

Partners in Report Back: Roles and Expectations

PEPH Conference December 2018

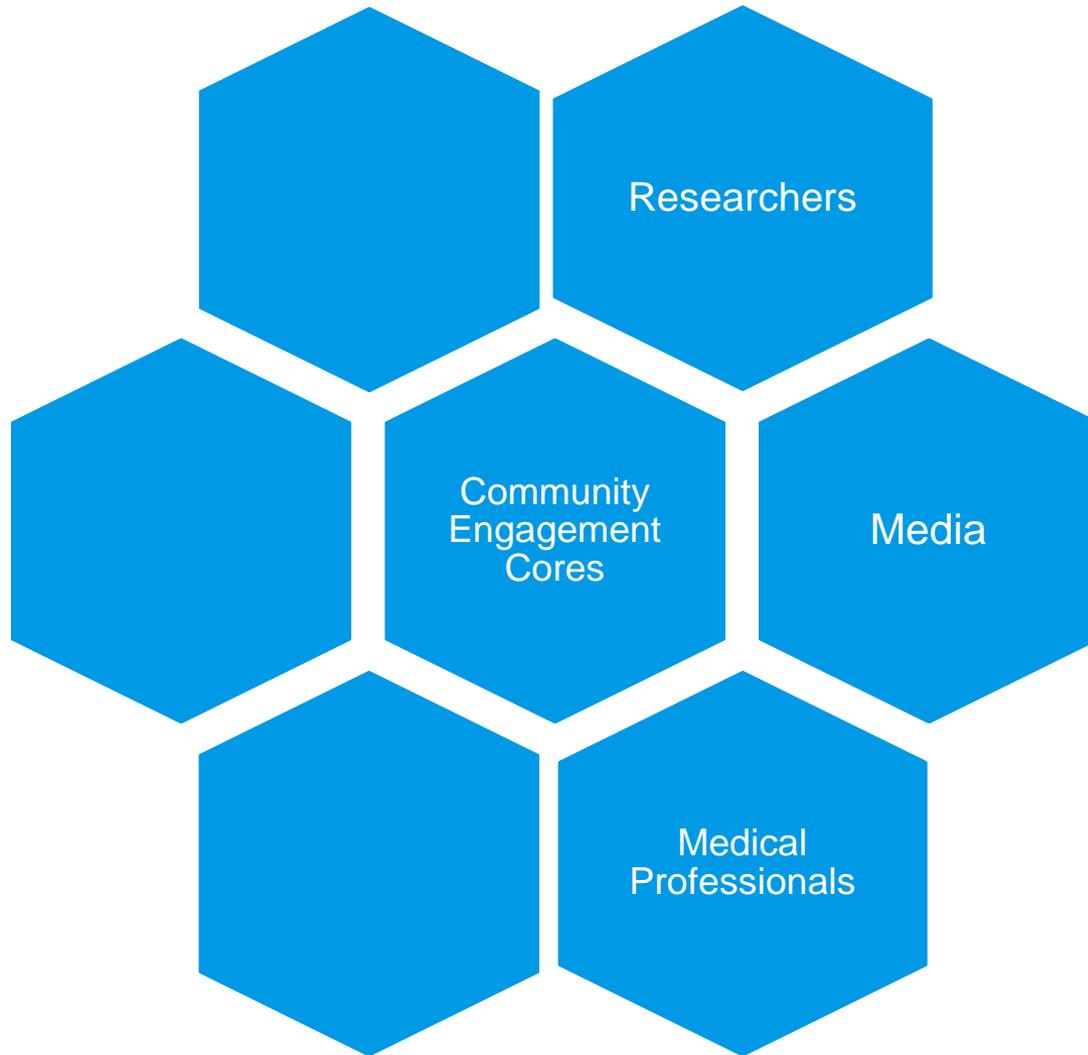
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Director, Community Engagement Core



