

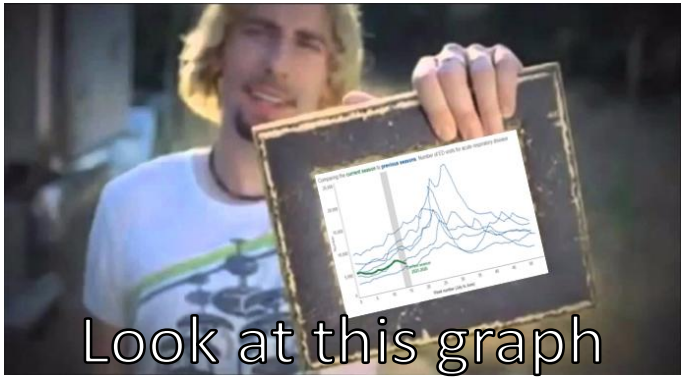

# Data Sharing Guidance in Massachusetts

Actionable steps to effectively communicate relevant data to your community

# Who we are: Mass. Epi Collaborative

- Established in March 2022, we are a collaborative working group of **local, regional, and state epidemiologists**.
- Our goal is to **strengthen public health decision-making across jurisdictions** through collaboration and shared knowledge.



# The Problem: Data sharing in local public health

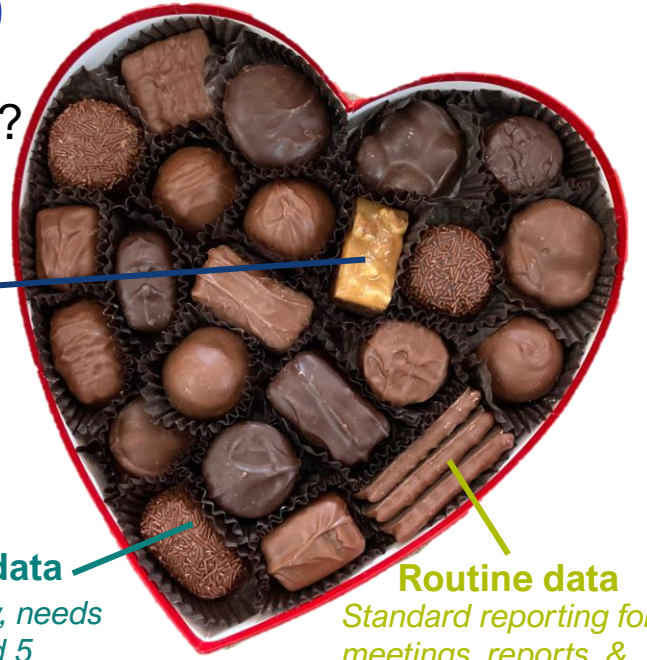
## Home rule > state guidance

So why not just use state guidance in local public health?

1. Too restrictive at the local level
2. Inconsistent across municipalities

Poor public communication

Data is also like a box of chocolates - **you never know what you're going to get.**



**Global pandemic**
*Rare treat. The wild west of data chocolate.*

**Emergent data**
*Received now, needs to be reported 5 minutes ago*

**Routine data**
*Standard reporting for meetings, reports, & public communication*

Photo: Roboflow Universe


Public Health
Prevent. Promote. Protect.
To release or
not to release

# Taking Inventory: What Have Others Done?

## National importance

- 2020: The Council of State and Territorial Epidemiologists created a workgroup in 2020 to develop guiding principles for local- and state-level data sharing
- Washington also formed a statewide workgroup of local and state public health professionals to create a shared document that focuses on both data analysis and how to communicate it to the public, partners, and media.

## Local relevancy

- Our Massachusetts-specific work builds on this national context—not by issuing static rules, but by **creating a tailored, practical toolkit that helps local jurisdictions navigate the grey zones.**

# Guiding Principles of The MA Playbook

## Content

- Build for **diversity** in local public health
- A tool for **all local public health;** everyone needs information to make decisions
- **Emergencies** mean different approaches than **routine** work
- Ground the tools in **real-world examples**

