Community Involvement in Research and Investigation for Public Health

Welcome! Thank you for taking the time to complete this survey on **Community Involvement in Research and Investigation for Public Health**. This survey is being fielded by the RAND Corporation on behalf of the Centers for Disease Control and Prevention (CDC) and in partnership with the National Association of County & City Health Officials (NACCHO) to determine how local health departments can best respond to the opportunities and risks posed by the growing field of citizen science, particularly for disaster preparedness activities. By completing this survey, you are helping us determine what kinds of guidance, resources, and infrastructure will be necessary for health departments to take advantage of citizen science opportunities for public health.

We are sending this survey to local health officials as you have broad knowledge of all departmental activities, including any health department experiences with citizen science data collection and data uses. **However, please feel free to send this survey to individuals you feel would be most knowledgeable about departmental experiences and perceptions of citizen science and its applications for health department services.**

All responses to this survey will remain anonymous and will be reported in aggregate in any public reports. We will not associate survey responses with any individual health department. All information provided on this survey will be recorded, stored, and used securely. The survey is entirely voluntary, and you may stop at any time.

This survey contains multiple choice (single and multi-answer options) and fill in the blank questions. We ask that you please complete the survey in one sitting, however, if you need to stop the survey before answering all the questions you may save your responses and return at a later time.

If you have any questions about this survey or require assistance, please contact the Survey Support Center.

Background Information

1. What is your job title? _____

2. What is the name of your agency? _____

3. Approximately what size population does your agency serve?

   ❑ < 25,000
   ❑ 25,000-49,999
   ❑ 50,000-99,999
   ❑ 100,000-249,999
   ❑ 250,000-499,999
   ❑ 500,000-999,999
   ❑ 1,000,000+

4. With respect to emergency planning and response, which of the following disasters has your agency focused on in the past 5 years?

   Check all that apply.

Disasters	Planned for	Responded to
a. Extreme temperature events	❑	❑
b. Hurricanes	❑	❑
c. Storms/ flooding	❑	❑
d. Tornadoes	❑	❑
e. Earthquakes	❑	❑
f. Wildfires	❑	❑
g. Droughts	❑	❑
h. Infectious disease outbreaks	❑	❑
i. Vector control (mosquitos, rodents, etc.)	❑	❑
j. Food safety and defense (e.g. outbreaks)	❑	❑
k. Water-borne disease	❑	❑
l. Terrorist threats	❑	❑
m. Accidental hazardous material releases	❑	❑
n. Accidental nuclear/ radiation releases	❑	❑
o. Active shooter incidents	❑	❑
p. All hazards	❑	❑
q. Other	❑	❑

Citizen Science Experiences and Perceptions

5. **<u>Citizen science</u>** is a broad term that covers many different types of activities. It has also been called "public participation in scientific research," "community science," and "participatory research." At its core, ***citizen science is the engagement of members of the public in research processes.*** Examples of citizen science could be community members providing data to the health department or a university for aggregation or community members independently collecting and analyzing data on a public health issue.

   Prior to starting this survey, how familiar were you with the concept of citizen science?

   ❑ Extremely familiar
   ❑ Moderately familiar
   ❑ Somewhat familiar
   ❑ Slightly familiar
   ❑ Not at all familiar

6. How familiar are staff members in your agency with the concept of citizen science?

   ❑ Extremely familiar
   ❑ Moderately familiar
   ❑ Somewhat familiar
   ❑ Slightly familiar
   ❑ Not at all familiar

Contributory citizen science

7. **One specific form of citizen science is called <u>contributory citizen science</u>. Contributory citizen science** refers to activities initiated by the health department that involve the public as data gatherers only. Examples include community members carrying air quality sensors that report readings to an online database or the health department crowdsourcing self-reported flu symptoms from volunteers in online forums.

   In which programs has your agency carried out **contributory citizen science** activities? If you are unsure about activities across programs, ***provide your best guess.***

   Check all that apply.

   - ❑ Air quality
   - ❑ Chronic disease prevention and health promotion
   - ❑ Drinking water supply & quality
   - ❑ Emergency preparedness, response, and recovery
   - ❑ Environmental health & environmental hazards
   - ❑ Food safety & security
   - ❑ Health care services
   - ❑ Healthy aging/elder care
   - ❑ Housing
   - ❑ Infectious diseases
   - ❑ Maternal & child health
   - ❑ Occupational safety & health
   - ❑ Public safety
   - ❑ Recreational water safety
   - ❑ Other, please describe: _____
   - ❑ None
   - ❑ Don't know

8. [For respondents checking any program in Q7.] You indicated that your agency carried out **contributory citizen science** activities for the following programs [list checked programs in Q7]. How has your agency used information resulting from these activities? (If your agency did not end up using any information, check "Did not use.")

