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Supplemental Table 2

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Note. The authors submitted this supplemental table as an additional resource for readers. The *Journal of Environmental Health* did not copy edit or format the text.

Supplemental Table 2. Summary of Articles by Research Questions

Author (Publication Year)	Publication Type	Registry Discussed	Research Questions (RQs)			
			RQ1: Foundational Activities	RQ2: Implementation Challenges	RQ3: Recruitment & Engagement	RQ4: Sustainability
Flint Registry (2023)	Annual report	Flint Registry	The Flint Registry was designed and implemented through strong community involvement and sustained CDC and state funding.	The Registry addressed challenges such as economic hardship, healthcare access, community mistrust, and long-term retention by providing service referrals and integrating participant feedback into operations.	The Registry overcame recruitment and engagement challenges by using diverse outreach strategies and centering community voices in its leadership and messaging.	Long-term follow-up and data quality were ensured through regular health and follow-up surveys.
Cone (2011)	Journal article	World Trade Center Health Registry	This article documents early planning and multimodal survey design.	The WTCHR faced challenges such as limited early exposure data, self-report bias, and potential underrepresentation, which it addressed through validation studies, diverse recruitment strategies, multiple survey modes, and advisory board input.	The registry overcame outreach barriers by partnering with over 200 organizations.	The WTCHR maintains data quality and follow-up through scheduled triennial surveys and registry linkage with mortality and cancer databases.
Schultz (2010)	Journal article	National Exposure Registry	The article describes that successful design involves selecting contaminants and populations, collecting and managing data, and clearly defining goals.	The article identifies major limitations such as inadequate exposure assessment, unverified self-reported data, lack of biomarkers, and missing control populations, and suggests that future registries should	The article discusses difficulties in engaging minority populations and inadequate efforts to garner participation in follow-up studies.	-

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				improve exposure measurement, include biomonitoring, and verify outcomes.		
Vearrier (2017)	Journal article	N/A; general guidelines	This paper explores the legal implications of establishing a registry for medical monitoring. Recommendations include ensuring all criteria are met for an exposure event such that scientific justifications and medical risks suggest a net public health benefit to establishing a registry.			
Chen-Lim (2024)	Journal article	Health Worker Exposure and Outcomes Registry	The HERO Registry was designed with rapid deployment, inclusive definitions of healthcare workers, and integration of a diverse subcommittee guided by GPP to inform design, outreach, and research priorities.	The article identifies challenges such as underrepresentation of geographic regions, limited initial goals, and unclear member roles, which were mitigated through bidirectional communication, regular feedback, and participant driven revisions to recruitment.	Challenges such as lack of diverse representation and unclear role definitions were addressed by creating inclusive recruitment materials.	-

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David (2011)	Journal Article	BASF Registry	The article details that developing BASF's nanomaterials worker registry required a structured inventory of nanomaterials, collaboration across departments, clear definitions of nanomaterials, and linked data systems.	Key challenges included the lack of a universally accepted nanomaterial definition, difficulty identifying legacy nanomaterials, and coordinating global data collection.	The registry faced challenges in identifying exposed workers due to unclear product labeling and inconsistent site knowledge, which were mitigated through structured surveys, and drop-down tools for plant managers.	Long term follow-up is pending the development of validated exposure endpoints and integrated reporting systems.
Haggerty (2023)	Conference abstract	Flint Registry	-	-	This abstract describes motivations for enrollment in a voluntary registry, highlighting engagement challenges and the importance of addressing both individual needs and collective justice to build trust and participation.	-
Yousef (2024)	Journal article	Flint Registry	The Flint Registry was designed as a university-administered, community-requested surveillance system with targeted recruitment, multi-modal survey options, and partnerships with health systems and state databases to enroll	The study notes challenges such as reliance on self-reported diagnoses, lack of baseline lead exposure data, and population representativeness.	Recruitment challenges were addressed using general and targeted outreach to ensure enrollment of people who lived, worked, or attended school in Flint during the crisis.	The Flint Registry plans continued follow-up through repeated survey waves, stratified analysis, and integration into local policy efforts.

