



Biobanking Training

MAKING SURE THAT THE BEST OF SCIENCE
REACHES ALL OF OUR COMMUNITIES

Developed by the PLANET MassCONNECT Team, 2019; Funded by the National Cancer Institute (U54 CA156732)
Content draws on trainings from the National Cancer Institute, CDC, Fred Hutchinson Cancer Research Center, and cited sources

Today's agenda

Introductions

Overview of U54 Outreach Core



Resource review

Lunch

Working session to adapt a small group discussion guide

Logistics and next steps

Introductions

Please share:

- Your name
- Your organization
- One thing you love to do in the summer



PLANET MassCONNECT

Outreach Core of the U54 Partnership



Boston Alliance *for*
Community Health



Brazilian Worker Center

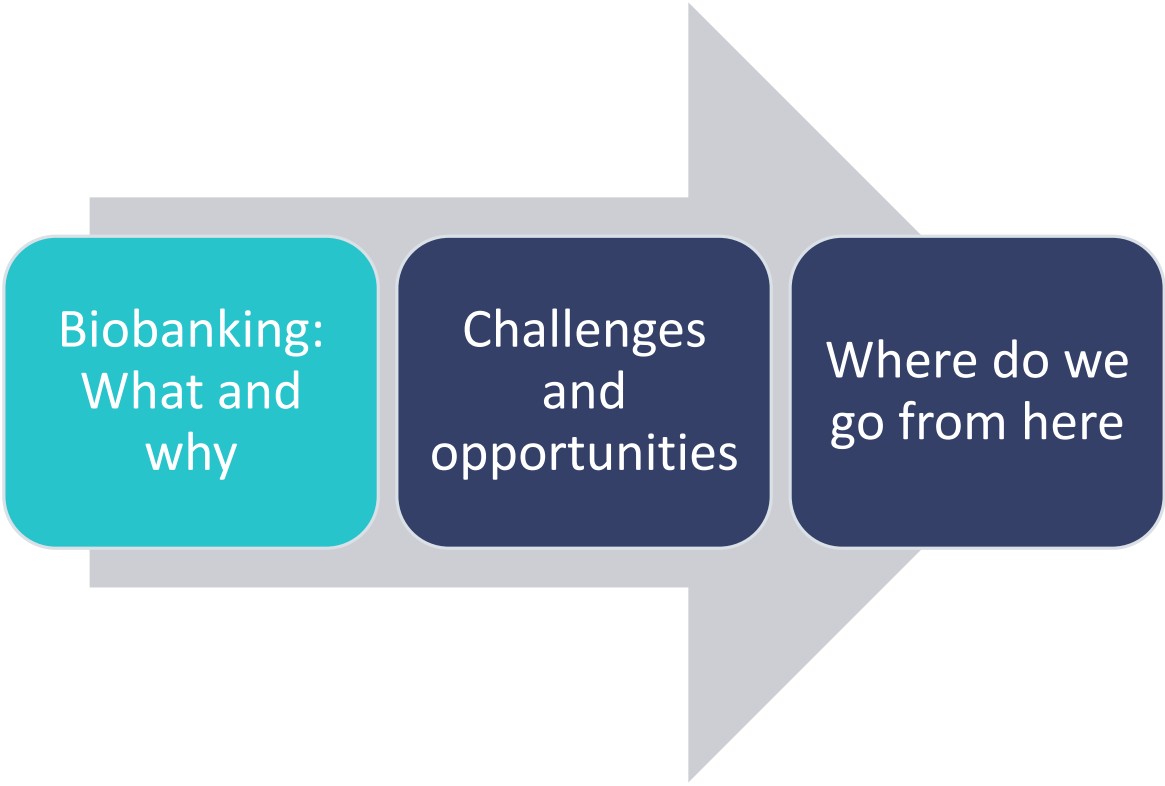


Greater Love Tabernacle
"The Church with A Heart for People"



What we can offer

- Trainings and technical assistance (TA) on
 - Using evidence-based programs
 - Biobanking education (plus mini-grant)
 - HPV education (plus mini-grant) – *coming soon*
- Localized website for program planning: www.planetmassconnect.org
- Quarterly newsletter
- Outreach programs
 - Colorectal cancer
 - Breast cancer
- Science cafés



Biobanking:
What and
why

Challenges
and
opportunities

Where do we
go from here



Biospecimens

- Tissues (such as skin and hair)
- Fluids (such as blood and urine)

Collected through

- Blood draw
- Cheek swab
- Urine collection
- Biopsy
- Surgery



Photo credits: Katherine Briant | Source: Fred Hutchinson Cancer Research Center

How would someone donate?

Who: Anyone can be considered for donating biospecimens.

