

# Understanding Legionnaires' Disease Outbreak Response Gaps and Resource Needs: Results from a Survey of State and Territorial Health Agencies

## Executive Summary

The Association of State and Territorial Health Officials (ASTHO) conducted the Legionnaires' Disease (LD) Outbreak Response Gap Analysis survey between March and April 2019. Participants included LD subject matter experts in state and territorial health agencies (S/THAs) who were identified by members of ASTHO's Health Security Team and CDC's National Center for Immunization and Respiratory Diseases. Forty-seven individuals responded to this gap analysis, representing a response rate of almost 80 percent. The survey aimed to improve ASTHO's understanding of the LD guidance available to S/THAs, to learn about S/THAs' response to suspected or confirmed LD outbreaks, and to identify resource needs and gaps in existing guidance. This information will inform the development of tools and resources for public health officials. ASTHO is also supporting S/THAs in LD outbreak response efforts by cataloging and developing new guidance and tools for public health officials. This initiative builds upon existing work and ongoing engagement to improve S/THA capacity for LD prevention, diagnosis, surveillance, outbreak response, and water management program (WMP) implementation.

The survey focused on how LD is identified; the basic structure and processes of LD surveillance programs, including states' clinical protocols, outbreak response, prevention, and risk communication; and gaps in existing guidance, protocols, and tools. Forty-seven states and territories were represented in the survey responses, which covered the following topics:

- Overall structure of LD response
- Diagnosis and clinical testing protocols
- Surveillance and reporting protocols
- Gaps in surveillance guidance
- Gaps in LD reporting guidance
- Outbreak response
- WMPs and prevention
- Risk communication

Results indicated that:

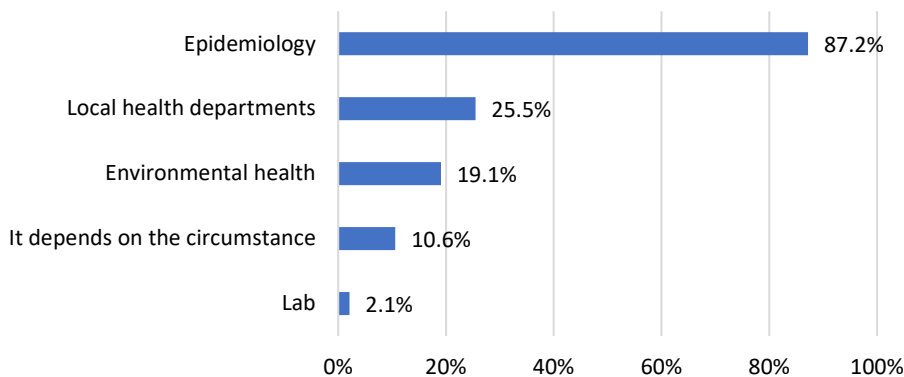
- **Epidemiology** programs take the lead in addressing LD outbreaks in **87 percent** of jurisdictions.
- In 2018, **43 percent** of the jurisdictions opened **single case LD investigations** on a smaller scale (between 1-50 cases). In that time, **53 percent** of jurisdictions opened between 1-5 **full investigations**.
- About **80 percent** of the jurisdictions are **satisfied with CDC guidance** on diagnosis and clinical testing protocols.
- **Twenty-eight percent** of the jurisdictions have their **own state-specific guidance** for collecting and processing specimens.
- **Seventy-five percent** of the jurisdictions have their **own guidance documents** for LD surveillance and reporting.
- In **53 percent** of jurisdictions, the greatest gap in LD surveillance guidance is a **need for standardized approaches and methodologies** to collect denominator data to calculate testing rates over time.

- **Seventy-five percent** of jurisdictions cite **reporting to multiple federal systems** as their greatest challenge in reporting guidance.
- **About 21 percent** of participating jurisdictions **do routine preventive outreach** for WMP promotion.
- The [CDC WMP Toolkit](#) and the [ASHRAE Standard 188 document](#) (preferred by 91% and 70% of jurisdictions, respectively) are by far the favored guidance documents on this topic.

