

Best Practices for the Development, Implementation, and Sustainment of Exposure Registries: A Rapid Review

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Abstract The objective of this rapid review was to synthesize lessons learned from past exposure registries developed in response to environmental and occupational exposure events and provide guidance for the development and implementation of future exposure registries. A rapid review was conducted following the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines and interim guidance for the reporting of rapid reviews. Peer-reviewed articles and gray literature were identified through searches in Ovid MEDLINE, Google Scholar, and official websites. Selected literature focused on U.S.-based registries developed in response to environmental and occupational exposures. A total of 22 documents were retained and analyzed.

Existing exposure registries demonstrate the importance of early community engagement, well-defined eligibility criteria, multimodal data collection, and partnerships with health agencies. Key challenges we identified included limited exposure measurement tools, delays in registry implementation, participant mistrust, and difficulties in maintaining long-term follow-up. Strategies to overcome these challenges include the use of community advisory boards, culturally relevant messaging, structured referral systems, and routine data integration with health records. Additionally, our review identified lessons and best practices from prior exposure registries that can inform the implementation of forthcoming registries. Successful registries rely on transparent governance, proactive community engagement, robust follow-up procedures, and integration with existing health systems.

Keywords: exposure registry, health registry, exposure science, environmental epidemiology, Red Hill, Flint

Introduction

Disasters that involve environmental exposures, such as chemical spills, biological agents, and radiological contamination, can have severe and lasting consequences on the health of affected communities. Monitoring the health outcomes of exposed populations over time is essential for the clinical care of affected individuals and future pub-

lic health preparedness (National Academies of Sciences, Engineering, and Medicine [NASEM], 2017). One tool for achieving this goal is the public health registry, also known as a patient, exposure, or disease registry (Gliklich et al., 2020).

According to the Agency for Healthcare Research and Quality (AHRQ), a patient registry is an “organized system that uses observa-

tional study methods to collect uniform data (clinical and other) to evaluate specified outcomes for a population defined by a particular disease, condition, or exposure and that serves predetermined scientific, clinical, or policy purpose(s)” (Gliklich et al., 2020). Registries serve multiple purposes, such as documenting disease progression, evaluating healthcare effectiveness, conducting public health surveillance, improving care quality, and tracking responses to health threats or interventions (Gliklich et al., 2020; NASEM, 2017). Exposure registries help assess health outcomes among individuals negatively affected by hazardous environmental or occupational events and can connect affected individuals with health services and social resources.

A recent exposure event that required the implementation of a public health registry is the Red Hill Bulk Fuel Storage Facility crisis in Oahu, Hawaii. This fuel storage facility, operated by the U.S. Navy, supports military operations in the Pacific and was designed to hold up to 250 million gallons of fuel (U.S. Environmental Protection Agency [U.S. EPA], 2026). On November 20, 2021, an estimated 5,500 gallons of jet fuel leaked into the Red Hill water supply shaft, contaminating the drinking water system that serves Joint Base Pearl Harbor-Hickam (JBPHH) and the greater Red Hill community (Miko et al., 2023). Widespread health symptoms were

TABLE 1		
Inclusion and Exclusion Criteria		
Category	Inclusion Criteria	Exclusion Criteria
Document type	• Peer-reviewed journal articles • Government reports • Conference proceedings	• Editorials • Commentaries • Opinion pieces • Media articles not peer reviewed
Language	• English	• Non-English
Country	• Registry or exposure event originated within the U.S.	• Registry or exposure event originated outside the U.S.
Content	• Description of registries established to monitor populations exposed to hazardous substances due to a discrete environmental event • Real-world registry operations	• General patient or disease registries not tied to environmental exposures • Pregnancy exposure registries

reported, leading the Hawaii State Department of Health to issue an advisory to stop all drinking, bathing, and washing due to the contaminated water. The advisory was not lifted until 4 months later on March 28, 2022. An estimated 93,000 water system users were affected by the contaminated drinking water (U.S. EPA, 2026).