Aims: Understanding Challenges and Solutions

- ◆ **Marilyn Howarth-** Partners in Report Back: Roles and Expectations
- ◆ **Robert Laumbach-** Barriers and Challenges to Report Back from the Medical and Public Health Perspective
- ◆ **Rebecca Fry-** Barriers and Challenges to Report Back from the Toxicologist Perspective
- ◆ **Susan Pinney-** Dilemma in Reporting Back When the Values are Very High

Who are the Partners in Report Back



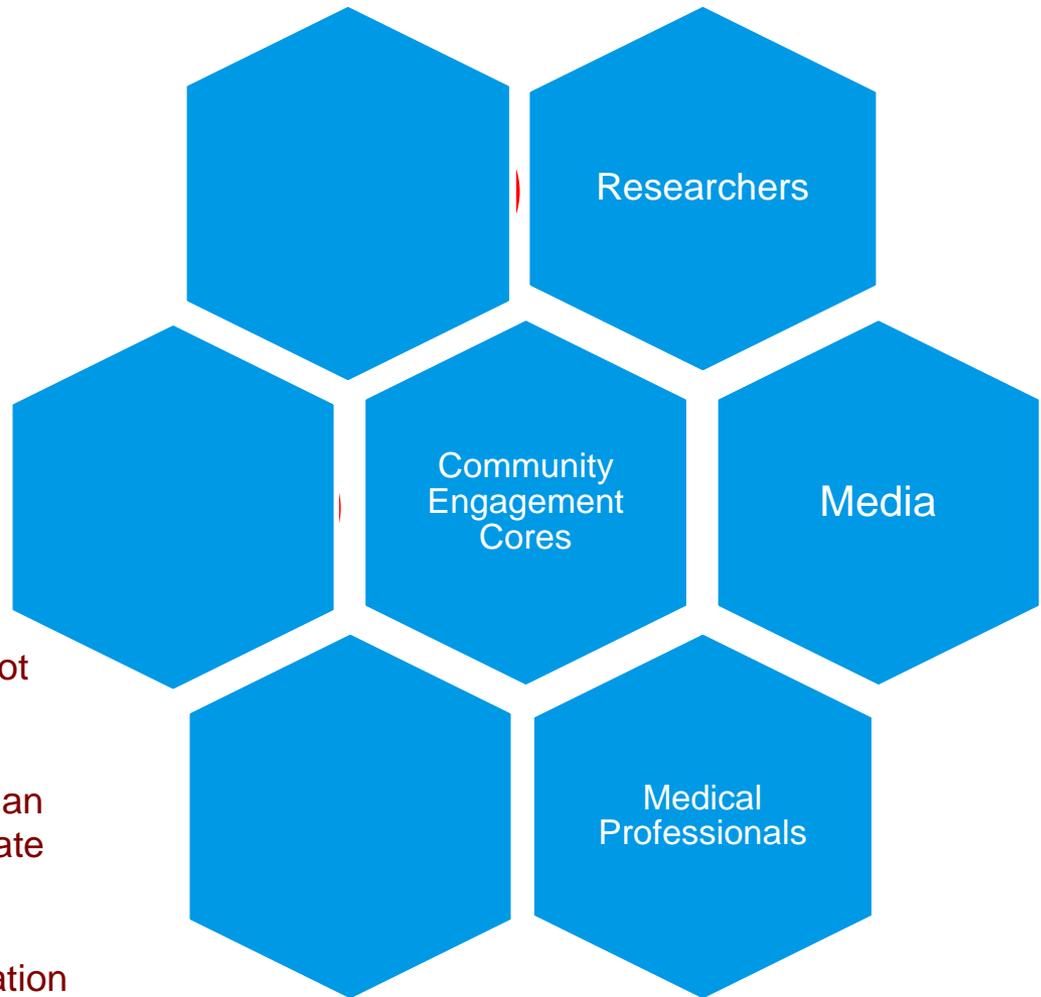
Roles and Expectations

Roles:

- Engaged from the beginning (CBPR) framing the research question and performing the research
- Help to craft the report back strategy
- Trusted communicators of information

Expectations:

- Have their questions and concerns addressed
- Learn results before others or decide not to receive results
- Expect researchers to communicate in an understandable and culturally appropriate way
- Expect results to have personal application
- Receive data that can support advocacy



DERBI

Digital Exposure Report-Back Interface

1. Personalized headlines

Chemicals We Found

- 1 Your sample had more [flame retardants](#) than most others in the study.
- 2 Your sample had more [old pesticides](#) than most others in the study.