Check all that apply.

- ❑ Informing the public (public communications)
- ❑ Providing education and educational materials
- ❑ Supporting community health or needs assessments
- ❑ Building or strengthening partnerships and collaborations
- ❑ Setting priorities
- ❑ Resource allocation
- ❑ Tracking and monitoring health or environmental conditions
- ❑ Research or scientific public health investigation
- ❑ Developing or improving programs, policies, or interventions
- ❑ Managing public health responses or interventions
- ❑ Regulatory or policy decision-making
- ❑ Enforcement actions and decisions
- ❑ Evaluation of health department activities and responses
- ❑ Other uses, please describe: _____
- ❑ Too early/we have not used information yet
- ❑ Did not use
- ❑ Don't know

Please indicate the extent to which you agree or disagree with each of the following statements.

[If respondent checks any program in Q7 reframe Q9 and Q10 to present tense.]

9. Contributory citizen science activities would benefit our agency.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

10. Contributory citizen science activities would fit into current departmental functions.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

Collaborative citizen science

11. Another form of citizen science is <u>collaborative citizen science.</u> Collaborative citizen science activities are typically initiated or led by health departments or academic experts in partnership with the public. Community members may be involved with problem definition and design, data collection, analysis, or interpretation. An example of a collaborative citizen science activity is when a health department initiates a mosquito surveillance project and asks community members to set up, monitor, and report on community mosquito populations.

In which programs has your agency carried out **collaborative citizen science** activities? If you are unsure about activities across programs, ***provide your best guess.***

Check all that apply.

- ❑ Air quality
- ❑ Chronic disease prevention and health promotion
- ❑ Drinking water supply & quality
- ❑ Emergency preparedness, response, and recovery
- ❑ Environmental health & environmental hazards
- ❑ Food safety & security
- ❑ Health care services
- ❑ Healthy aging/elder care
- ❑ Housing
- ❑ Infectious diseases
- ❑ Maternal & child health
- ❑ Occupational safety & health
- ❑ Public safety
- ❑ Recreational water safety
- ❑ Other, please describe: _____
- ❑ None
- ❑ Don't know

12. [For respondents checking any program in Q11.] You indicated that your agency carried out **collaborative citizen science** activities for the following programs [list checked programs in Q11]. How has your agency used information resulting from these activities? (If your agency did not end up using any information, check "Did not use.")

Check all that apply.

- ❑ Informing the public (public communications)
- ❑ Providing education and educational materials
- ❑ Supporting community health or needs assessments
- ❑ Building or strengthening partnerships and collaborations
- ❑ Setting priorities
- ❑ Resource allocation
- ❑ Tracking and monitoring health or environmental conditions
- ❑ Research or scientific public health investigation
- ❑ Developing or improving programs, policies, or interventions
- ❑ Managing public health responses or interventions
- ❑ Regulatory or policy decision-making
- ❑ Enforcement actions and decisions
- ❑ Evaluation of health department activities and responses
- ❑ Other uses, please describe: _____
- ❑ Too early/we have not used information yet
- ❑ Did not use
- ❑ Don't know

Please indicate the extent to which you agree or disagree with each of the following statements.

[If respondent checks any program in Q11 reframe Q13 and Q14 to present tense.]

13. Collaborative citizen science activities would benefit our agency.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

14. Collaborative citizen science activities would fit into current departmental functions.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

Community-led citizen science

15. A third form of citizen science is community-led citizen science. Community-led citizen science
refers to research or data collection activities initiated, controlled, and managed by community members
with little support or input from governmental agencies or academic institutions. Unlike collaborative
citizen science, citizens in community-led citizen science retain control over scientific or data collection
processes. An example of a community-led citizen science activity is a mosquito surveillance project
initiated, maintained, and controlled by community members.

In which programs has your agency worked with information from **community-led citizen science**
activities? If you are unsure about activities across programs, ***provide your best guess.***

Check all that apply.