Ongoing efforts related to this contamination are now focused on environmental remediation and public health protection. The U.S. Congress required completion of a feasibility assessment to determine the necessity of an epidemiological health outcomes study of individuals exposed to fuel releases from the Red Hill Bulk Fuel Storage Facility (National Defense Authorization Act, 2023). In June 2024, the National Institute for Defense Health Cooperation, formerly the National Center for Disaster Medicine and Public Health, awarded a cooperative agreement to the University of Hawaii to complete the required feasibility assessment and implement the Red Hill Independent Health Registry (Red Hill Registry), with support from members of Hawaii’s Congressional Delegation, the Agency for Toxic Substances and Disease Registry (ATSDR) at the Centers for Disease Control and Prevention (CDC), the Hawaii State Department of Health, and the Defense Health Agency, in addition to many members of the community (Cocke, 2023; U.S. EPA, 2026). The feasibility assessment was completed in September 2024, and the Red Hill Registry launched in August 2025.

Designing and implementing an exposure registry in this context requires careful consideration of its scientific, clinical, and policy intentions. AHRQ’s guidelines for patient registries emphasize that the design must align with the registry’s objectives, whether focused on surveillance, service provision, or long-term research (Gliklich et al., 2020). Past exposure registry efforts in the U.S.—including those in response to the 9/11 World Trade Center attacks, the Flint water crisis, and exposure to toxins from burn pits during military service—offer a substantial foundation for the identification of best practices and lessons learned.

The National Institute for Defense Health Cooperation conducted a rapid review to examine and synthesize key lessons from previous exposure registries that were established in response to environmental and occupational exposures in the U.S. The purpose of conducting our review was to inform the development and implementation of the Red Hill Registry and other future exposure registries.

Methods

Search Strategy

Our rapid review was conducted in accordance with the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) 2020 guidelines, as well as with interim guidance for reporting rapid reviews, to identify studies and reports focused on the design, implementation, and evaluation

of U.S-based exposure registries (Page et al., 2021; Stevens et al., 2025). Our research team developed questions based on key concepts identified by AHRQ to facilitate search strategy decisions (Gliklich et al., 2020).

The research questions developed were:

1. What are the key foundational activities required to successfully design and implement exposure registries in response to environmental and occupational exposures?
2. What challenges and limitations related to establishing and implementing exposure registries have been reported in the literature, and how can these be prevented?
3. What challenges related to identifying, recruiting, engaging, and enrolling exposed populations have been described in the literature, and how can these challenges be prevented?
4. How have existing exposure registries ensured sustainability over time?

We first conducted a comprehensive search in Ovid MEDLINE on April 4, 2025. The research questions were used to guide the development of search terms and strings, and a research librarian at the George Washington University was consulted to ensure that our strategy was comprehensive and appropriate for the scope of this review. Additional search strings were developed to ensure identification of literature relevant to the Flint Registry and the World Trade Center Health Registry, as these are two of the most prominent U.S.-based exposure registries in recent history.