## Process

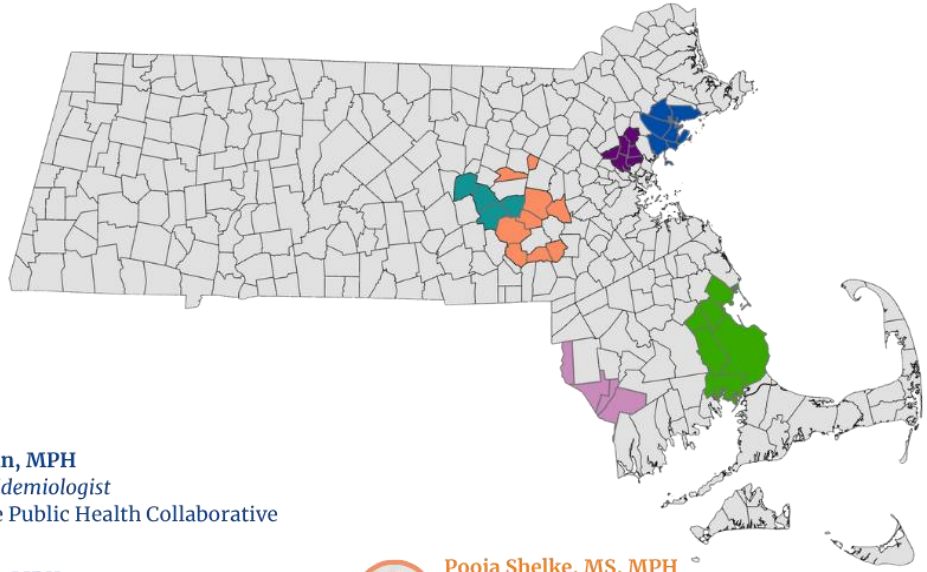
- **Together**, we can build capacity to meet our needs
- This is a **living document**
- **Progress**, not perfection
- **Take what you need**; leave what you don't



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# Our team

**Launched**
December 17, 2024

Composed of
**10 Epidemiologists**

Representing
**82** municipalities

Over **17** meetings
(and counting!)

Reviewed **6** other state small number guidelines

**2** meetings with outside SMEs

# What has changed since last year?

## Version 1

- Who is an “analyst”
- Assessing small numbers
- Communicating small numbers
- Emergent concern data sharing
- Additional information

## Version 2

- Guidance for local populations under 5,000 and 10-50,000 residents
- Helpful software for data analysis
- Division of content
  - Good Science
  - Good Communication
  - Good Partnerships
- Helpful tips for writing a press release
- Real world data sharing scenarios and guidance

# Common measures in public health surveillance

| | |
|---|---|
| Sex | |
| Age | |
| Race | |
| Time period | When did they get sick? How long were they sick? |
| Geographic location | Where are they from? Where do they work, worship, and play? |
| Case status | Did their illness kill them? |
| Risk factors | Did something in their genetics or lifestyle put them at risk for this illness? |

Which of these are OK to share? When is it appropriate?

# MA Data sharing guidance for populations under 5,000 residents

| *Variable* | **Age** (years) | **Sex** | **Race/Ethnicity** | **Geographic level** | **Risk factors** |
|---|---|---|---|---|---|
| | | | | *County, SSA, or municipality* | |
| **Release?** | **May be released** in groupings like single categories or ten-year age groups. | Binary sex **may be released**. | Advise **against**. | **May be released,** but consider using SSA or county level data. | Advise **against** |
| **Notes** | **Use standardized groupings*** per report or jurisdiction for consistency. | Sensitive information **in counts <5** about behaviors, treatments, or conditions that are considered to be socially stigmatized **must be suppressed from all reports.** | Use trends/risk factors to support results without using small numbers | Can add additional context that is driven by data. | Consider using risk factor **data from larger areas** to support trends (i.e. SSA, county, state) |

| **Time period** | **Case status** |
|---|---|
| **Release?** | May be released, but should vary on condition<br>• **Acute:** monthly<br>• **Chronic**: quarterly or annually<br>• **Both:** Aggregated multi-year trends | Advise **against.** |
| **Notes** | | **Ask:** what are the benefits/drawbacks to releasing vital statistics? |

- Generally, can be released.
- Important considerations prior to any release.
- Advise against release.