- ❑ Air quality
- ❑ Chronic disease prevention and health promotion
- ❑ Drinking water supply & quality
- ❑ Emergency preparedness, response, and recovery
- ❑ Environmental health & environmental hazards
- ❑ Food safety & security
- ❑ Health care services
- ❑ Healthy aging/elder care
- ❑ Housing
- ❑ Infectious diseases
- ❑ Maternal & child health
- ❑ Occupational safety & health
- ❑ Public safety
- ❑ Recreational water safety
- ❑ Other, please describe: _____
- ❑ None
- ❑ Don't know

16. [<u>For respondents checking any program in Q15.</u>] You indicated that your agency worked with information from **community-led citizen science** activities for the following programs: [<u>list checked programs in Q15</u>]. What has your agency used the information for? (If your agency did not end up using the data, check "Did not use.")

Check all that apply.

- ❑ Informing the public (public communications)
- ❑ Providing education and educational materials
- ❑ Supporting community health or needs assessments
- ❑ Building or strengthening partnerships and collaborations
- ❑ Setting priorities
- ❑ Resource allocation
- ❑ Tracking and monitoring health or environmental conditions
- ❑ Research or scientific public health investigation
- ❑ Developing or improving programs, policies, or interventions
- ❑ Managing public health responses or interventions
- ❑ Regulatory or policy decision-making
- ❑ Enforcement actions and decisions
- ❑ Evaluation of health department activities and responses
- ❑ Other uses, please describe: _____
- ❑ Too early/we have not used information yet
- ❑ Did not use
- ❑ Don't know

Please indicate the extent to which you agree or disagree with each of the following statements.

[<u>If respondent checks any program in Q15 reframe Q17, Q18, and Q19 to present tense.</u>]

17. Community-led citizen science would benefit our agency.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

18. Community-led citizen science may negatively impact our agency's functions and services.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

Additional characteristics of health department citizen science activities

19. [For respondents who checked any data use box except for "Did not use" and "Don't know" and "Too early/we have not used information yet" in Q8, Q12, or Q16.] What impacts resulted from your agency's use of information collected from contributory, collaborative, or community-led citizen science activities?

Check all that apply.

- ❑ Regulatory changes
- ❑ Health department internal policy change
- ❑ Direct intervention by the health department
- ❑ New or improved public health programming
- ❑ Increased awareness or knowledge among the public
- ❑ Behavior change among members of the public
- ❑ Improved health outcomes among members of the public
- ❑ Reprioritization of agency activities
- ❑ Helped secure research or program funding for the health department
- ❑ Enhanced strength and quality of agency partnerships
- ❑ Enhanced agency communication or dissemination of activities or materials
- ❑ Prevented or mitigated an adverse event
- ❑ Other impacts, please describe: _____
- ❑ No impacts
- ❑ Don't know

20. [If respondent responded affirmatively to Q8 OR Q12 OR Q16] You indicated that your agency had experience with [list citizen science form in Q7 or Q11 or Q15] that resulted in use of the information collected. Please select all factors that contributed to the success of your citizen science efforts.

- ❑ Existing trust between our agency and the community
- ❑ Knowledgeable and trained staff
- ❑ Ability to leverage existing agency programs to build a citizen science effort
- ❑ Ability to leverage community resources
- ❑ Adequate resources (time, money, labor) to engage with citizen scientists
- ❑ Departmental culture prioritizes community outreach and engagement
- ❑ Policies and procedures for using citizen science data are already in place
- ❑ Partner and partnership strength and quality was high
- ❑ Collaborative activities and partnership roles were defined and structured well
- ❑ Citizen scientist volunteers were knowledgeable and skilled
- ❑ Citizen scientist volunteers were highly motivated
- ❑ Communication between partners was clear
- ❑ Activities had clearly defined goals and methods
- ❑ Activities were scoped appropriately in terms of timing and length
- ❑ Other contributors to success, please describe: _____
- ❑ None

21. [If respondent responded affirmatively to Q8 OR Q12 OR Q16] You indicated that your agency had experience with [list citizen science form in Q7 or Q11 or Q15] that resulted in use of the information collected. Please select the factors that contributed to the initiation of your citizen science efforts.