All your results:

[Pesticides](#) [Flame Retardants](#) [PCBs](#) [PFCs](#) [Lipids](#)

4. Options for action



Home

What you can do in your home

Try to keep dust levels low. For example, wipe surfaces with a damp cloth and use a vacuum with a HEPA (high-efficiency particulate air) filter to prevent dust from recycling into the air.

2. Chemical exposure information



Your Results: Flame Retardants

Chemicals added to many products to make it harder for them to catch fire.

[Click here to jump to your results](#)

Where do these chemicals come from?

Flame retardants are used in some furniture cushions...

Why might these chemicals be a health concern?

PBDEs affect thyroid hormones and the brain and nervous system, so they can affect brain development and IQ, weight, depression, energy, and muscle control...

How can I reduce my exposure?

- Fix rips in furniture so foam isn't exposed...

3. Individual results plots

PBDE99



Each gray circle represents a woman that didn't have a detectable level of PBDE99 in her blood.



Roles and Expectations

Roles:

- Help to craft the report back strategy
- Frame the implications of the results
- Engage with Medical, Public Health professionals and Media to describe work



Expectations:

- Stakeholders will be interested and engaged
- CEC members will design report back strategies
- Medical and public health professionals will assist in explaining health implications to community members



Data Box Sample, near Pascagoula, MS

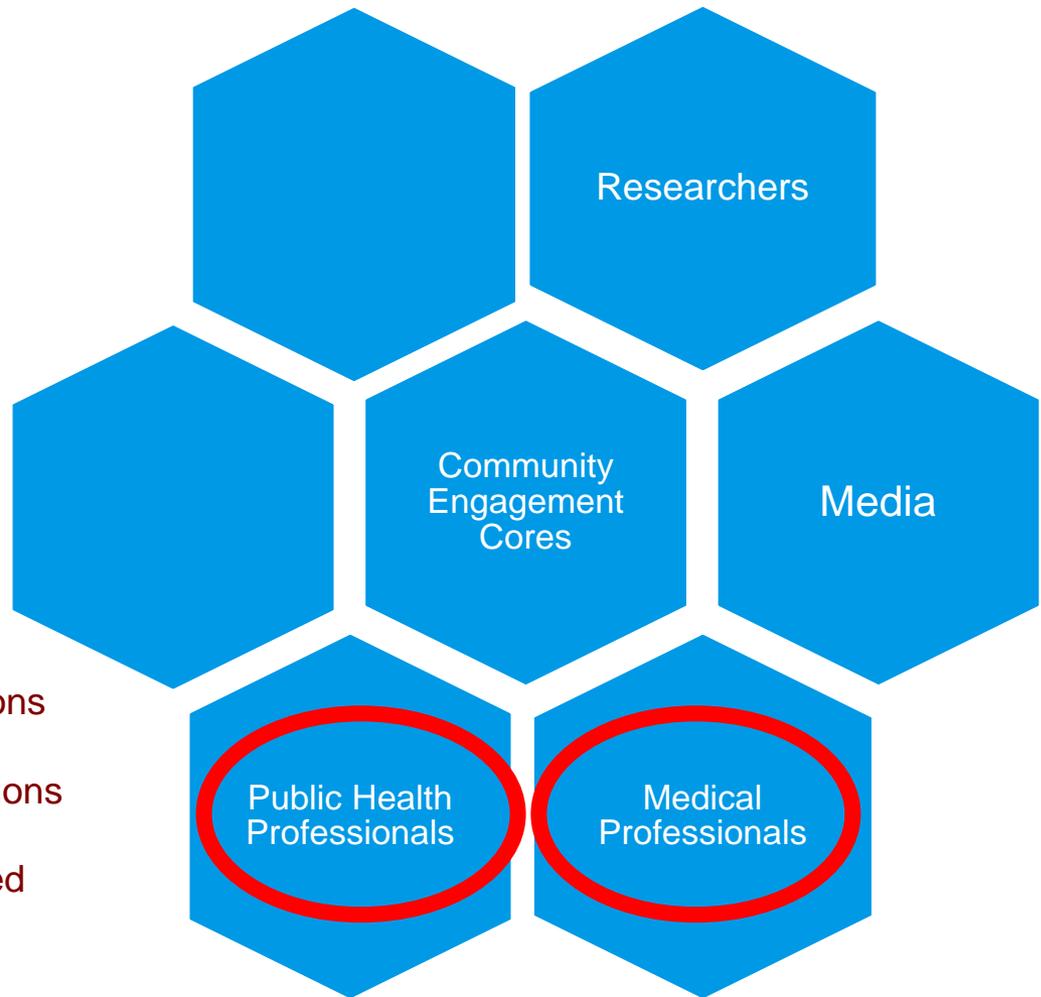
Roles and Expectations

Roles:

- Receive study information and communicate meaning with patients or community
- Help to craft the report back strategy
- Public Health Professionals may be prompted to do additional study
- Medical Professionals may alter practice or patient advice

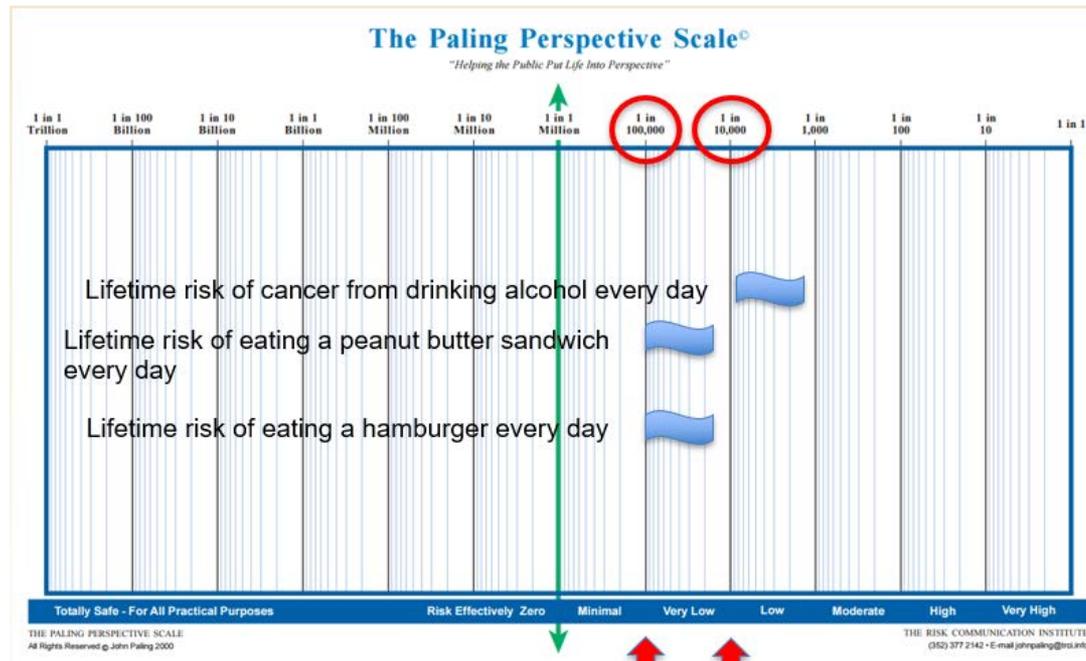
Expectations:

- Researchers will provide enough information to understand the implications
- Researchers will be available for questions
- Patients will have already been informed about the purpose, limitations and implications