## Overall Structure

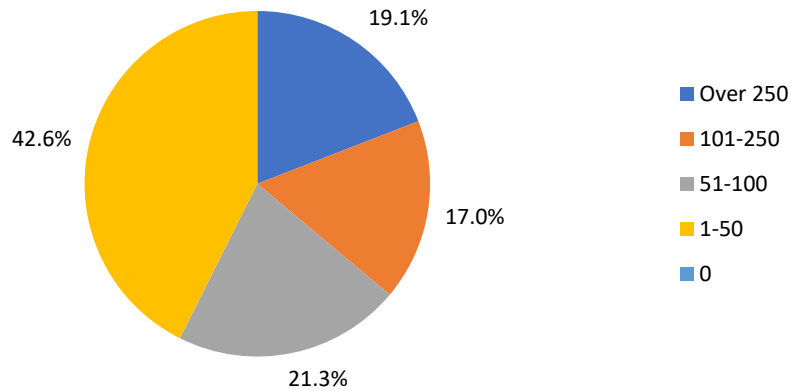
For most jurisdictions (87.2%), the health departments' epidemiology programs lead the investigation during an LD outbreak. Local health departments, environmental health programs, and laboratories are also frequently called upon to take the lead during outbreaks (see Figure 1). A handful of participants noted particular circumstances that affect leadership protocol, including a healthcare-associated infection or a nosocomial event in a jurisdiction associated with a clinical care inpatient facility, a large outbreak that may span beyond more than one local jurisdiction, or an outbreak in a jurisdiction where the local health department does not have the capacity to respond. In these specific cases, additional programs may take the lead or co-lead.

**Figure 1. Lead programs during LD outbreak (n=47)**



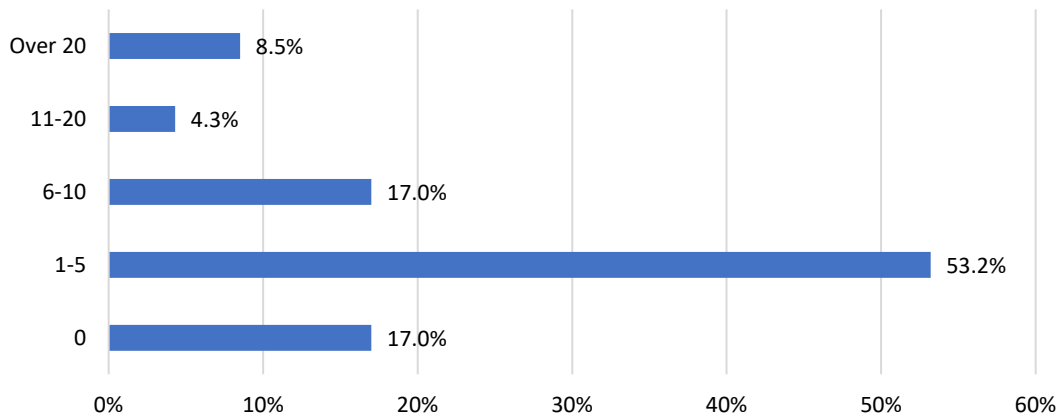
The number of single case LD investigations (epidemiology portions) opened in 2018 ranged broadly. While the most common single response was fewer than 50 investigations (42.6%), the majority of participants opened more than 50 investigations, including nine jurisdictions that opened over two-hundred and fifty investigations (see Figure 2).

**Figure 2. Single case LD investigations opened in 2018 (n=47)**



The number of full investigations of environmental sources for cases or clusters (epidemiological portions and environmental assessments) performed in 2018 was generally low for most jurisdictions, with the majority (53.2%) performing between one and five investigations (see Figure 3).

**Figure 3. Full investigations performed in 2018 (n=47)**



### Diagnosis and Clinical Testing Protocols

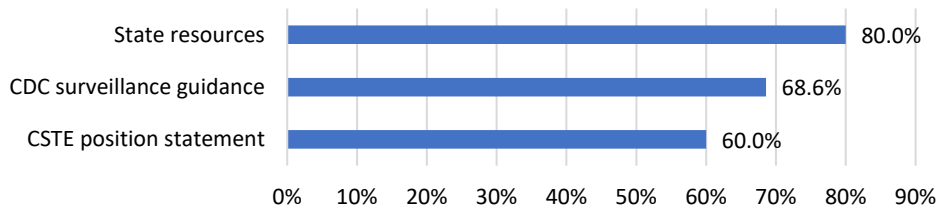
Only nine participating agencies (19.1%) reported that their jurisdictions have state-specific guidance or LD testing protocols for clinicians. Some participants volunteered to share their state-specific guidance, and these are available in [Appendix A](#). Of the 38 responding jurisdictions that lack guidance (80.9%), almost all (97.4%) are satisfied with CDC’s guidance. About a third of participating jurisdictions (27.7%) have state-specific guidance for collecting and processing specimens for procedures such as urinary antigen testing or respiratory cultures. These documents are available in [Appendix B](#).