- ❑ Priority of the community
- ❑ Our agency was interested and wanted to explore using citizen science methods
- ❑ Citizen science methods were the best way to investigate the problem (e.g., needed lots of observations)
- ❑ Citizen science methods were the best way to achieve public trust and buy-in of results
- ❑ Priority of policymakers or other influential parties
- ❑ Issue(s) were high visibility in community or media
- ❑ Other reasons for initiation, please describe: _____
- ❑ None

22. [For respondents who checked emergency preparedness in Q7, Q11, OR Q15, a table will populate with only relevant forms appearing.] You indicated that your agency used the following form(s) of citizen science for emergency preparedness, response, and recovery actions: [list checked forms]. We are interested in learning how health departments use citizen science across the disaster lifecycle (including pre, during, and post disaster). For each form of citizen science, what did your agency use resulting information for? If your agency did not use the information, indicate what the information was intended to be used for.

Check all that apply.

Citizen science form	Citizen science information was used to:			
	Help prepare for a future event	**Aid in response efforts during an event**	**Support recovery efforts post-disaster**	**Other, specify below**
a. Contributory citizen science (activities initiated by the health department that involve the public as data gatherers only)	❑	❑	❑	❑
b. Collaborative citizen science (activities initiated or led by the health department or academic experts in partnership with the public where all parties work together to design and implement projects)	❑	❑	❑	❑
c. Community-led citizen science (research or data collection activities initiated controlled, and managed by community members with little support or input from governmental agencies or academic institutions)	❑	❑	❑	❑

Other: _____

23. Imagine that you had the resources to start a citizen science project related to emergency preparedness, response, or recovery. What kinds of data could the public collect that would be useful for your agency? Please list your ideas. _____

Integrating citizen science with health department culture, activities, and structure

Please indicate the extent to which you agree or disagree with each of the following statements.

24. Citizen science is an important data resource for health department surveillance or epidemiological investigations.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

25. Given available resources, citizen science is not a priority for our agency.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

26. Citizen science could improve health department decision-making processes.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

27. Citizen science is no different from other forms of community engagement our agency engages in.

- ❑ Strongly disagree
- ❑ Disagree
- ❑ Agree
- ❑ Strongly agree

28. Please select the barriers that <u>limit</u> your agency's ability to implement citizen science activities generally and for emergency preparedness.

Barriers	General public health	Emergency preparedness	Does not apply	Don't know
Departmental cultures are not receptive.	❑	❑	❑	❑
Lack of established community partnerships.	❑	❑	❑	❑
Lack of trust between community and health department.	❑	❑	❑	❑
Lack of partnerships with relevant expertise and skills	❑	❑	❑	❑
Unclear IRB policies	❑	❑	❑	❑
Legal and ethical issues would need to be addressed in departmental policies and procedures.	❑	❑	❑	❑
Volunteers require vetting.	❑	❑	❑	❑
Protection of volunteers is necessary.	❑	❑	❑	❑
Citizen scientist activities may conflict with required departmental procedures.	❑	❑	❑	❑
Value is currently unclear.	❑	❑	❑	❑
Specialized skills are necessary.	❑	❑	❑	❑
Volunteers need training and coordination	❑	❑	❑	❑
Large changes to organizational policies or procedures required.	❑	❑	❑	❑
Data quality may not be adequate for health department actions or decision-making.	❑	❑	❑	❑
Data would need to be independently verified by the health department.	❑	❑	❑	❑
There are concerns about data privacy.	❑	❑	❑	❑
Short and long-term funding is uncertain.	❑	❑	❑	❑
Other, please describe:_____	❑	❑	❑	❑

29. Please check the box that indicates your agency's readiness to engage in contributory, collaborative, and community-led forms of citizen science.

Citizen science activity	Not at all ready	Not very ready	Somewhat ready	Fully ready / already doing
a. Contributory citizen science (activities initiated by the health department that involve the public as data gatherers only)	❑	❑	❑	❑
b. Collaborative citizen science (activities initiated or led by the health department or academic experts in partnership with the public where all parties work together to design and implement projects)	❑	❑	❑	❑
c. Community-led citizen science (research or data collection activities initiated controlled, and managed by community members with little support or input from governmental agencies or academic institutions)	❑	❑	❑	❑

30. What resources does your agency need to improve its readiness to engage in citizen science activities?

Check all that apply.

- ❑ Additional staff
- ❑ Staff training/education
- ❑ More/different partner types
- ❑ Equipment (e.g., software, hardware, mobile technologies, monitoring devices)
- ❑ Data infrastructure improvements (e.g., coordinated or interoperable systems, data collection systems or data repositories)
- ❑ Budget/money/funding
- ❑ Other, please describe: _____

31. [If respondent selected "Staff training/education" in Q31] What kinds of trainings or education would help your agency to engage in citizen science activities?