# MA data sharing guidance for populations between 10,000 to 49,999 residents

| *Variable* | **Age** (years) | **Sex** | **Geographic level** | **Race/Ethnicity** |
|---|---|---|---|---|
| | | | *County, SSA, or municipality* | |
| **Release?** | **May be released** in grouping of at least 5 years or greater | Binary sex **may be released**. Gender non-conforming data may be released in counts ≥5 if appropriate. | **May be released,** but consider using SSA or county level data. | In populations <15,000 **advise against public release** but may be appropriate for internal use only. In populations over 15,000, may be released only if appropriate and in counts >5. |
| **Notes** | **Use standardized groupings*** per report or jurisdiction for consistency. | Sensitive information **in counts <5** about behaviors, treatments, or conditions that are considered to be socially stigmatized **must be suppressed from all reports.** | Can add additional context that is driven by data. | **Consider how you categorize races, especially with mixed race individuals**. Appropriate uses of local race data: 1) If there is increased prevalence amongst specific groups (i.e. national trends with local translation) 2) If it addresses racial inequities and considers cultural differences 3) If used internally, with thorough discussion and consideration before any public release. |

- Generally, can be released.
- Important considerations prior to any release.
- Advise against release.

| **Risk factors** | **Case status** | **Time period** |
|---|---|---|
| **May be released with caution**. Consider using higher level data. Modifiable risk factors are generally more readily releasable than non-modifiable risk factors. | **May be released if deaths are ≥5.** If deaths are <5, consider sensitivities and populations affected | May be released, but should vary on condition<br>• **Acute:** monthly<br>• **Chronic**: quarterly or annually<br>• **Both:** Aggregated multi-year trends |
| Suppress data if cell size is <5 AND/OR risk factor + geography could risk re-identification | **Consider aspect of sensitivity of cause of death.** This may depend on sub-population and total deaths occurred. **Consider using higher level data** that may be more readily available. | |

# Let’s try a real world scenario!

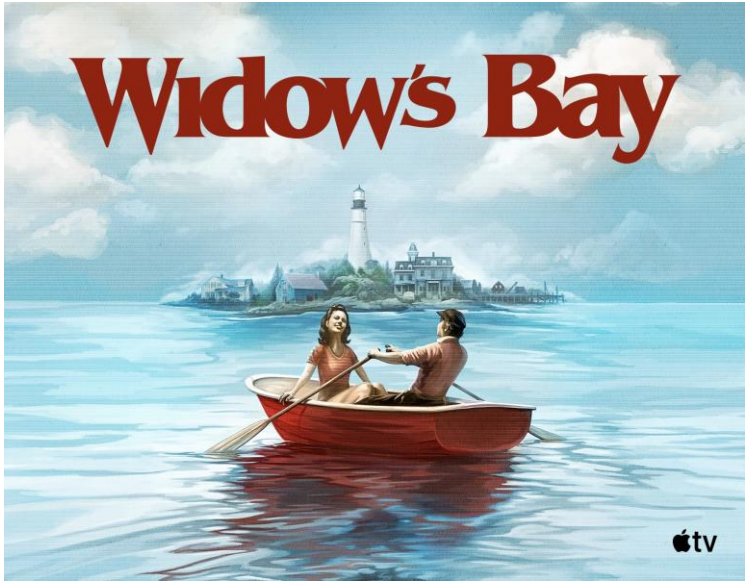


# Welcome to Widow's Bay!

- **Demographics & Governance:** Widow's Bay has a population of approximately 11,000 residents. It is classified as an urbanized rural coastal community. The local health department is staffed by a part-time administrative assistant and one health agent – there is no formal local Director of Public Health.

- **Board of Health (BOH):** The BOH meets monthly and consists of four appointed members (two have clinical/public health backgrounds).

- **Regional Shared Services:** Widow's Bay is a member of the Coastal Public Health Excellence (PHE) Collaborative (representing 4 towns). Through this arrangement, Widow's Bay shares a Public Health Nurse (PHN), a Food Inspector, and a Regional Epidemiologist.



