

A group of children in a refugee camp, some making peace signs. The background shows tents and other people, suggesting a camp environment.

# Developing Partnerships for Research and Evaluation

## *Public Health, Community and Clinical Research*

**NARHC 2016**

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# Agenda

- Sign In
- Case study: *Hepatitis C screening and prevalence*
- Professional Speed Networking
- Wrap Up
- Evaluation

# Hepatitis C screening and prevalence among primary refugees resettling in the U.S., 2010-2015

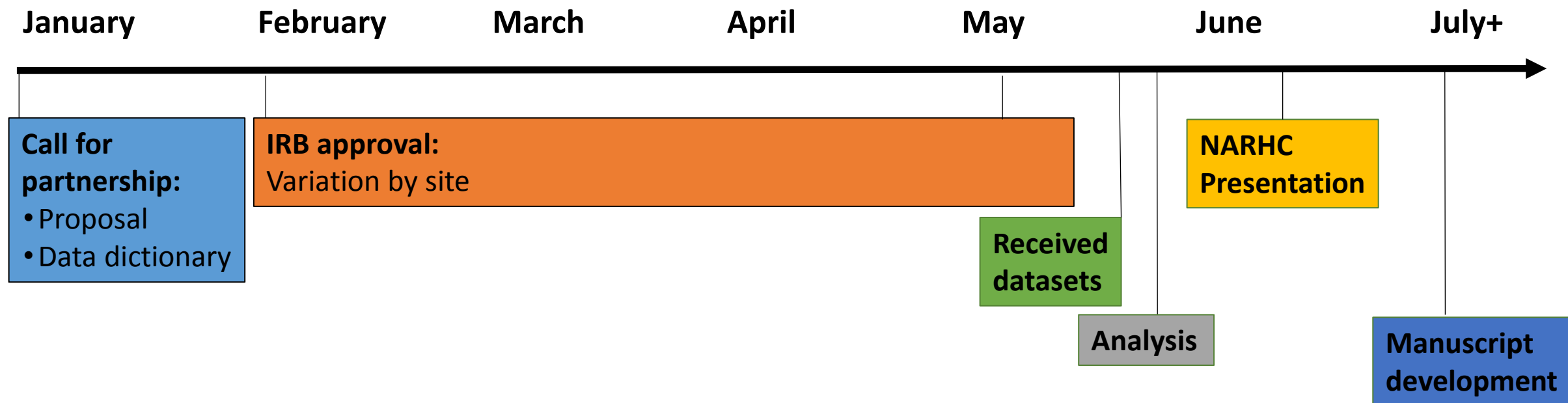
## A multi-site collaborative

Minnesota Department of Health  
Texas Department of State Health Services  
Thomas Jefferson University  
Washington State Department of Health

# Purpose

To estimate the prevalence of Hepatitis C infection among primary refugees and refugee groups resettling to the United States to inform refugee-specific screening standards.

# Project Timeline (2016)



# Challenges and Lessons Learned

Community	Public Health
Clinical	Hybrid

## Data sharing

- Laws and IRB (Institutional Review Board) requirements differ across states and institutions (academic, state, and public health)
- Impact project feasibility and timeline

## *Tips*

- Develop detailed proposal including variables that each site can use for their IRB.
- Allow plenty of time, as some sites will take longer (some have IRB reviews only once a month).

# Challenges and Lessons Learned

Community	Public Health
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## Data Limitations

- Analyses are only as granular as the strictest standard for de-identification allows
  - E.g., some data included year of arrival, not date

## *Tips*

- Meet with all sites early in the project and regularly throughout to develop common standards and ensure good communication
- Consider what data you really need to answer the research question.
- Develop codebook. Have sites provide data dictionaries.

# Challenges and Lessons Learned

Community	Public Health
Clinical	Hybrid

## Data collection variability across sites

- No two screening sites collect information in exactly the same way

### *Tips*

- Ask about data requirements right away, when you're discussing potential collaboration, so you can decide whether the site's data will work to answer your research question



# Challenges and Lessons Learned

Community	Public Health
Clinical	Hybrid

## Data submission timelines

- Timelines for data availability vary, especially for more recent data
- Some sites will have a longer lag time before more recent data is collected and entered

## *Tips*

- Allow flexibility around timeline
- Work with sites to get their most recent complete/reliable dataset

# Challenges and Lessons Learned

Community	Public Health
Clinical	Hybrid

## Role determination: analysis, authorship

### *Tips*

- Discuss expectations up front.
- Have one person in charge of analysis and write-up and everyone else serves as reviewers.
- Consider using students if you have limited staff capacity. For example, students can be used for cleaning and mapping data.

# Strengths

- We were able to achieve a large and diverse sample with just four sites with enough power to detect trends by country, even for a relatively rare disease.
- Our sample size was almost equal to the NHANES US prevalence study of Hep C, allowing for meaningful comparisons against existing datasets on US prevalence of disease.

# Summary

- Build relationships with other sites to learn about their data, capacity, potential to collaborate
- Set expectations early for: authorship, funding, time, data
- Be flexible: create opportunity to collaborate even if you're dealing with a small site
- Engage students (medical, public health, fellows) to assist with data management and analysis
- Repeat collaboration, improve process

# Professional Speed Dating

- 25 minutes total
  - 5 minutes per meeting
- Objective: Start a professional relationship with someone new
  - Exchange contact information
  - Learn a little about where they work & what they do
- Ground rules:
  - Start with someone you don't know
  - Change seats each time the buzzer sounds
  - Have realistic expectations

# Evaluation