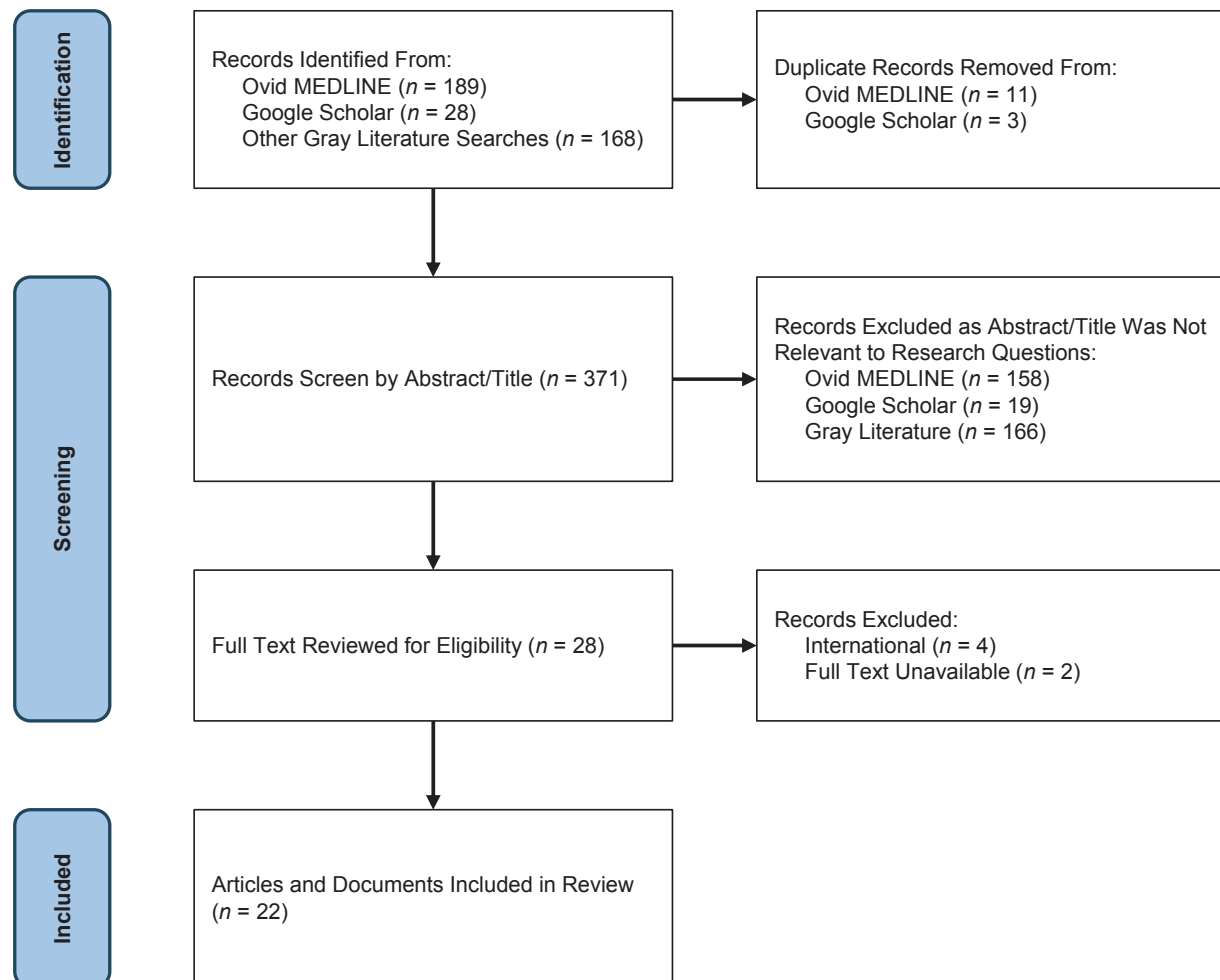
To supplement our database searches and capture gray literature and publicly available reports, additional queries were conducted on April 7, 2025, using Google Scholar and relevant websites (e.g., ones associated with the Flint Registry, U.S. Department of Veterans Affairs [VA], CDC, Defense Health Agency). These subsequent searches were conducted to identify additional relevant evaluations, policy briefs, summary documents, and academic articles not indexed in Ovid MEDLINE. Search strings, databases, and corresponding results are summarized in Supplemental Table 1.

Inclusion and Exclusion Criteria

Inclusion and exclusion criteria are outlined in Table 1. Documents were eligible for inclusion in this review if they 1) described a registry established to monitor populations exposed to hazardous substances due

FIGURE 1

Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) Flow Diagram of the Study Selection Process, 2020



to a discrete environmental event (e.g., fuel spill, lead contamination, chemical release); 2) focused on real-world registry operations such as planning, participant recruitment and enrollment, data collection or follow-up, legal and ethical considerations, or community engagement; and 3) were written in English and publicly available in peer-reviewed journals, government reports, or conference proceedings. Both peer-reviewed literature and gray literature from relevant government and organization websites (e.g., CDC, VA, Flint Registry) were considered. Inclusion criteria did not include date ranges.

Studies were excluded if they 1) addressed general patient or disease registries not tied to

environmental exposures; 2) described pregnancy exposure registries; 3) originated outside the U.S. and lacked applicability to U.S. public health infrastructure; or 4) were limited to editorials, commentaries, opinion pieces, or media articles that were not peer reviewed. We excluded studies lacking sufficient methodological or implementation detail as well as studies focused solely on exposure assessment without a registry framework.

Screening, Review, and Data Extraction

Each document's title and abstract were screened, and full-text reviews were conducted by a single reviewer and independently confirmed by a second reviewer to ensure

documents adhered to our established inclusion and exclusion criteria. The following information was extracted from the included documents: title, author(s), year of publication, type of publication, the registry and/or exposure described, key themes, and answers to our four research questions.