What: A person can donate samples, including skin cells, urine, and blood.

When: Linked to a surgery / procedure or through a sample donation process.

With what permissions: Informed consent must be provided before a biospecimen is collected.

A range of questions to answer

Why does cancer develop?

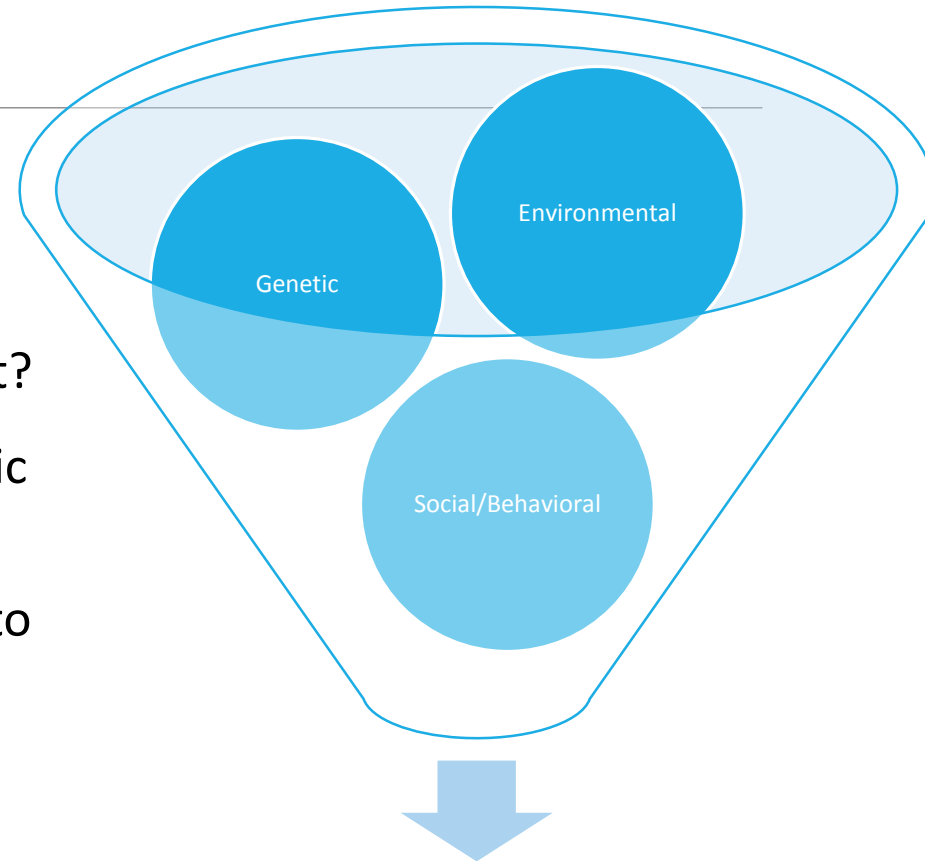
How does cancer grow?

Who is at greater risk of developing it?

How best can we get a drug to specific cells?

Which patients are most/least likely to respond to specific drugs?

To develop screening tests to detect certain stages or types of a disease



Health or Disease

Example: Targeted therapies

EGRF-2





Biobanking:
What and
why

Challenges
and
opportunities

Where do we
go from here

Getting to “all of us” takes all of us





More information at: <https://www.broadinstitute.org/count-me-in>

Video: <https://www.youtube.com/watch?v=qF77K31u-ww>

Mistrust

Conversations in your community?
How might you find a starting point?

[There's] already a preconceived notion [by] most of the community about health professionals and research- we're harvesting body parts... They immediately think of things like Henrietta Lacks, where John Hopkins harvested her cells without her family's consent. There is a need to do it. I completely agree. But there are those in the community who would say, nope, we can't do that, nope.

- Boston area church leader

Belmont Report

Issued in 1979 by a national commission

Sets forth three principles for the ethical conduct of research:

- Respect for persons
- Beneficence
- Justice



What is informed consent?



Photo credit: Rhoda Baer | Source: NCI

A document

A process

It should:

- Provide adequate information
- Ensure participant understands information
- Include voluntary consent

Informed consent for biospecimens

Collection of the biospecimen(s)

- Ex) how the sample will be taken, potential impacts to collection site, storage and use plans

Anticipated use(s)

- Ex) how long will it be kept, will it be available to other researchers

Findings from the research using the biospecimen(s)

- Ex) What will happen with finders, will donors be contacted

Brainstorming: Addressing barriers to participation

Privacy levels and risks

Privacy levels

- Identified – linked to an identifier, such as a medical record number
- Identifiable – can be linked back through a code
- Anonymized – personal information is unlinked
- Anonymous – no personal information is collected

Risks

- Pain at the excision site, bruising or swelling at the excision site, and possible infection.
- Non-physical risks include the potential loss of privacy, and breach of confidentiality as a result of the release of information from a person's health records.