### Surveillance and Reporting

The majority of participating agencies (74.5%) have state-specific guidance documents for LD surveillance and reporting. These state-specific resources are the most common “go-to” documents for

LD surveillance and reporting, but the CDC surveillance guidance and the Council for State and Territorial Epidemiologists (CSTE) position statement were also considered useful (see Figure 4).

**Figure 4. "Go-to" LD surveillance and reporting documents  
(n=35)**

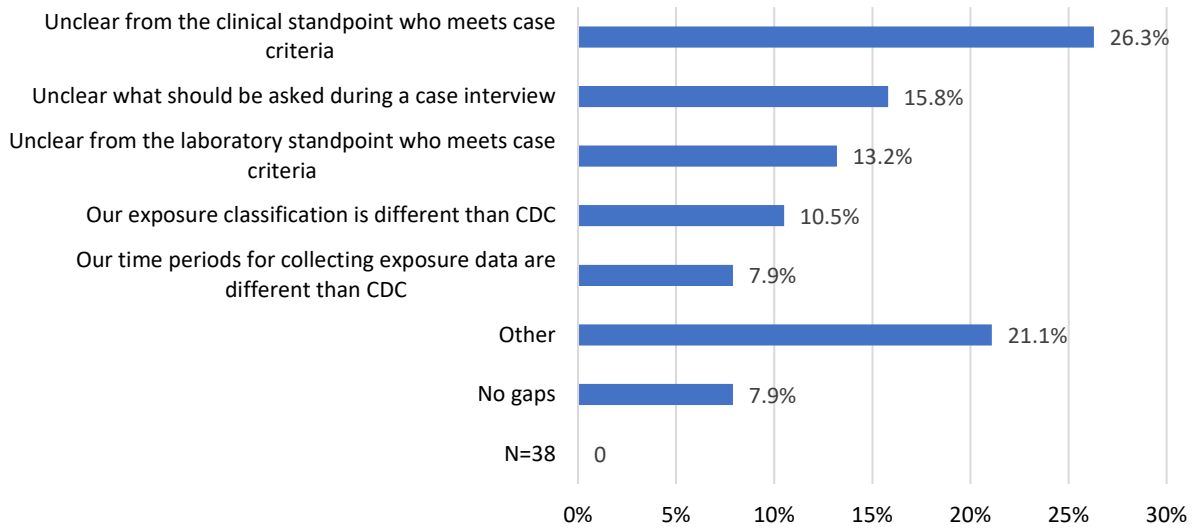


### Gaps in Surveillance Guidance

More than half of survey participants (53%) noted that the greatest gap in LD surveillance guidance is a lack of standardized guidance for deciding which patients with pneumonia should be tested for LD. Testing practices may differ between jurisdictions and may change over time which could negatively affect LD surveillance activities. It is currently not known whether recent increases in LD rates are due solely to differences in the actual rate of LD, differences in current testing practices, or a combination of factors. Improved collection of data such as the total number of LD tests performed and number of patients with diagnosed pneumonia are necessary to answer this question. This could lead to improvements in the effectiveness of the *Legionella* surveillance strategies across jurisdictions.

The second greatest challenge identified is a lack of clarity regarding who meets case criteria for LD. Three participants commented that there were no gaps in their jurisdictions' LD surveillance guidance (see Figure 5). In addition to the options provided, eight participants identified other gaps, including pinpointing the date of onset for healthcare-associated infections; lack of respiratory cultures for *Legionella*; use of other testing techniques, including urinary antigen testing; and lack of personnel to interview patients.