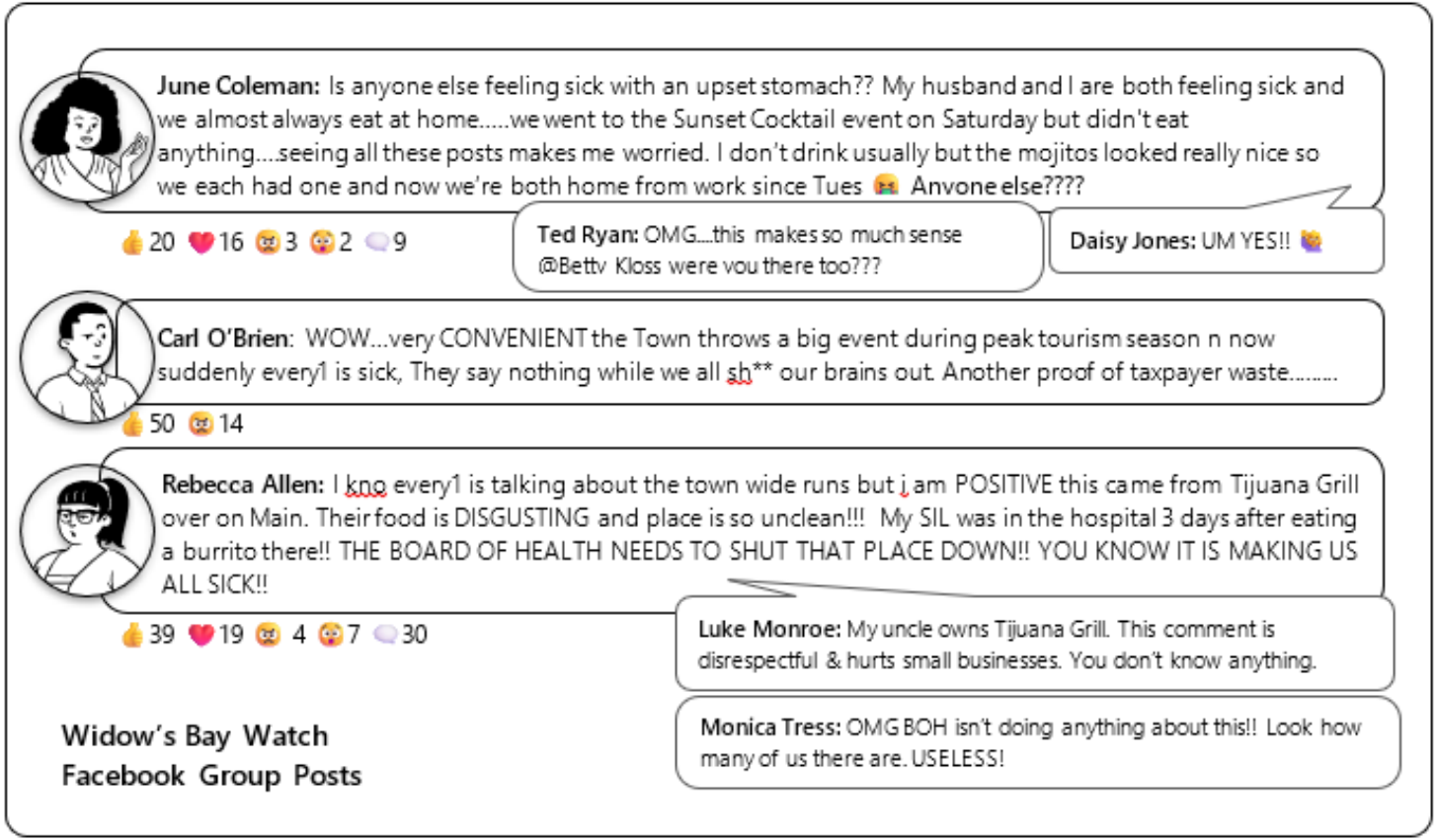
# The Problem

- On Thursday, July 6th, the Widow's Bay Board of Health launched an investigation following multiple reports of foodborne illness linked to a town-wide **Sunset Cocktails** event held on Saturday, July 1st.

- **The initial data collected**:
  - 6 MAVEN notifications of laboratory-confirmed *Salmonella* cases.
  - 11 resident complaints (via phone and office walk-ins) reporting acute vomiting and diarrhea.
  - 1 ReportMyMeal submission citing food poisoning symptoms after attending the Sunset Cocktails event.



# The Pressure



# Let’s discuss

Review the 6 MAVEN cases. Which specific data fields can be shared publicly, and which must be suppressed under Playbook V2 rules? Should Case #3's occupation (prep cook) be disclosed in a press release?

June Coleman posted that she got sick from mojitos without eating food. Should the health department mention suspect items (like mojitos/ice) in an initial release, or keep the message broad?

Residents are demanding the town close Tijuana Grill. Based on inspection findings (0 violations), why is it appropriate to name the Sunset Cocktails event explicitly while withholding restaurant names?

# We want to hear from you!



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Please take a few minutes to complete our feedback survey. Your input is essential to keeping this document accurate, relevant, and applicable to local public health efforts.

Scan the QR code or click the link to provide feedback on the playbook: https://forms.office.com/g/krLkGJiyKW