ISBER is the only global forum that addresses harmonization of scientific, technical, legal, and ethical issues relevant to repositories of biological and environmental repositories.

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Member Benefits:
- Reduced registration rates for society meetings
- Subscription to Biopreservation and Biobanking (BIO) Journal
- Access to tools and resources such as ISBER Best Practices
- Connect globally with ISBER members-only forums
- And much more!
Public Education for BioBanking

Suzanne Vercauteren – Director, BC Children’s Hospital BioBank
Sheila O’Donoghue – Biobank Leader, BC Cancer Agency, Chair of ISBER Education and Training Committee
Tamsin Tarling – Manager, BC Children’s Hospital BioBank
Objectives

• Describe the importance of public education about biobanks
• Report on a public education workshop we hosted at ISBER in May 2017
• Hear webinar participants thoughts on public education
Time line

• Presentation: 25 minutes
• Results from ISBER Public Education Workshop: 15 minutes
• Group discussion and questions: 20 minutes
Public Engagement

Public engagement is "the involvement of specialists listening to, developing their understanding of, and interacting with, non-specialists"
Why is public engagement important to biobanks?

• Educates public
• Develops trust
• Opportunity to provide opinions
• Forum for discussion
• Informs Policy
• Promotes research
• Increases participation
• Develops ongoing “relationship” with participant/family
History of Public Engagement Biobanks

• Historically the public have participated solely in a passive way as donors participants

• In the past 20 years there has been an effort internationally to engage the public as partners/decision makers
Patient Oriented Research

• Patient-oriented research approach

• A continuum of research that engages patients as partners, focusses on patient-identified priorities and improves patient outcomes.

• SPOR is a coalition of federal, provincial and territorial partners – all dedicated to the integration of research into care
Public education

- There is now a requirement for a patient engagement framework

- Education is required in order to have research-literate public so they can work and communicate effectively and meaningfully with researchers
Public Research education
What have we done so far in regard to public education?
Literature review results - 2015

- 1911 articles
- 77 articles selected as relevant (health care, biobanks or public input)
- 14 articles describing previous public engagements

<table>
<thead>
<tr>
<th>Engagement method described</th>
<th>Number of articles reporting on method</th>
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<tr>
<td>Participation (governance)</td>
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<tr>
<td>Novel methods</td>
<td>5</td>
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<td>Knowledge translation</td>
<td>2</td>
</tr>
<tr>
<td>Public deliberations</td>
<td>8</td>
</tr>
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</table>
Patient and public engagement at BCCH and in Vancouver schools
Survey Design

Recruitment of hospital outpatient and school participants
Adolescents aged 14-18 at the time of survey completion, and their parents
Parents have to consent for the adolescent to participate!

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### BioBanking Form

- **Purpose:** Collection and storage of human samples for research purposes.
- **Consent:** Required prior to submission.
- **Contact:** Information about the BioBank is provided for any queries.

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### Questions

1. **Age:**
   - Gender:
   - First 3 digits of postal code:

2. **Location:**
   - School:
   - BC Children's Hospital
   - Oncology Clinic
   - Cardiology Clinic
   - Orthopedic Clinic

3. **Previous Knowledge:**
   - Before participating in this survey, had you heard of a BioBank before?
     - Yes
     - No
     - Uncertain

4. **Consent:**
   - If you answered "Yes" or "Uncertain", what did you think a BioBank was?

5. **Medical Conditions:**
   - Do you have any chronic medical conditions for which you see a doctor on a regular basis?
     - Yes
     - No
     - Uncertain
   - If yes, what medical condition(s)?

6. **Medication Use:**
   - Are you currently taking any doctor-prescribed medications?
     - Yes
     - No
     - Uncertain

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### BioBanking Notes

- **Data Privacy:** Data is protected under strict confidentiality guidelines.
- **Ethical Considerations:** The BioBank follows ethical standards for participant welfare.