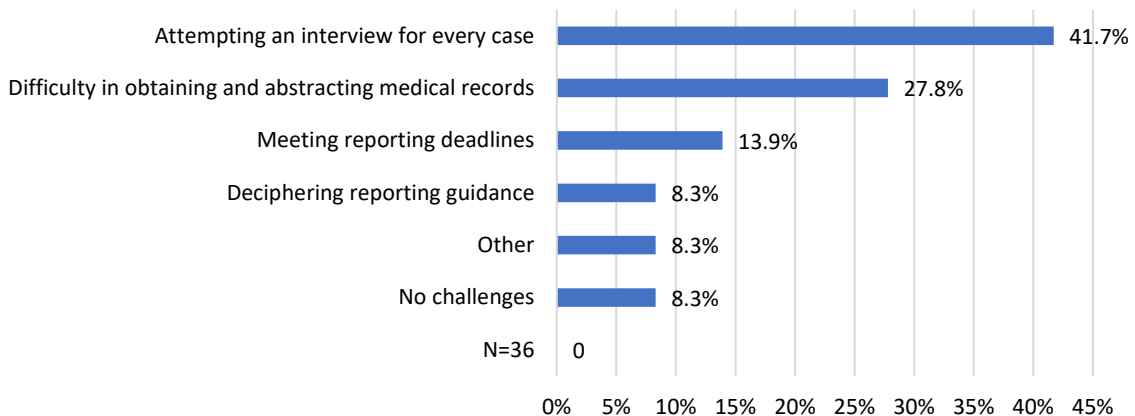
**Figure 5. Gaps in LD surveillance guidance (n=38)**



### Gaps in Reporting Guidance

According to survey participants, the single greatest challenge when reporting a case of LD to national surveillance systems is having to report to multiple federal systems such as the National Notifiable Diseases Surveillance System (NNDSS) and the Supplemental Legionnaires’ Disease Surveillance System (SLDSS) (75%). Many participants are also challenged when attempting an interview for every case, and by obtaining and abstracting medical records (see Figure 6). Three participants commented that they have experienced no challenges with reporting guidance. Besides the options provided, three participants identified other challenges, including implementing case reports messaging electronically through their current systems and allocating staff to conduct interviews, review charts, and report to SLDSS.

**Figure 6. Challenges in reporting LD cases (n=36)**



### Outbreak Response

Most agencies represented in this survey have adequate personnel and capacity to interviewing individuals in suspected cases and detect clusters, and more than half have the personnel and capacity

to respond to LD clusters. However, a minority of agencies reported adequate internal expertise for both performing environmental assessments of LD outbreak sites and making recommendations for remediation. In addition, a minority of agencies have laboratory capacity to perform environmental sampling for *Legionella* (see Table 1).

**Table 1. Agency capacity to respond to LD cases (n=47)**

Performance area	Percent with adequate capacity and personnel
Interviewing cases	80.9%
Detecting clusters	80.9%
Responding to LD clusters	53.2%
Expertise to perform environmental assessments of LD outbreak sites	46.8%
Expertise to make recommendations for remediation	40.4%
Laboratories to perform environmental sampling for <i>Legionella</i>	40.4%

Most jurisdictions (61.7%) have their own LD response protocol, and about a third (27.6%) of the 29 LD response protocols are publicly available (see [Appendix C](#)). Participants generally agreed that all types of resources, including checklists (65.1%), toolkits and factsheets (60.5%), online training (60.5%) and peer-to-peer training (55.8%) could enhance their protocols. In addition to the options provided, twelve respondents (27.9%) suggested the following as other potential resources:

- State environmental health and environmental assessment resources for that portion of the response
- Resources setting specific diagnoses, such as hotel clusters or healthcare facility clusters
- Tabletop exercises for training
- Risk communication guidance
- Outbreak response protocols
- Access to certified industrial hygienists with *Legionella* experience
- Guidance interpretation of results once state public health labs transition to whole genome sequencing
- Examples of model protocols

