



# Fueling Research by Saving Body Bits: BC Children's Hospital BioBank

Suzanne Vercauteren

Director, BC Children's Hospital BioBank

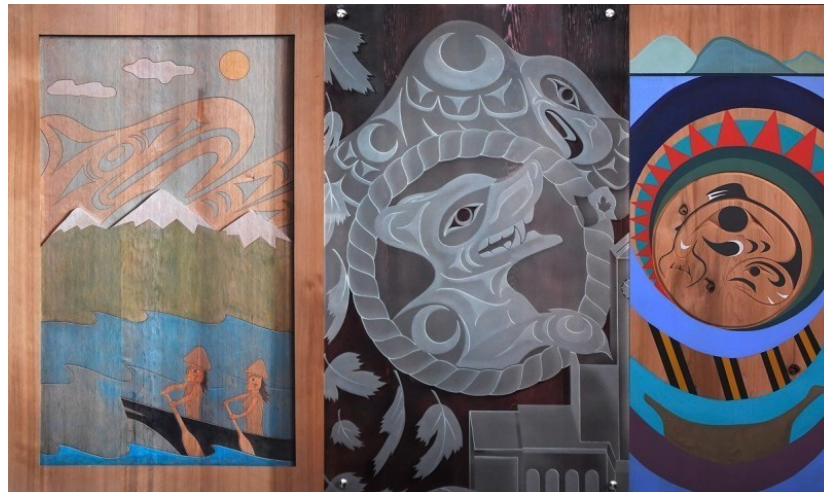
January 9 2023

ATM Rounds



# Land Acknowledgement

- The BCCH BioBank acknowledges with gratitude and respect that we operate on the traditional, ancestral and unceded territories of the x<sup>w</sup>məθk<sup>w</sup>əy̓əm (Musqueam), Sk̓wx̓wú7mesh (Squamish), and Səlílwətał (Tsleil-Waututh) Nations.
- We also acknowledge that we serve communities throughout BC located on many ancestral indigenous territories throughout the province.



# Objectives

- What is the BC Children's Hospital BioBank?
- What consent methods can be used for biobanking
- How can we better inform patients and public about biobanking?



4

The number of cases of childhood cancer seen by a full-time pediatrician in their career

# 65

Different types of childhood cancer

The commonest non-accidental cause  
of death in children

# 51 years ago.....

October 28<sup>th</sup>, 1971

Thank you for referring this 4 year old boy. I am sorry to say that he has Acute Lymphoblastic Leukemia. There is no effective therapy for this condition.

Please let me know when the inevitable happens.

Yours Sincerely,

Courtesy of Dr. Anne Junker  
and Dr. Sheila Pritchard

# Now

- 78% overall cure rate from childhood cancer
- >90% survival rate for ALL



# Biobanks provide us with high quality specimens

“one of the most significant roadblocks to progress in cancer research is the lack of standardized, high quality biospecimens“, NCI







## Definition of a BioBank

“A biobank is a facility for the collection, preservation, storage and supply of biological samples and associated data, which follows standardized operating procedures and provides material for scientific and clinical use”