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### Additional Questions

7. **Sample Consent:**
   - Would you be willing to give an additional sample of blood or similar sample for research purposes?
   - Yes
   - No
   - Uncertain

8. **Sample Consent:**
   - Would you be willing to have an extra procedure performed (e.g., a poke to take a tube of blood) for research purposes?
   - Yes
   - No
   - Uncertain

9. **Sample Consent:**
   - Would you be willing to give any samples, such as blood that are left over from medical tests for research purposes?
   - Yes
   - No
   - Uncertain

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### Contact Information

- **Website:** www.isber.org
- **Email:** info@isber.org
- **Phone:** 1-800-555-5555

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### Footer

- **Connecting Repositories:** Globally through Best Practices
- **ISBER Since 1999**
Survey Demographic

- Male:Female ratio of respondents ~1:1

<table>
<thead>
<tr>
<th>BCCH CLINIC COUNTS</th>
<th>Adolescent surveys</th>
<th>Parental surveys</th>
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<tr>
<td>Cardiology clinic</td>
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<td>30</td>
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<td>School 2</td>
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<td>School 3</td>
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<td>19</td>
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<tr>
<td><strong>Subtotals</strong></td>
<td><strong>116</strong></td>
<td><strong>104</strong></td>
</tr>
</tbody>
</table>
Have you ever heard of a biobank?

Adolescents: Have you ever heard of a biobank before?

Parents: Have you ever heard of a biobank before?
Would you be willing to donate samples to a biobank?

![Bar chart showing % participants willing to donate samples]

- Leftover samples
- Extra sample during medical procedure
- Sample from extra procedure

Legend:
- Clinic Adolescents
- Clinic Parents
- School Adolescents
- School Parents

Significance levels:
- *P < 0.01
- †P < 0.001
Conclusions

• First survey gathering opinions of adolescents and parents about biobanking
• Most survey participants had not heard of a biobank
• Most adolescents and parents are willing to donate samples

Extended school survey

• Previous survey - assume that clinic participants are more willing to donate to a biobank because of prior education about research
• Surveyed adolescents and parents in high schools after giving them a 15 minute education session about biobanking
• Compared the opinions with adolescents and parents who had not received this prior education
## School Survey Demographic

<table>
<thead>
<tr>
<th></th>
<th>Adolescents</th>
<th>Parents</th>
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<tbody>
<tr>
<td># responding to survey with no prior</td>
<td>219</td>
<td>176</td>
</tr>
<tr>
<td>education session</td>
<td></td>
<td></td>
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<tr>
<td># responding to survey with 15 minute</td>
<td>106</td>
<td>44</td>
</tr>
<tr>
<td>education session</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Total</td>
<td>325</td>
<td>220</td>
</tr>
</tbody>
</table>
Preliminary results

• Parents who watched the video (education) are more willing to donate under all three conditions than parents that did not watch the video (P<0.02)

• Adolescents who had/did not have prior education are equally willing to donate under all three conditions.

• After an education session, adolescents thought reconsent was less important than their parents (P=0.01)
Challenges and Limitations

• Recruitment rate is low (~25%)
• Consent is an issue
• We don’t know that parents watched the video
• Parents that do watch video may inherently have more interest in research
Giving patients and healthcare providers a voice in pediatric biobanking

Project funding provided by CIHR SPOR Patient Collaboration Grant and BC Children’s Hospital Foundation
Project Objectives

- Engage the community as partners in research.
- Understand patient and public opinions on biobanking practices
- Understand needs and opinions of clinicians and researchers

→ Utilize this knowledge to compile recommendations and improve biobanking practices.
Project process

Phase 1: Focus Group

Gather opinions from patients and advocates on biobanking, and refine questions/topics/wording for the interactive workshops

Phase 2: Three Workshop Events

Based on results of focus groups, discuss biobank topics of interest with:

- General public,
- BioBank participants and patients/families,
- Pediatric health professionals and researchers

Phase 3: Town Hall Meeting

Present findings to general public and stakeholders
Examples of questions asked:

- Is research important to you?
- What information is important to hear when you are being asked to participate in research?
- How do you feel about biological samples (i.e. blood samples) being stored for future research?
- What role does a biobank have in medical research?
Preliminary Themes identified in workshops

