	5%					12%		2%
Measuring Resilience	2%	3%		4%			43%	6%
Communication between disciplines	3%			9%	0%			5%
Clinical Translation				1%				0%
Mixed methods approach				6%				3%
Human centered design	1%			0%	3%			0%
succession planning				2%				1%
Behavioral economics				3%				1%
Generational differences				11%	2%			6%
Infrastructure					2%			0%
Elasticity / Scale	2%		2%					0%
Real-time response	2%		11%	7%	1%			5%
Data Sovereignty	3%		3%	0%	8%		1%	1%
Disinformation + Misinformation			1%	2%			1%	1%

Supplementary Files

Figures

Brainstorming document for codebook development.



Multimedia Appendixes

Frequency of Codes in transcript and notes documents included in qualitative analysis from MAXQDA.

URL: <http://asset.jmir.pub/assets/7b7f458cdbb782629287ead8560b91c5.docx>

Codebook with definitions and examples used for qualitative coding and analysis.

URL: <http://asset.jmir.pub/assets/7b70a6d83e568cf3362ee03a1cb064d9.docx>