*Hewitt and Watson, 2013*



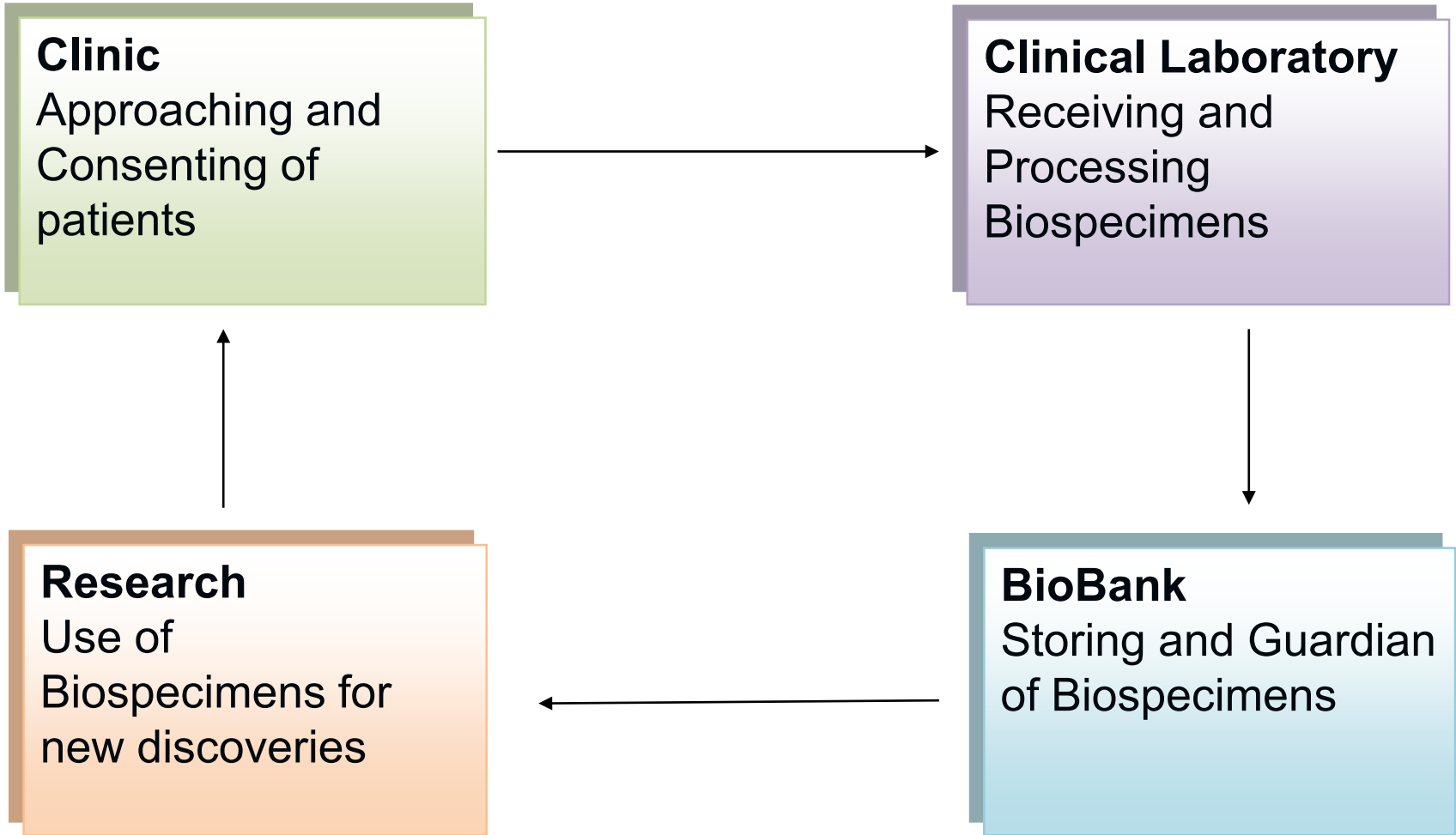
# BCCH BioBank

An institutional biobank collecting samples and data from children and women seen at BC Children's Hospital and BC Women's Hospital for research purposes