## Water Management Programs and Prevention

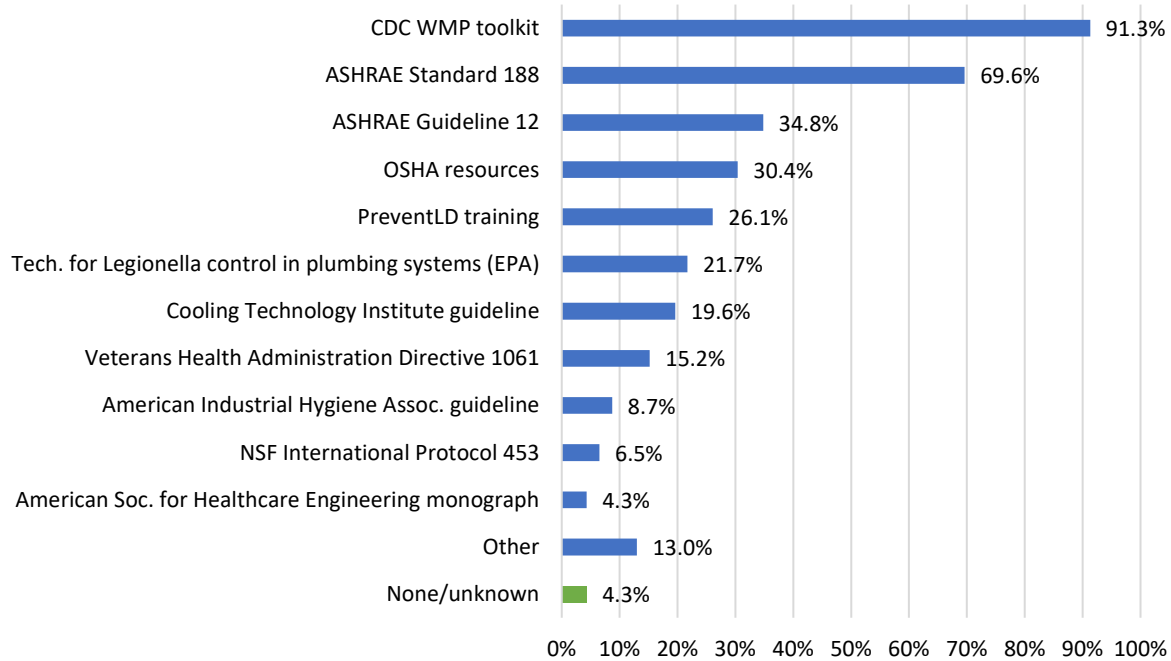
Most participating agencies (65.2%) currently promote the uptake of water management programs (WMPs), on an ad-hoc basis, as part of an outbreak response. Additionally, 21.7 percent do preventive outreach routinely to buildings at increased risk, and thirteen percent have not yet had the opportunity to promote WMP uptake.

Eight respondents indicated that their agencies have attempted to measure WMP implementation. Of these, seven have attempted measurement in the healthcare setting, two in the hospitality setting (hotels and resorts), one in the recreational setting (hot tubs), and one in cooling towers.

Almost all participants (91.3%) indicated that their organizations primarily use the CDC WMP toolkit as their standard guidance document for the prevention of *Legionella* growth and transmission. Four of the six participants who listed other guidance documents indicated CDC sources (see Figure 7). Other guidance documents noted by participants included CDC's Guidelines for Preventing Healthcare-

Associated Pneumonia, World Health Organization *Legionella* guidance, CSTE position statement, and internal templates.

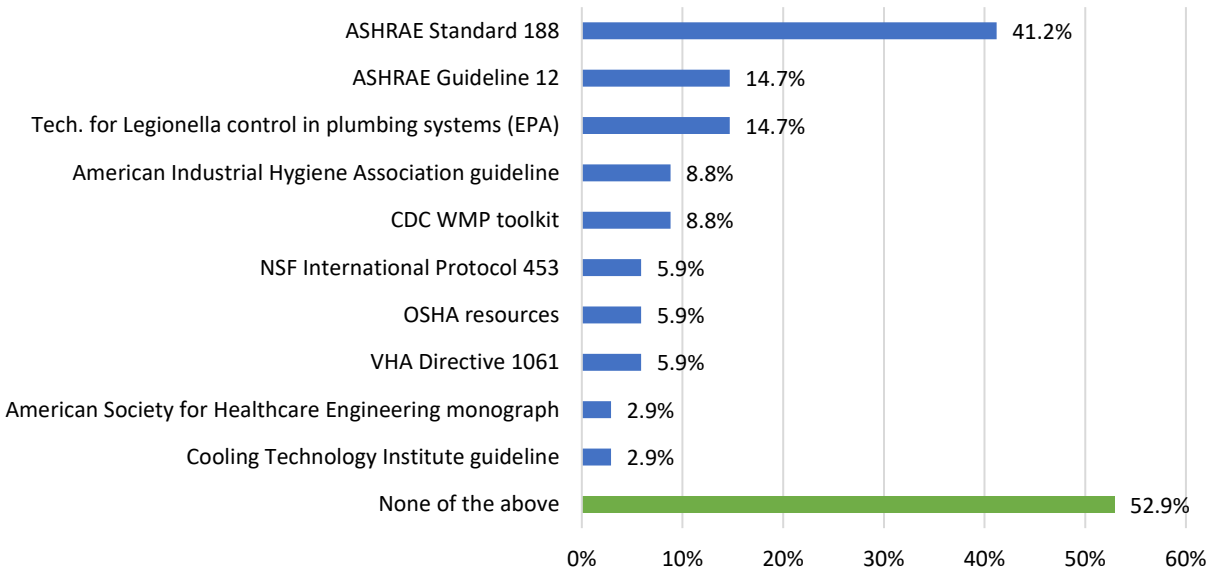
**Figure 7. Guidance used for prevention of Legionella growth and transmission (n=46)**