Helping Individuals Estimate Personal Risk

- ◆ Personalizable calculator was designed
- ◆ Incorporates data from seafood sampling on Petrogenic PAHs
- ◆ Allows individuals to determine the level of risk they are comfortable with
- ◆ Allows individuals to enter their weight and seafood eating habits



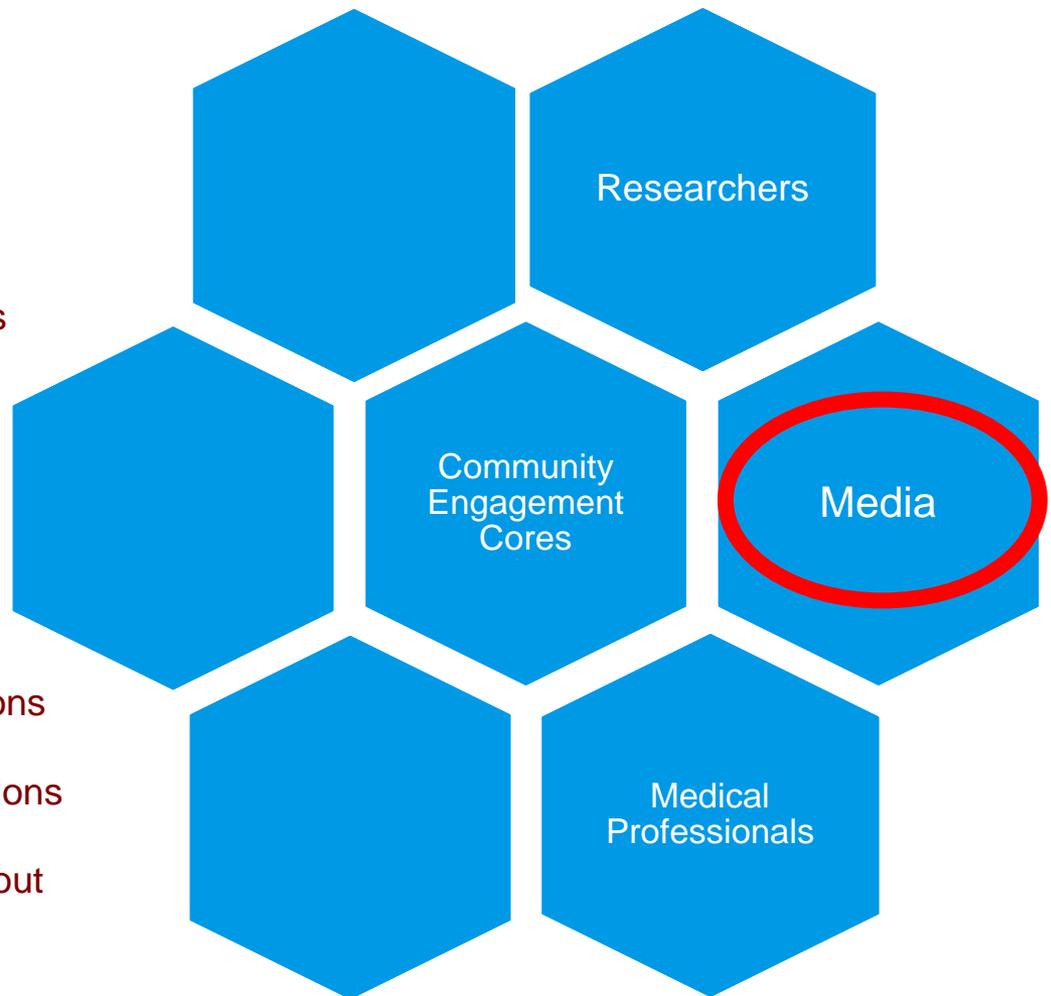
Roles and Expectations

Roles:

- Receive study information and communicate to the public
- Help to amplify message
- Apply pressure to regulatory authorities to stimulate public health action

Expectations:

- Researchers will provide enough information to understand the implications
- Researchers will be available for questions
- Find an 'Angle', something exciting about the findings