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			individuals exposed during the Flint Water Crisis.			
Jones (2024)	Journal article	Flint Registry	The Flint Registry was built using a multi-tiered, community-partnered engagement strategy that included co-outreach, advisory boards, community ambassadors, focus groups, and continuous feedback to shape design.	The article discusses challenges such as historical mistrust, barriers to accessibility, funding and staffing constraints, and unmet expectations, which were addressed through trauma-informed engagement, inclusion of diverse community voices, multilingual and multi-modal surveys, and responsive governance structures.	Recruitment challenges were met with targeted strategies like CER, local hiring, co-outreach with trusted partners, and continuous input from advisory groups.	The Flint Registry uses strategies such as cohort maintenance systems, ongoing CER, regular community feedback, and registry evaluation efforts to sustain data quality and long-term engagement.
Sadler (2023)	Conference abstract	Flint Registry	This abstract highlighted that capturing residential histories through GIS geocoding is a critical design activity in exposure registries, especially in mobile populations, to accurately define exposure classes over time.	The abstract identifies that relying solely on blood lead surveillance led to underestimation of long-term exposure due to its short half-life and low testing rates, challenges that were addressed by supplementing with geospatial residential data.	-	-

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Sico (2024)	Journal article	VA Airborne Hazards and Open Burn Pit Registry	The study used data from the AH&OBP Registry, which was established through federal legislation and systematically linked to Department of Defense and VA health records to enable longitudinal monitoring of deployment-related exposures and health outcomes.	The article notes limitations such as reliance on self-reported exposure data, lack of environmental exposure measurements, and potential selection bias, and partially addresses them through linkage to electronic health records, exclusion of pre-existing conditions, and sensitivity analyses.	AH&OBP Registry relies on voluntary self-enrollment, suggesting potential barriers to full representativeness.	Long-term follow-up is enabled by data linkage across VA and DoD health systems.
Burg (1997)	Journal article	National Exposure Registry	The TCE sub-registry of the National Exposure Registry was implemented through site-specific identification of exposed individuals, baseline and follow-up interviews and structured data collection on demographics, health outcomes, and exposure history.	The study identifies limitations including attrition, demographic differences between respondents and non-respondents, and misunderstanding of registry goals, recommending regular reminders, better baseline contact information, and clear communication about the purpose of participation to prevent bias.	Challenges included locating offsite participants, incomplete contact information, refusal due to misconceptions about eligibility, and higher attrition among younger, male, and less-educated individuals, which the study suggests can be mitigated through tailored follow-up and enhanced baseline outreach.	The registry-maintained follow-up through biennial interviews, proxy use, contact verification mailings, and private tracing services, while also analyzing attrition patterns to assess and minimize potential bias in longitudinal data.

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Welch (2014)	Journal article	World Trade Center Health Registry	The article describes implementing a referral initiative within the World Trade Center Health Registry required personalized outreach, motivational interviewing training for staff, eligibility criteria based on self-reported symptoms, and collaboration with clinical partners to facilitate care access.	Challenges such as low service uptake, outdated contact information, and survivor mistrust were mitigated using personalized mailings and staff training in motivational interviewing to overcome emotional and logistical barriers.	The article highlights difficulties reaching younger, lower-income, and non-white enrollees, and overcoming stigma and low awareness of services, which were addressed through multi-channel outreach, tailored messaging, and language accessible materials.	The Registry maintained updated contact through ongoing mailings and surveys, integrated outreach into routine Registry operations, and evaluated engagement outcomes to support continuous improvement in follow-up.
Antao (2015)	Journal article	N/A; general guidelines	The article outlines that designing a registry requires evaluating public and scientific significance, registry purpose and outcomes, duration and scope of data collection, existing data alternatives, timeliness, funding, staffing, communication capabilities, and legal/ethical frameworks.	The article identifies limitations such as lack of individual exposure data, high cost, administrative delays, and mistrust from affected populations, and suggests prevention strategies like community involvement, transparent communication, use of alternative data sources, and leveraging administrative and scientific partnerships.	The article notes challenges including small or mobile populations, time lags after exposure, and language barriers, which can be mitigated through participatory mechanisms, early outreach, and use of culturally and linguistically appropriate materials.	Long-term follow-up and data quality can be ensured through structured data collection protocols, recurring surveys, integration with administrative data systems, cohort maintenance infrastructure, and careful attention to sustainability and funding.