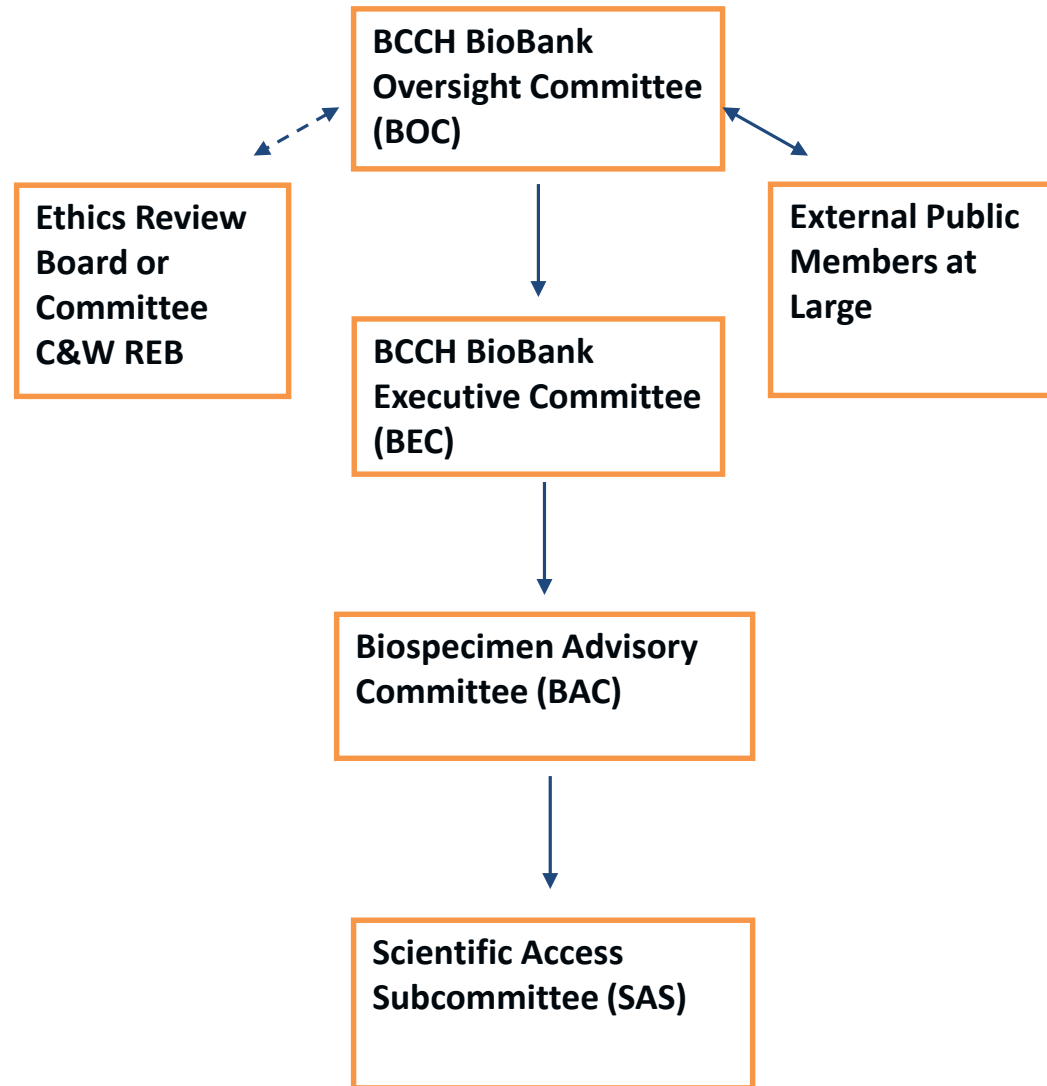
Started in January 2015  
Certified through CTRNet