One reviewer performed initial extractions, and an independent reviewer performed a final consensus review of the extracted information. Our methodology differs from the concurrent and iterative approach typically performed for systematic reviews and was used due to the shortened timeframe for performing our review (Stevens et al., 2025).

Results

A total of 385 documents were identified using the search criteria (Figure 1). After deduplication, 371 documents were retained for title and abstract screening, which resulted in 28 documents available for full-text review. After full-text review, 22 documents were deemed eligible for inclusion and data extraction; in total, 4 documents were excluded for describing registries established outside the U.S., and 2 documents were excluded because the full text was unavailable.

Of the 22 documents selected for inclusion, 2 documents (9%) were from the official Flint Registry website, and 20 documents (91%) were peer-reviewed journal publications identified in formal scientific literature databases. Document publication years ranged from 1995 to 2024. The documents represented evaluations or descriptions of U.S.-based exposure registries that had been developed in response to environmental disasters and exposures, or the documents provided general guidance for exposure registry implementation. Specifically, 6 documents (27%) described the Flint Registry, 5 (23%) discussed the World Trade Center Health Registry, 3 (14%) discussed the National Exposure Registry, 5 (23%) described other exposure registries, and 3 (14%) provided general guidance and recommendations.

The documents addressed common themes, including community engagement, exposure measurement limitations, participant outreach and follow-up, and legal considerations. Table 2 summarizes major themes related to each research question and their corresponding references. Supplemental Table 2 summarizes the contributions of each document to our four research questions.

Foundational Activities

A total of 17 documents (77%) described foundational activities for the design and implementation of exposure registries, such as defining exposure classification, establishing eligibility criteria, setting up data collection infrastructure, and incorporating community advisory input (Antao et al., 2015; Boufides et al., 2022; Burg et al., 1997; Burg & Gist, 1995; Chen-Lim et al., 2025; Cone & Farfel, 2011; David et al., 2011; Flint Registry, 2024; Jones et al., 2024; Murphy et al., 1999; Ruckart et al., 2019; Sadler et al., 2023; Schultz et al., 2010; Sico et al., 2024; Vear-

rier & Greenberg, 2017; Welch et al., 2014; Yousef et al., 2024).

For example, the Flint Registry used community-engaged approaches that involved residents in governance and outreach efforts (Flint Registry, 2024; Jones et al., 2024). The National Exposure Registry outlined structured procedures for building disease and exposure registries, including the use of demographic and environmental data to support hypothesis generation (Ruckart et al., 2019). The World Trade Center Health Registry (WTCHR) illustrated the importance of early documentation, establishing multimodal data collection methods, and developing partnerships with public health agencies (Cone & Farfel, 2011; Welch et al., 2014). Similarly, the Healthcare Worker Exposure Response and Outcome (HERO) Registry demonstrated that Good Participatory Practice (GPP) guidelines can shape registry design to reflect the lived experience of registry populations (Chen-Lim et al., 2025).

Implementation Challenges

Challenges and limitations in establishing exposure registries were reported in 16 documents (73%) and included inadequate exposure assessment methods, delays in implementation, and limited funding (Antao et al., 2015; Boufides et al., 2022; Burg et al., 1997; Burg & Gist, 1995; Chen-Lim et al., 2025; Cone & Farfel, 2011; David et al., 2011; Flint Registry, 2024; Jones et al., 2024; Murphy et al., 1999; Ruckart et al., 2019; Sadler et al., 2023; Schultz et al., 2010; Sico et al., 2024; Welch et al., 2014; Yousef et al., 2024).

For instance, the National Exposure Registry was limited by an inability to assess exposures accurately and was criticized for the lack of biomarkers and for relying on self-reported data (Schultz et al., 2010). Additionally, issues of attrition and data completeness were discussed in studies, such as the follow-up analysis of the National Exposure Registry's trichloroethylene (TCE) subregistry; the researchers reported finding minimal bias but emphasized the need for strategies to retain participants over time (Burg et al., 1997).