Consistent with the question on most-used guidance, participants (n=43) indicated that the most helpful documents are the CDC WMP toolkit (86.0%) and the ASHRAE Standard 188 document (27.9%). Other helpful guidance included PreventLD training (11.6%), OSHA resources (4.7%), Cooling Technology Institute guidelines (2.3%), and ASHRAE Guideline 12 (2.3%).

While most participants (59.2%) have not had difficulty with any guidance documents, almost half of respondents (41.2%) experienced difficulty with the otherwise-popular ASHRAE Standard 188 document (see Figure 8).

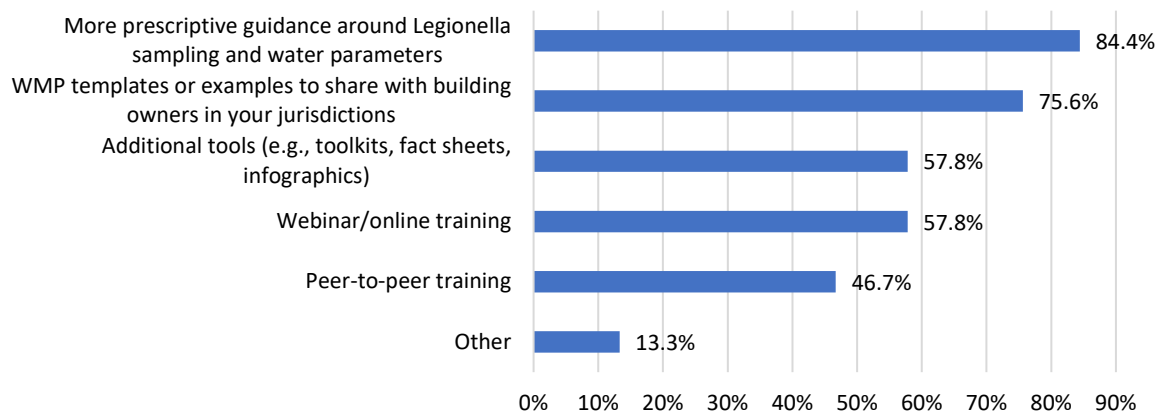
**Figure 8. Difficult to use guidance (n=34)**



The most common complaint across all difficult-to-use documents was that they are “too technical and difficult to understand” (41.7%, n=24). One-third of participants indicated that guidance was “not prescriptive enough and difficult to implement.” A few participants (8.3%) indicated that the documents “seem to conflict with other available guidance,” and 16.7 percent indicated that the guidance was difficult for “other reasons.”

Participants indicated that most types of additional guidance or resources for preventing *Legionella* growth and transmission would be helpful, especially prescriptive guidance regarding *Legionella* sampling and water parameters (see Figure 9). Participants also suggested the following guidance resource needs: training for environmental health professionals to gain expertise and take on this role; training on environmental assessment sampling and for stakeholder industries (e.g., hotels); WMP templates or examples to share with building owners; WMP assistance in long-term care facilities; and materials that encourage local health departments to lead their own investigations.