What happens after research is completed?

Research results may not be ready for many years.

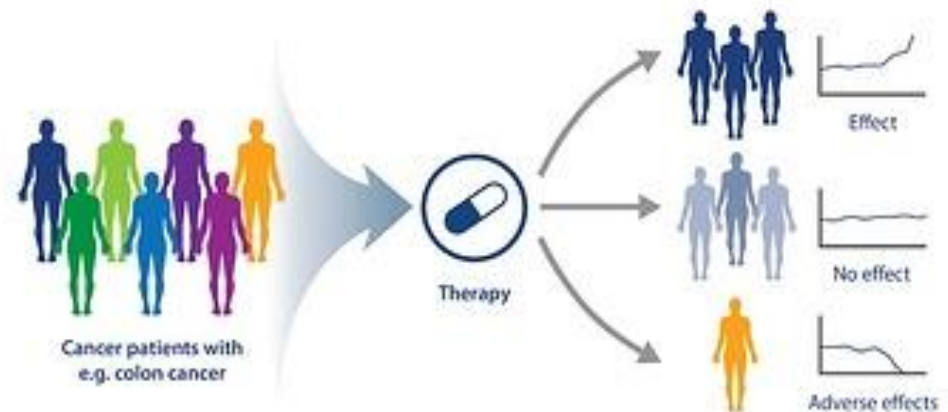
Donors receive results of own medical tests, but usually not results of research performed with leftover tissue.



All of Us Initiative

Current Medicine

One Treatment Fits All



Future Medicine

More Personalized Diagnostics





+ Engaged, partnered activities in communities

Adaptation exercise

Use our
step-by-step approach

Find resources

Get help

Sign up for
a training



Overview of
www.planetmassconnect.org

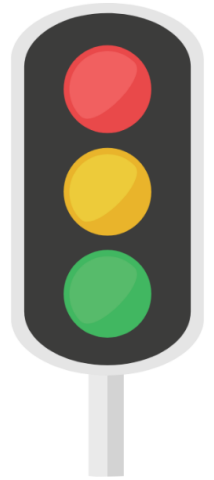
Adaptations

GO AHEAD

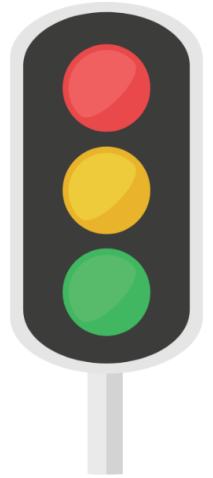
- Update statistics
- Customize scenarios
- Change word choices / language
- Modify activities
- Replace images
- Replace cultural references
- Use different outreach methods

PROCEED WITH CAUTION

- Change session number/length/order
- Lower participant engagement
- Eliminate key messages or skills
- Remove topics or sections
- Use untrained staff or volunteers
- Use too few staff



Adaptations (cont.)



AVOID THESE

Delete core components or whole sections of the program

Reduce program timeline or dosage

Change the health topic or behavior

Change the underlying theory or model of change

Contradict or compete with program goals

Adaptation exercise

Please work in pairs to adapt the small group discussion guide for your organizations.

If you are here with someone else from your organization, please work together.

Reporting back

Population served

Unique context / concerns

Kinds of changes you will make

Wrapping up

We will be in touch soon to help you report back.

Please reach out for help planning / running your event – we are ready to help!



Additional resources for requests
made during July 2019 training

The Belmont Report: Ethical Principles and Guidelines for the Human Subjects of Research

Respect

Definition: *an act of giving particular attention or consideration*

The principle of respect is captured in the consent process

Respect for persons requires the following:

- Acknowledgement of the subjects independence as an individual, and
- Protection of subjects who lack the capacity to make independent decisions



Vulnerable subjects are often individuals with little or no independence (ie they cannot fully participate in the consent process) and require additional safeguards to protect them from harm. Examples of vulnerable populations include: Prisoners; Children; Mentally disabled; Individuals with dementia or an acute illness; Students, including college students; Employees; Immigrants

The process of informed consent: Information, Comprehension and Voluntariness

Informed Consent includes the specific components in both the written consent and in the consenting process.

The written consent:

- Is in a language understood by the participant population
- Written in easy to understand lay language

The participant:

- Has time to read it and ask questions
- Time to consider the options presented
- Opportunity to agree or refuse to join the study
- Is made aware they can withdraw at anytime and participation in the study is voluntary

For participants who are unable to consent due to lack of capacity to make decisions, there is a process called assent. This gives those individuals the ability to say no to being involved in the study.