WTCHR noted challenges with bias due to underrepresentation of subpopulations and reliance on self-reported data, which was addressed by performing validation studies and implementing multiple data collection avenues (Cone & Farfel, 2011). The Flint

Registry faced challenges related to community trust, which was addressed by referring participants to health and social services, integrating participant feedback into operations, and providing multilingual and multimodal surveys (Flint Registry, 2024; Jones et al., 2024; Ruckart et al., 2019).

Recruitment and Engagement

Recruitment and engagement techniques, particularly ones for mobile participants or communities with histories of marginalization, were widely documented across 17 documents (77%) (Antao et al., 2015; Boufides et al., 2022; Burg et al., 1997; Burg & Gist, 1995; Chen-Lim et al., 2025; Cone & Farfel, 2011; David et al., 2011; Flint Registry, 2024; Haggerty et al., 2023; Jones et al., 2024; Murphy et al., 1999, 2007; Ruckart et al., 2019; Schultz et al., 2010; Sico et al., 2024; Welch et al., 2014; Yousef et al., 2024). Articles about the Flint Registry showed that motivations to enroll were rooted in justice, concern for community health, and participatory incentives—thus informing the need for culturally relevant messaging and trust building between registry facilitators and the community to boost engagement (Flint Registry, 2024; Haggerty et al., 2023).

The HERO Registry's healthcare worker subcommittee emphasized the value of giving voice to participant concerns and experiences, which enabled more responsive research (Chen-Lim et al., 2025). Similarly, WTCHR attempted to improve enrollment and engagement by building partnerships with more than 200 organizations, implementing multichannel outreach, tailoring messaging, and providing language-accessible materials (Cone & Farfel, 2011; Welch et al., 2014). Additionally, the National Exposure Registry addressed challenges in locating mobile or off-site participants and maintaining engagement using proactive outreach campaigns, mailings with educational brochures, public meetings, and repeated follow-up (Burg et al., 1997; Burg & Gist, 1995).

Sustainability

In all, 15 documents (68%) explicitly addressed topics related to registry sustainability, including follow-up and long-term data quality (Antao et al., 2015; Boufides et al., 2022; Burg et al., 1997; Burg & Gist, 1995; Cone & Farfel, 2011; David et al., 2011; Flint

TABLE 2

Key Themes Identified and Relevant References

Research Questions (RQs)	Themes	References
RQ1: Foundational activities	Defining registry population and eligibility criteria	Burg et al., 1997; David et al., 2011; Ruckart et al., 2019; Schultz et al., 2010; Yousef et al., 2024
	Data collection and management infrastructure	Antao et al., 2015; Boufides et al., 2022; Burg et al., 1997; Burg & Gist, 1995; Cone & Farfel, 2011; David et al., 2011; Flint Registry, 2024; Ruckart et al., 2019; Sadler et al., 2023; Schultz et al., 2010; Sico et al., 2024; Welch et al., 2014; Yousef et al., 2024
	Early community engagement	Antao et al., 2015; Burg & Gist, 1995; Chen-Lim et al., 2025; Flint Registry, 2024; Jones et al., 2024; Ruckart et al., 2019; Yousef et al., 2024
	Legal and organizational frameworks	Antao et al., 2015; Boufides et al., 2022; Flint Registry, 2024; Ruckart et al., 2019; Sico et al., 2024; Vearrier & Greenberg, 2017
RQ2: Implementation challenges	Exposure measurement limitations	Antao et al., 2015; Burg & Gist, 1995; Cone & Farfel, 2011; David et al., 2011; Sadler et al., 2023; Schultz et al., 2010; Sico et al., 2024; Yousef et al., 2024
	Social barriers and mistrust	Antao et al., 2015; Flint Registry, 2024; Jones et al., 2024; Ruckart et al., 2019; Welch et al., 2014
	Resource limitations	Antao et al., 2015; Boufides et al., 2022; Flint Registry, 2024; Jones et al., 2024; Ruckart et al., 2019
	Bias and nonrepresentative data	Burg et al., 1997; Chen-Lim et al., 2025; Cone & Farfel, 2011; Murphy et al., 1999; Schultz et al., 2010; Sico et al., 2024; Yousef et al., 2024
RQ3: Recruitment and engagement	Targeted and proactive outreach	Antao et al., 2015; Burg et al., 1997; Burg & Gist, 1995; Cone & Farfel, 2011; Flint Registry, 2024; Jones et al., 2024; Ruckart et al., 2019; Welch et al., 2014; Yousef et al., 2024
	Building trust and responding to evolving community needs	Antao et al., 2015; Chen-Lim et al., 2025; Flint Registry, 2024; Haggerty et al., 2023; Jones et al., 2024; Ruckart et al., 2019; Schultz et al., 2010; Welch et al., 2014
RQ4: Sustainability	Long-term data quality	Antao et al., 2015; Burg & Gist, 1995; Cone & Farfel, 2011; Flint Registry, 2024; Jones et al., 2024; Ruckart et al., 2019; Sico et al., 2024
	Participant follow-up	Antao et al., 2015; Boufides et al., 2022; Burg & Gist, 1995; Cone & Farfel, 2011; David et al., 2011; Flint Registry, 2024; Ruckart et al., 2019; Sico et al., 2024; Yousef et al., 2024; Yu et al., 2015, 2017; Zeig-Owens et al., 2021
	Sustained resources	Antao et al., 2015; Boufides et al., 2022; Flint Registry, 2024; Jones et al., 2024