5 questions: Your exposure to cancer risk factors in Philly could be killing you

by Sandy Bauers, For The Inquirer, Posted: February 3, 2017



MARY LEONARD / U. OF PENNSYLVANIA

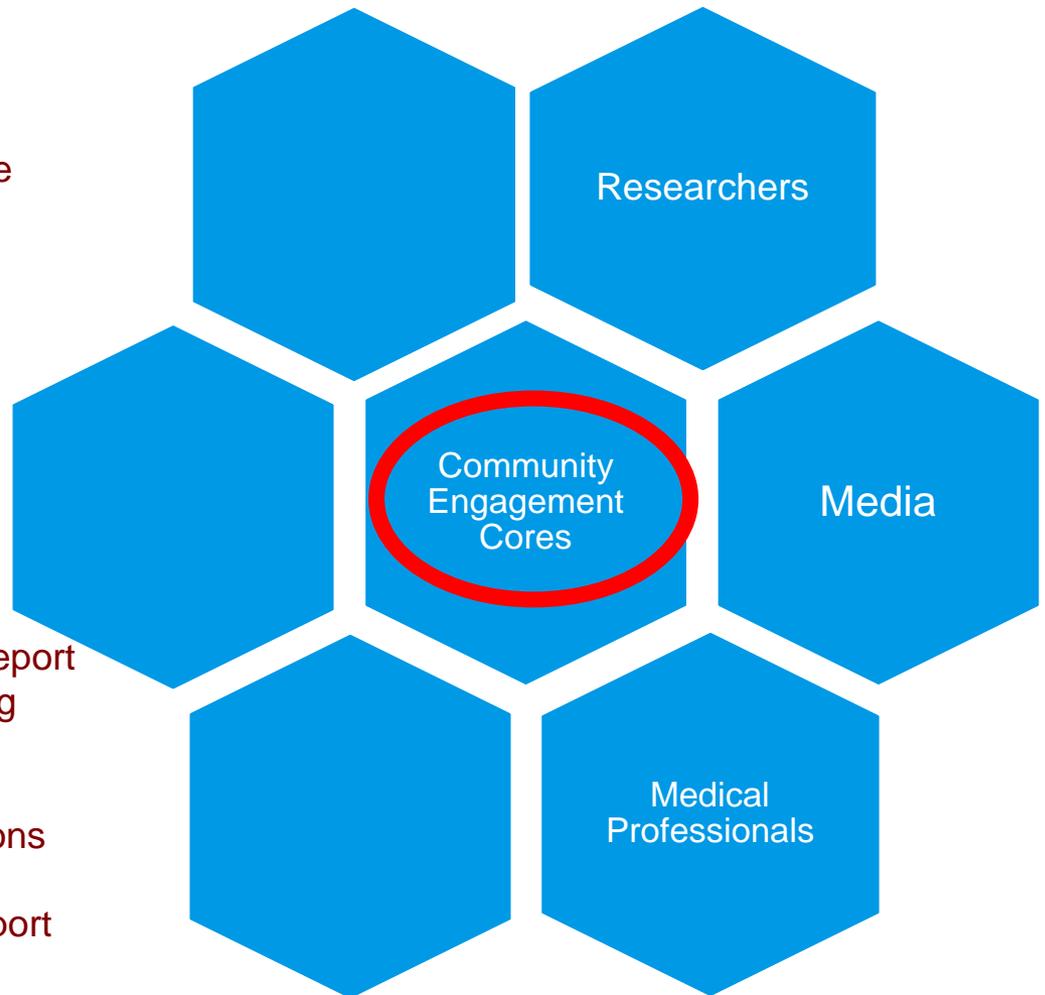
Roles and Expectations

Roles:

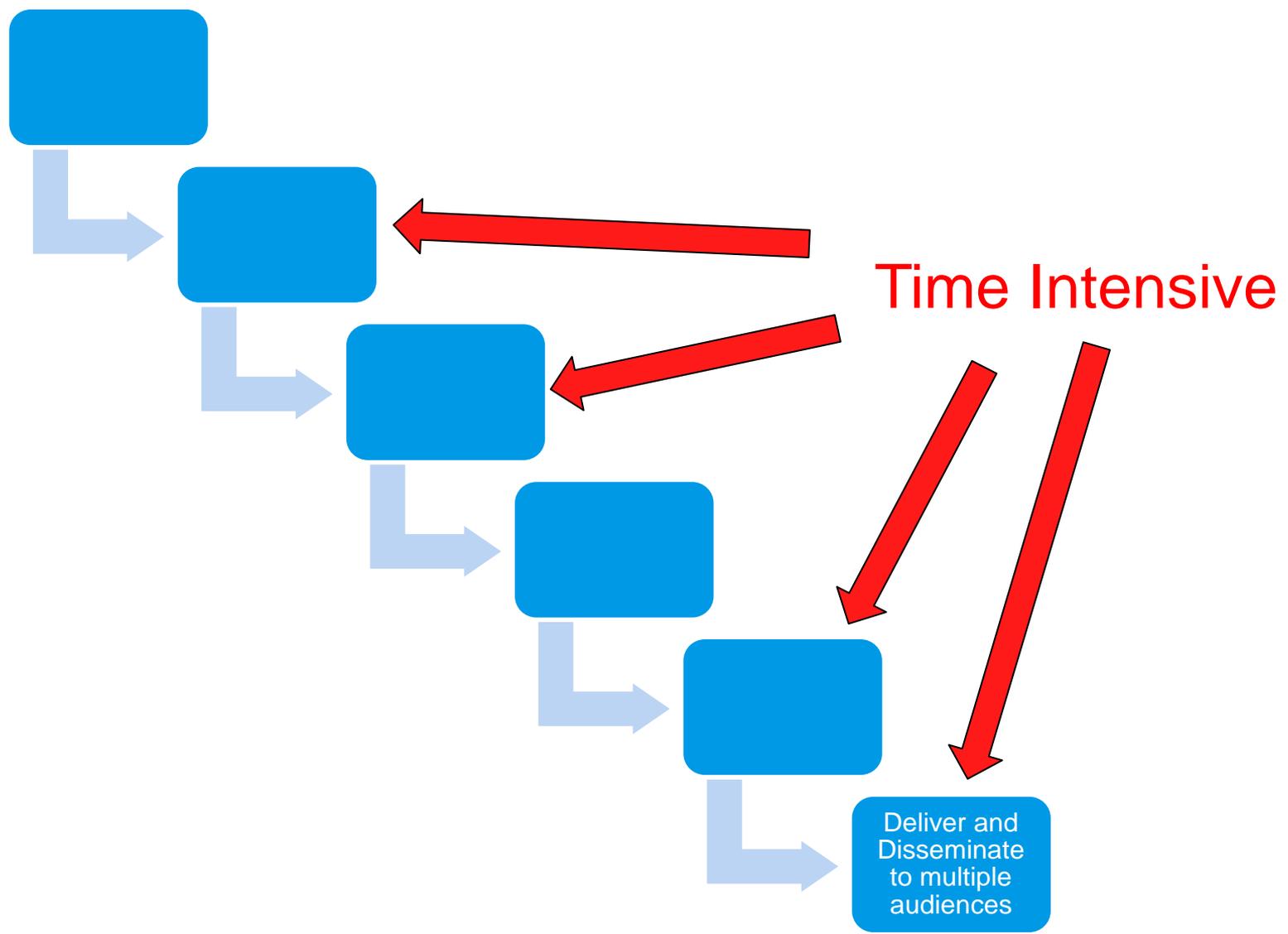
- Provide training to researchers to enhance capacity for report back
- Work with community partners to shape the message
- Identify appropriate stakeholders to shape and receive the report back
- Engage communities around report back information

Expectations:

- Researchers will include CECs in the report back strategy design from the beginning
- Researchers will provide enough information to understand the implications
- Researchers will include funding for report back materials and work by CECs



Steps in CEC Report Back Design



Thank you



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