- Themes we identified in patient and public workshops were remarkably similar
  - Altruism
  - Privacy and confidentiality concerns
  - Benefits outweigh risks

- Patient group has more to say and more experience to draw upon
Themes identified in workshops - adults

- Research is important
- Often there is a lack of awareness of research opportunities
- Concerns included appropriate use of samples
- General feeling of trust in biobanks
- Timing of consent is important
- Interest in hearing about biobank studies
Themes identified in workshops – adolescent (14-18 yrs)

- Research is important
- Willingness to participate
- Consent
  - Concern over lengthy consent forms
  - Understandable
  - Prefer to hear from someone they know
- Biological samples and data useful together
- Interest in hearing about biobank studies with opt in/out option
- General trust of biobanks
- Need for better education about biobanks
Themes identified in workshops – children (11-13 yrs)

- Most participants were not aware of research before the session
- General agreement research is important
- Consent should be visual
- Willingness to participate in a biobank if does not conflict with other things
- Wanted feedback if their sample was able to help others, also wanted an official thank you after donating!
- Opt in/out of newsletter
- Increase in education/advertising about biobanks required
- General feeling of trust about samples and health information
A Collaborative Initiative to Integrate Mental Health Research Efforts with Clinical Care

A project funded by the Michael Smith Foundation for Health Research (MSFHR)
Overview of the MSFHR Project

• Aim: to identify barriers and facilitators of participation in Mental Health Research and Biobanking from a patient, parent and healthcare professional perspective.
ISBER Public Education Workshop
What Did We Do?

• Conducted an interactive workshop
• Gave a background presentation on biobank and public education
• Had 6-8 participants at round tables discussing 4 questions per table
• Allowed 20 minutes per question
• ISBER members registered to attend
• We recruited 8 member of the public to attend
What did the attendees say?
Why is public education about biobanks important?

- It is important to know what a biobank is and isn’t
- Having an engaged community has direct and indirect benefits
- Make it a partnership to facilitate mutually beneficial improvements
- Gain public trust and general awareness
What is the overall goal of a public education campaign?

Short-term goals

• Educate public on biobanks and their role in medical research
• Marketing standpoint – make it a normal household word
• Create a shared definition of a biobank
• Reach a diverse population with a culturally sensitive message
• Clarifying misinformation
• Create a common vocabulary
• People need to know what a biobank is-> in order to increase awareness and participation
What is the overall goal of a public education campaign?

Long-term goals

• Better enable new treatments
• Raise the profile of biobanking
Who should oversee a biobank public education campaign?

- A **committee** with representatives from biobanks, bioethics, community, schools, pharma, researchers, lawyers, communications

- **Purpose** of the committee:
  - Involve and inform all of the above groups about biobanks
  - Form professional associations and involve these with the education campaign.

- **Guidelines** for the committee:
  - Balance of professionals and public
  - Diverse socio economic groups

- **Future goals** of committee:
  - Form a Biobank network
  - National governance while maintaining flexibility for local issues
  - Integrate into legal systems
What are the key messages that should be included in an education campaign?

- How biobanks work - governance and low-risk, safe, easy
- Safeguards are in place – confidentiality, secure database
- Biobanks enable research
- Types of samples, and what is expected from participants
- Where samples are being stored
- No direct benefit
What methods should we use to communicate a public education campaign?

- Digital media, Newspaper articles, magazine articles
- Open days at biobanks
- Media kit
- Outdoor advertising (billboards/posters/bus stops?)
- Posters in waiting rooms and clinics
- Science organization newsletter mentions
- Workshops in schools
- Visit community groups
- Lobbying politicians
- Flyers, commercials, videos, and contact information posted online on various websites
What are some examples of failed public education campaign that we can learn lessons from?

- Organ donor - because not many people actually do it.
- Smoking - simple truth commercials
- Prevention of alcohol excesses
Proposed process for developing a Public Education Campaign

1. Plan Strategy
2. Select channels and materials
3. Develop materials and pretesting
4. Implementation
5. Assess effectiveness
6. Feedback to refine program
Questions?

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