Registry, 2024; Jones et al., 2024; Ruckart et al., 2019; Sico et al., 2024; Welch et al., 2014; Yousef et al., 2024; Yu et al., 2015, 2017; Zeig-Owens et al., 2021). WTCR ensured long-term follow-up and data quality by conducting periodic follow-up surveys every 3 to 4 years, maintaining regular communication with registrants via annual reports and personalized outreach, and conducting linkages with external data sources such as the National Death Index and state cancer registries for mortality and cancer surveillance (Cone & Farfel, 2011; Welch et al., 2014).

The Flint Registry, in contrast, demonstrated a comprehensive, community-driven approach by implementing a structured tiered consent process, baseline and follow-up surveys, and a custom referral platform that tracked service use and health outcomes (Ruckart et al., 2019). This registry also leveraged Medicaid data to assess changes over time.

Yet another example based on ATSDR experiences offered a conceptual framework emphasizing that successful long-term engagement depends on sufficient funding, staffing, and infrastructure for sustained operations (Antao et al., 2015).

Discussion

Our rapid review synthesized findings from 22 peer-reviewed and gray literature sources to extract lessons from prior exposure registries or other relevant articles. Across the reviewed documents and analyzed registries—including those related to the Flint water crisis, the World Trade Center attacks, and VA burn pit exposures—several reoccurring themes emerged regarding effective design, implementation, and long-term sustainability.

Key findings revealed that successful exposure registries require early community

engagement; clear and inclusive eligibility criteria; and flexible, multimodal data collection systems. The Flint Registry exemplifies good practices in community engagement, culturally relevant recruitment, and a flexible process that is informed by public input (Flint Registry, 2024; Haggerty et al., 2023; Jones et al., 2024; Ruckart et al., 2019; Yousef et al., 2024). These practices align with the guidance presented by AHRQ, which emphasizes the importance of clearly defined objectives, inclusive planning for interested parties, and robust governance structures to ensure registry quality and utility (Gliklich et al., 2020).

Many registries, however, encountered limitations, particularly in the recruitment of underserved populations and the maintenance of longitudinal data integrity. Attrition bias, underrepresentation of key subgroups, and ethical or legal considerations were prevalent themes.

Furthermore, several documents described inadequate exposure measurement (Antao et al., 2015; Burg et al., 1997; Sadler et al., 2023; Schultz et al., 2010; Sico et al., 2024; Yousef et al., 2024) and frequent reliance on self-reporting of exposure (Cone & Farfel, 2011; Schultz et al., 2010; Sico et al., 2024; Welch et al., 2014; Yousef et al., 2024), which is criticized as unreliable and imperfect.

Biomarkers, however, are often unknown, particularly for previously unencountered environmental or occupational exposures, and thus they are difficult to measure (Bongers et al., 2008). To more effectively collect exposure-associated specimens and information, the Disaster Research Response Program at the National Institute of Environmental Health Sciences (NIEHS, 2026) created the Rapid Acquisition of Pre- and Post-Incident Disaster Data Protocol Designer. These resources guide the development of protocols for swiftly collecting biological specimens and ascertaining details of exposures following expedited institutional review board processes. Without a rapid response, important biomarkers can be metabolized and become unrecognizable relative to the exposure; however, this exposure can still contribute to deleterious health effects. The preservation of biospecimens can enable biomarker assay development and more precise exposure histories in registry participants (Bongers et al., 2008; NIEHS, 2026).