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Ruckart (2019)	Journal article	Flint Registry	The Flint Registry was designed with public health authority status, clear eligibility criteria, a community-partnered leadership structure, a multimedia outreach campaign, a tiered consent process, and a data-sharing framework that enables participant identification and referrals.	The article identifies challenges such as legal and data-sharing barriers, fragmented data sources, and participant distrust, which were addressed by establishing the Registry's legal authority, leveraging diverse stakeholder input, and building systems for direct referrals and feedback loops.	Challenges like enrolling highly mobile and underserved populations were addressed through population-based lists, targeted multimedia recruitment, pre-enrollment feedback collection, and strong community partnerships to ensure inclusive engagement.	The Flint Registry maintains long-term data quality through baseline and annual follow-up surveys, structured service referral tracking, Medicaid data linkage, and ongoing evaluation of registry impact on health outcomes and service use.
Burg (1995)	Journal article	National Exposure Registry	The NER was implemented through a structured five-step process involving contaminant/site/population selection, rigorous eligibility verification, multi-phase data collection, informed outreach, and longitudinal data maintenance to support hypothesis generating epidemiologic research.	The article notes limitations such as absence of concurrent control groups, multiple chemical exposures, participant expectations, and low precision in exposure measures, recommending strategies like using national norm datasets, detailed community outreach, and careful site selection to reduce confounding and mistrust.	Challenges such as locating mobile or deceased individuals, clarifying eligibility, and maintaining cooperation were addressed through proactive outreach campaigns, mailings with educational brochures, public meetings, and repeated follow-up contact.	Long-term follow-up and data quality were ensured via six-month verification mailings, biennial computer-assisted telephone interviews, continued community engagement, data confidentiality protocols, and a defined sub-registry with conditions for continuation or termination.

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Murphy (1999)	Journal article	Gulf War Registry	The VA Registry was implemented as a voluntary health surveillance system offering standardized clinical exams, diagnostic coding, and a computerized database to monitor Gulf War veterans' symptoms, diagnoses, and military histories across the U.S.	The article identifies limitations including self-selection bias, non-representativeness of participants, and limited diagnostic specificity, which suggests these could be mitigated by conducting population-based epidemiologic studies to validate findings.	Recruitment challenges included underrepresentation of active-duty personnel and reliance on self-enrollment, which the VA addressed through national outreach campaigns, toll-free hotlines, newsletters, and coordination with veterans service organizations.	-
Boufides (2022)	Handbook	N/A; general guidelines	The handbook outlines that registry implementation requires establishing legal authority, securing multi-source data sharing agreements, designing consent procedures, ensuring HIPAA compliance (or exemption), and aligning operational planning with ethical and public health practice principles.	The handbook details challenges such as data-sharing reluctance, conflicting legal interpretations, school and agency refusals to release contact data, and HIPAA/FERPA restrictions prevented in part through legal grants of authority, tailored data use agreements, participant consent procedures, and persistent legal negotiation.	The handbook describes difficulties obtaining recruitment data from schools and agencies and outlines how these were addressed through community outreach, mailed consent forms, agency collaboration, and fallback efforts to distribute information via schools and public channels.	The handbook recommends ensuring long-term follow-up through structured consent, periodic surveys, service referrals, legally compliant data retention policies, and sustained partnerships with MDHHS for outcomes tracking, all outlined as part of its ongoing legal and operational infrastructure.
Murphy (2007)	Journal article	World Trade Center Health Registry	-	-	This paper recommends careful consideration of all exposure groups when developing recruitment and enrollment	-

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					strategies and engaging multiple pathways for engagement to enable equal coverage between groups. To minimize over-coverage, this paper recommends standardization of data across all sources and exposure groups, and implementation of regular automatic deduplication.	
Zeig-Owens (2021)	Journal article	NIOSH Career Firefighter Health Study	-	-	-	This paper describes challenges with survey response. Recommendations for future registries include maintaining up-to-date contact information for those enrolled, monitoring of which contact methods are most successful with the population, and maintaining contact through participant places of work, schools, organizations, etc.

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Yu (2015)	Journal article	World Trade Center Health Registry	-	-	-	This study identified bias when exploring associations between health outcomes due to a lack of health data from participants that only responded to survey wave 1. Recommendations include tracing enrollees lost to follow-up, sharing Registry findings with enrollees by distributing an annual report, and personalized outreach to refer enrollees to treatment resources.
Yu (2017)	Journal article	World Trade Center Health Registry	-	-	-	This study found that monetary incentives were an effective method of boosting registrant participation and long-term follow-up for the WTCHR, especially towards the end of the study.

CDC, Centers for Disease Control; WTCHR, World Trade Center Health Registry; HERO, Healthcare Worker Exposure Response & Outcomes; GPP, Good Participatory Practice; CER, Community-Engaged Recruitment; GIS, Geographic Information System; VA, Veterans Affairs; AH&OBP, Airborne Hazards and Open Burn Pit Registry; DoD, Department of Defense; TCE, Trichloroethylene; HIPAA, Health Insurance Portability and Accountability Act; FERPA, Family Educational Rights and Privacy Act; NIOSH, National Institute for Occupational Safety and Health.