**Figure 9. Helpful additional guidance (n=45)**



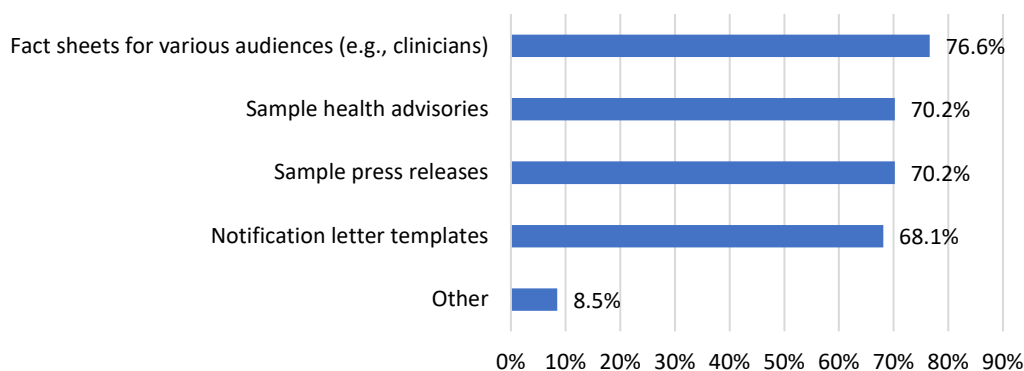


## Risk Communication

Most jurisdictions (54.3%, n=43) do not have communications staff dedicated to LD risk communication. Therefore, during an LD outbreak, this role is filled by press officers (54.3%), communications specialist (34.8%), CDC support staff (30.4%), and health educators (15.2%). Other related personnel that participants mentioned included communication staff to help notify the public of outbreaks and managers or offices of epidemiology and environmental health.

Participants generally agreed that factsheet, sample health advisories, sample press releases, and notification letter templates are all important content for risk communication guidance (see Figure 10). Participants also suggested using a notification matrix or flow chart that identifies appropriate triggers, audiences, and methods and employing clear guidance for communication thresholds, talking points for informational sessions, and facility-specific guidance (e.g., only communicating when there is a positive environmental sample, specific to facility type).

**Figure 10. Important content for risk communication guidance (n=47)**



Participants (n=42) indicated that the most helpful formats for additional risk communication guidance would be additional templates (76.2%), such as notification letters or press releases; additional tools (76.2%) such as toolkits, factsheets, and infographics; online training (57.1%); and peer-to-peer training (33.3%). Other suggestions included a best practice guide for common scenarios that require a full investigation (e.g., a single definite healthcare-associated case, or two or more travel-associated cases in a single lodging facility) and guidance for homeowners on reducing the risk of *Legionella* colonization and exposure in the home and how to perform or order remediation.

## Summary and Next Steps

Epidemiology programs frequently take the lead in addressing LD outbreaks in most jurisdictions. How often these investigations occur, whether as single-case or full LD investigations, ranges broadly across the states.

Because most jurisdictions are satisfied with CDC guidance on diagnosis and clinical testing protocols, relatively few have their own state-specific guidance for collecting and processing specimens for procedures such as urinary antigen testing or respiratory cultures. However, jurisdictions frequently do have their own guidance documents for LD surveillance and reporting.

Participants felt that the greatest gaps in LD surveillance guidance are (1) not having consistent approaches and methodologies for collecting denominator data to calculate testing rates over time and (2) a lack of clarity regarding who meets case criteria. Participants' greatest challenges regarding reporting guidance are (1) having to report to multiple federal systems and (2) attempting interviews for every case. Agencies, in general, have high capacity for interviewing cases and detecting clusters, but low-to-moderate capacity for making recommendations for remediation and performing environmental sampling.

Only about one-fifth of participating agencies do routine preventive outreach for WMP promotion. Most promote the uptake of WMPs on an ad-hoc basis, as part of an outbreak response, but many do not promote WMP uptake at all. Even among those that do promote WMP implementation, few have attempted to measure the success of these efforts. The CDC WMP Toolkit and the ASHRAE Standard 188 document are by far the favored guidance documents on this topic. However, many participants also report that the ASHRAE Standard 188 document is difficult to use. Participants would like to see more prescriptive guidance regarding *Legionella* sampling and water parameters and WMP templates to share with building owners.

Most jurisdictions have communications staff that are capable of handling LD risk communication, but few have dedicated LD risk communication staff. Participants would like additional guidance on LD risk communication in all topics and forms, especially additional templates and tools.

ASTHO plans to further examine the challenges identified in this survey and follow up with S/THA staff via key informant interviews to better understand the context and additional details around the observed gaps and resource needs in LD outbreak prevention, detection, and response. This information will be used to supplement the report findings and inform the future resource development and technical assistance that ASTHO and CDC staff provide to S/THAS.

## **Acknowledgements**

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