Lastly, results from this rapid review also demonstrate how long-term follow-up and sustainability can be operationalized. Registries such as the WTCR and the Flint Registry employed strategies such as routine follow-up surveys, integration with state and federal health databases, and continuous participant outreach. The AHRQ echoes these points, urging designers to consider the life cycle of a registry for long-term viability (Gliklich et al., 2020).

Although our review adhered to PRISMA 2020 guidelines in documenting the search, screening, and selection processes, one important limitation of our review is that the scope was constrained to English-language documents about U.S.-based registries, as our review was intended to inform the Red Hill Registry. This limitation could have excluded relevant international case studies or non-indexed gray literature that could further enrich the lessons learned.

Additionally, due to time and resource limitations in performing our rapid review, we had limited opportunity to consult with subject matter experts in relevant fields. Similarly, to streamline the review process, reviewers used nonconcurrent screening and extraction methods. Concurrent review and expert consultation, which are standard in high-quality systematic reviews, could have enhanced the depth and rigor of our review (Page et al., 2021). Moreover, the recommendations for future registries provided in this document might not fully reflect the unique needs of every community or exposure event that requires a public health registry. Our recommendations are not exhaustive and are meant to inspire further research into these topics.

Conclusion

Our rapid review identified several crosscutting lessons from prior exposure registries that can inform the implementation of future registries. Recommendations for developing, implementing, and sustaining exposure registries based on study findings include:

- Establish community advisory boards to guide registry operations and maintain transparent communication with participants.
- Adopt multiple data collection strategies, including biological specimens, and ensure ongoing data integration with health systems to enhance data validity and reliability.
- Prioritize ethical and legal compliance.

- Ensure sustained funding and staffing to manage long-term follow-up effectively.
- Include targeted training for healthcare professionals and registry staff to address specialized health concerns resulting from environmental exposures.

When implemented with these considerations in mind, exposure registries can serve as an effective tool to drive policy change, restore community trust, and contribute to the long-term health of affected populations. 🌸

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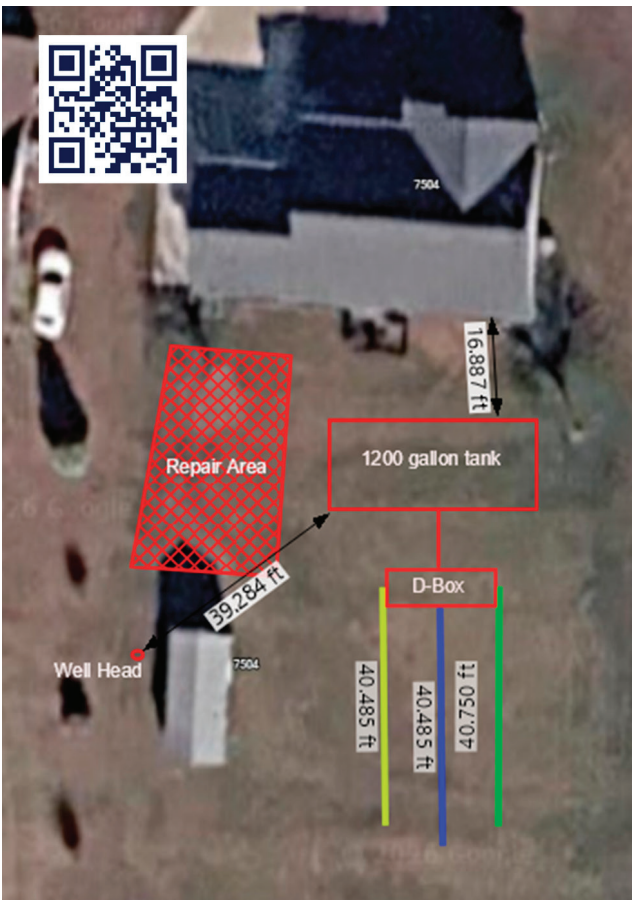
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