Signs of Health Equity: Developing public-health survey instruments in American Sign Language

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Conflicts of interest

- No conflicts of interest

Background: How is deafness defined?

- Most data sources define deafness in **audiological** terms
  - American Community Survey: "Are you deaf or do you have serious difficulty hearing?"

- Deaf/hard-of-hearing people do not all use ASL

Background: ASL & Literacy

ASL users are not all fluent in English

- American Sign Language (ASL) is *unrelated* to English

- Data on ASL use and general English fluency are limited, but we know ASL users communicate best in their first language

- Health surveys are nearly always written only

Background: Health Inequities

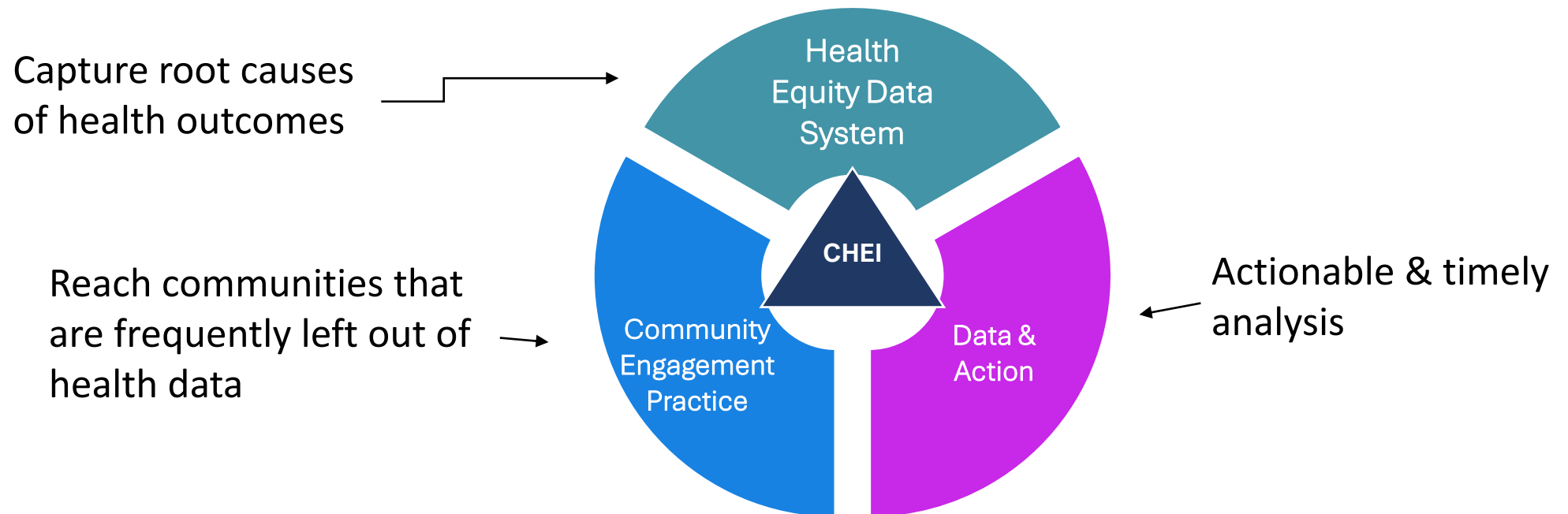## *Limited data on health inequities impacting Deaf people*

- ## Health literacy
  - Knowledge of nutrition, cardiovascular disease, preventive health, etc.

- ## Healthcare access
  - Communication difficulties, lack of access to interpreters & native signers

- ## Little data on outcomes

(Kuenburg et al., 2016; McKee et al., 2011, 2015)

The Community Health Equity Initiative (CHEI)

CHEI promotes the health of MA residents through a **health equity data & response system**

Capture root causes of health outcomes →

Reach communities that are frequently left out of health data →

Actionable & timely analysis ←

Health Equity Data System

CHEI

Community Engagement Practice

Data & Action

Background: The Programs (2)

The Health & Disability Program (HDP)

- HDP helps people across Massachusetts understand and act on health inequities affecting the disability community

- Conducting a large health needs assessment of adults with disabilities in Massachusetts

Methods: The Surveys

Health & Disability Needs Assessment
(August – December 2023)

Community Health Equity Survey
(February – March 2024)

- Similar length: ~60 questions, typical response time 10-30 min
- REDCap

Methods: Animated GIFs (HDP survey)