Check all that apply.

- ❑ Guidance on working with community citizen scientists
- ❑ Educational training/materials on working with crowdsourced data
- ❑ Software or programming applications
- ❑ Statistical analyses
- ❑ Community-based participatory research training
- ❑ Legal and privacy concerns
- ❑ Ethical issues
- ❑ Training community members to collect and handle data
- ❑ Cultural competence skills development
- ❑ Data quality assessment and evaluation
- ❑ Data governance (appropriate data use and administrative protocols)
- ❑ Volunteer management
- ❑ Intersector collaboration
- ❑ Partnership building
- ❑ Other technical skills training, please describe: _____
- ❑ Other, please describe: _____

32. Below is a list of potential benefits that could result from citizen science activities. Please choose <u>up to 3</u> benefits that you believe your agency would consider the most important.

- ❑ Improve health department visibility and reputation
- ❑ Improve partnerships and collaborative community relationships
- ❑ Ability to leverage community resources for public health activities
- ❑ Enhance overall public scientific literacy and knowledge of public health
- ❑ Enhance community resilience and community preparedness for disaster events
- ❑ Better tracking of new or emerging threats
- ❑ Better community understanding of public health messages or risk communications
- ❑ Better agency responses in terms of programs, policies, and interventions
- ❑ Improve understanding of the community, including health equity impacts of departmental actions
- ❑ Other benefits, please describe: _____
- ❑ None

33. Below is a list of potential concerns with citizen science activities. Please choose <u>up to 3</u> concerns you believe your agency would consider the most important.

- ❑ Citizen science data may not be high enough quality for use in departmental activities or decisions
- ❑ Citizen science data may be falsified
- ❑ Citizen science data may conflict with health department data
- ❑ Citizen science may distract from other more important priorities
- ❑ Citizen science data may not be representative of the population at large
- ❑ Unverified citizen science data may be used inappropriately for advocacy or political purposes
- ❑ Small-scale technological developments used by citizen scientists may pose new threats (e.g., bioengineering)
- ❑ Other concerns, please describe: _____
- ❑ None

34. For each organization type, please indicate how your agency has partnered with each organization in the past year. If the organization does not exist within your community service area, check N/A.

Check all that apply.

Organizations	Shared personnel/ resources	Written agreement	Regularly scheduled meetings	Exchange information	No relationship	NA
Healthcare providers	❑	❑	❑	❑	❑	❑
Mental/behavioral health providers	❑	❑	❑	❑	❑	❑
Neighborhood groups/community leaders	❑	❑	❑	❑	❑	❑
Advocacy groups	❑	❑	❑	❑	❑	❑
Citizen science or data groups	❑	❑	❑	❑	❑	❑
Schools and childcare	❑	❑	❑	❑	❑	❑
Volunteer organizations	❑	❑	❑	❑	❑	❑
Private business, industry	❑	❑	❑	❑	❑	❑
Emergency management	❑	❑	❑	❑	❑	❑
Cultural and faith-based organizations	❑	❑	❑	❑	❑	❑
Housing and sheltering	❑	❑	❑	❑	❑	❑
Academic research institutions	❑	❑	❑	❑	❑	❑
Media	❑	❑	❑	❑	❑	❑
Social services	❑	❑	❑	❑	❑	❑
Senior services	❑	❑	❑	❑	❑	❑
Other, please list: _____	❑	❑	❑	❑	❑	❑

35. Which of the following research activities has your agency participated in over the past five years?

Check all that apply.

- ❑ Identifying research topics or questions that are relevant to public health practice
- ❑ Developing or refining research plans for public health studies
- ❑ Recruiting study sites or study participants
- ❑ Analyzing and interpreting study data and findings
- ❑ Collecting, exchanging, or reporting data for a study
- ❑ Disseminating research findings to key stakeholders
- ❑ Applying research findings to practices within your own organization
- ❑ Helping other organizations apply research findings to practice
- ❑ Don't know
- ❑ Other, please describe: _____

36. Please provide the names and a brief description of any citizen science activities your agency has been involved in. If you have heard of citizen science activities carried out in health departments in other jurisdictions please describe those projects as well. _____