← GIF showing question

← GIF showing first response, displayed below the corresponding radio button

Methods: ASL Module (CHES)
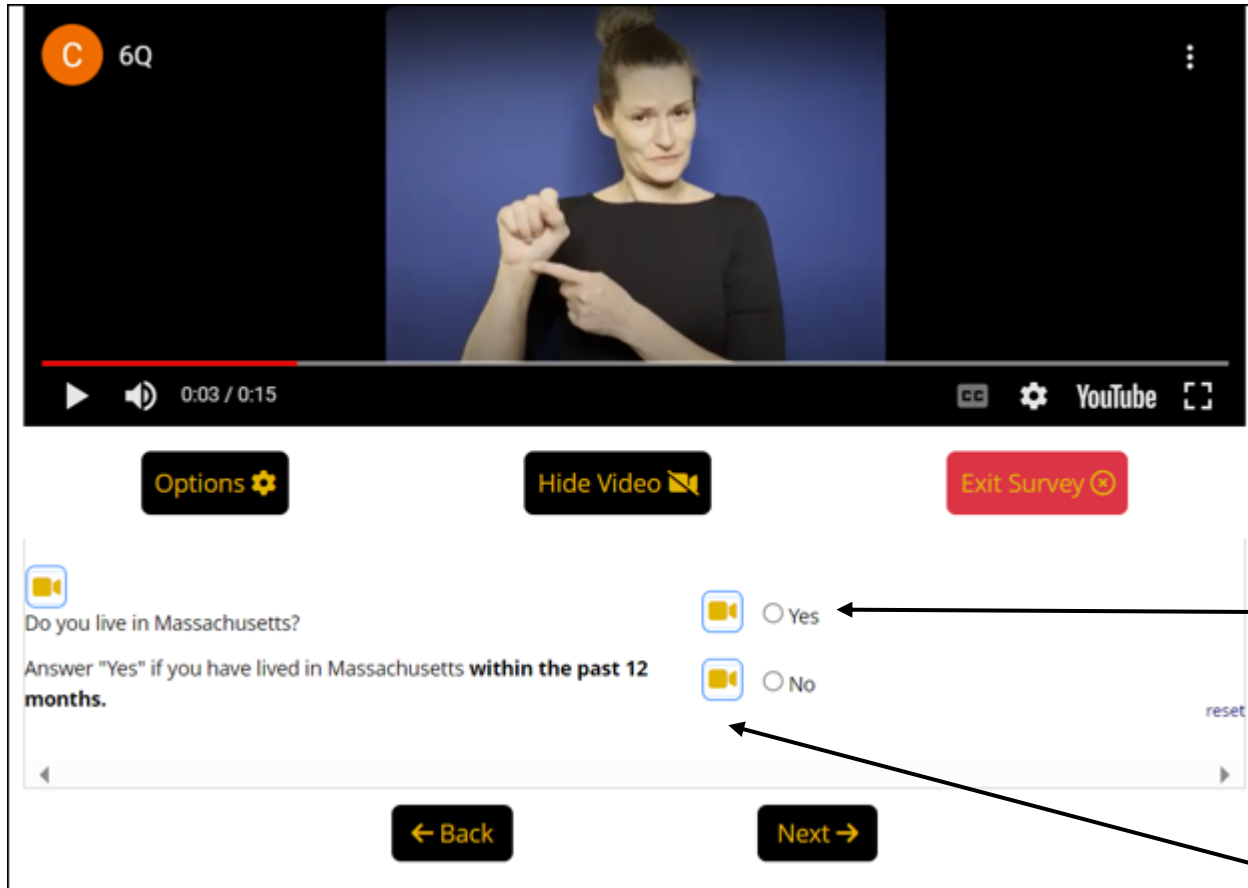
Dedicated video player (Auto-plays question & responses)

Response radio buttons

Buttons to select a video to play

What does the user need?

- Seamless video playing

Feedback: ensure signing begins in the first seconds of each clip

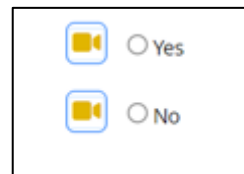## *What does the user need?*

- Matching response options to radio buttons
  - Captioning with English helps

Feedback: ensure caption timing matches exactly

Owned by you or someone in the household with a mortgage or loan

What does the user need?

- High-quality translations
  - Health surveys are likely to include some precise and nuanced concepts that are critical to convey accurately

The ASL User Survey Samples

- Surveys were disseminated in partnership with Advocates, Center for Living and Working, Deaf Inc, Viability

- Total: 108 respondents to the two surveys
  - Includes 87 deaf or hard of hearing respondents

Best Practices for ASL surveys

Effective outreach & understanding tools

- **Involve ASL users** throughout development

- **Research existing tools** and their pros & cons

- **Disseminate surveys** using tailored promotional materials, and create tutorial videos and user resources

Conclusion

- ASL surveys are feasible

- Community engagement is critical

- ASL surveys address a major language access problem

Thank you!

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- The Community Health Equity Initiative is supported by funding from the CDC Immunization and Vaccines for Children Program COVID Cycle 3 and Cycle 4 Supplemental Funding.
- The CHES survey used the Rochester Survey Accessibility module (https://github.com/vanderbilt-redcap/rochester-survey).

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Community Health Equity Initiative
mass.gov/chei

Health & Disability Program
mass.gov/health-and-disability-program-hdp

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