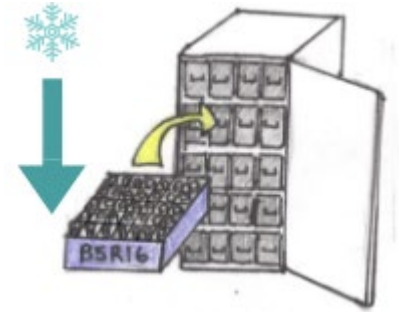
# BioBanking Flow Chart



# BCCH BioBank Governance Structure

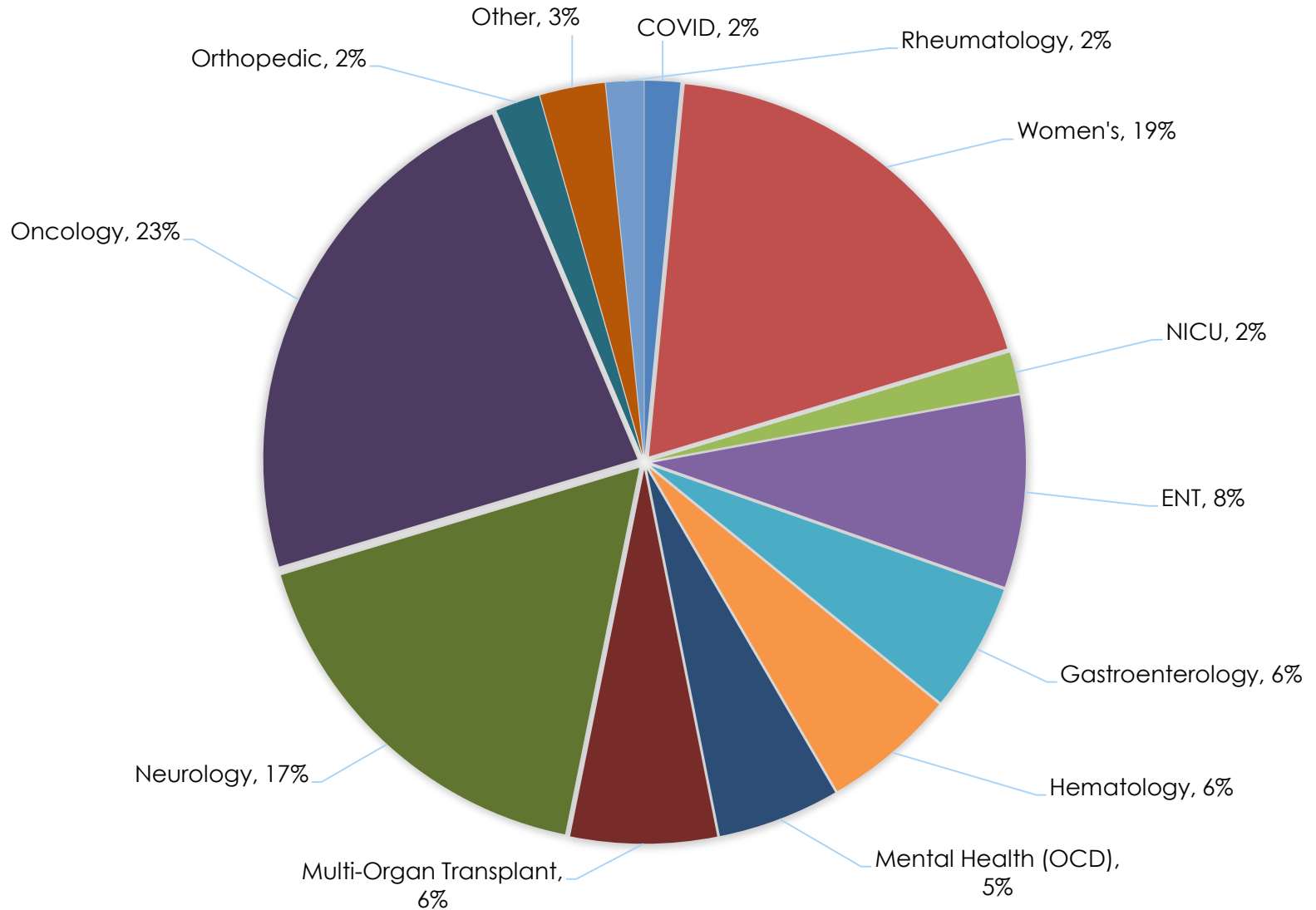


# 1. General BioBank



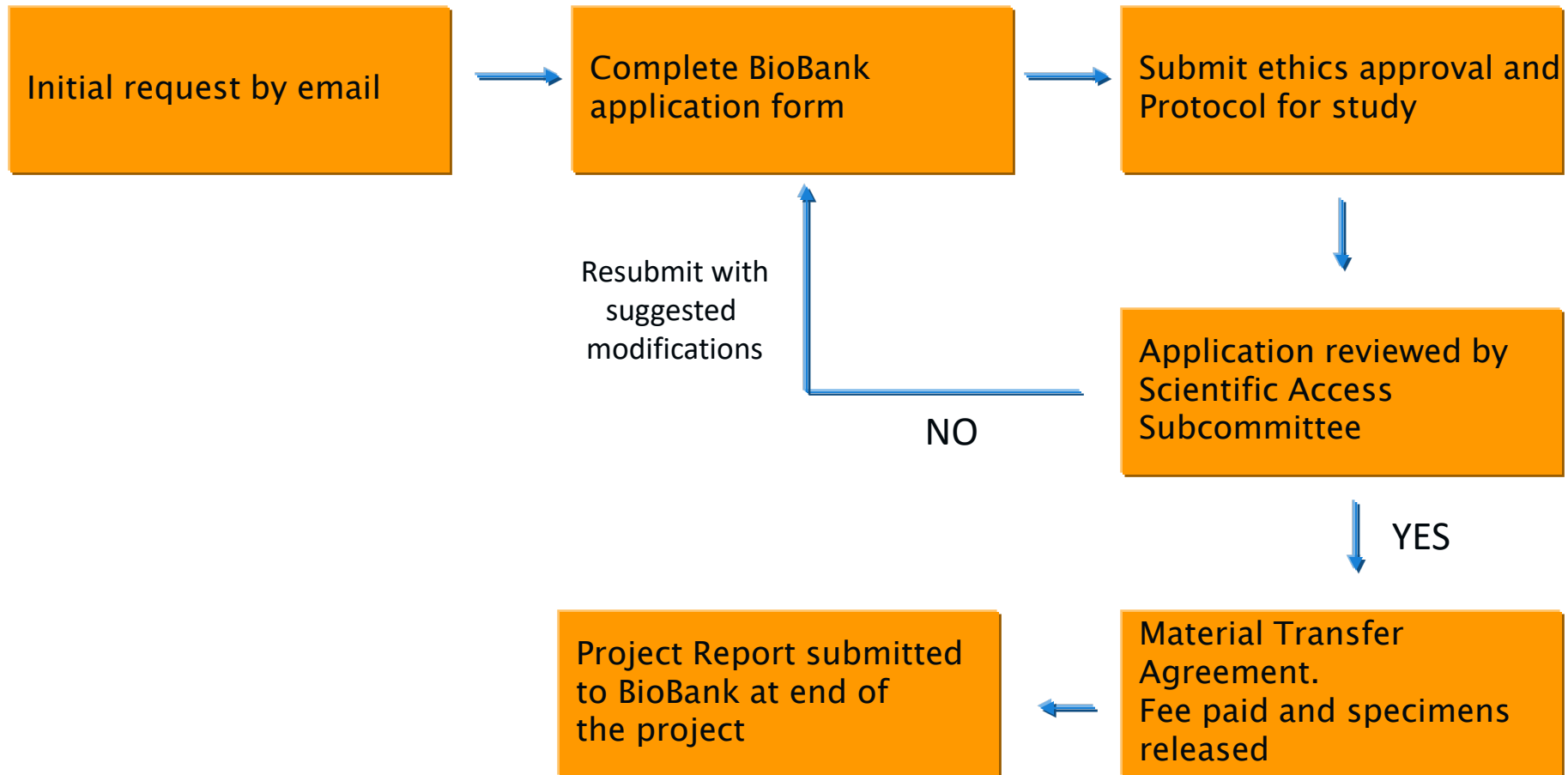
- Ongoing collection of high need specimens with annotated data.
- Consent form enables collection of variety of specimens throughout a patient's treatment
- BioBank is custodian of specimens and hold the linking data.
- Researchers with ethics approval apply to retrieve specimens and clinical data.
- Cost recovery charge for specimens upon retrieval.
- Patients consent to academic and industry research

# Clinic Representation





# Application Process





## 2. PI Driven Research

- PI request services to assist with the acquisition of specimens and/or clinical data.
- PI is the custodian of the specimens and may hold the linking data.
- Additional general BioBank consent requested for left over specimens at the end of the study
- PI's make decisions about release of their specimens to collaborators.



# BioBank Services

- Consent
- Coordinating specimen collection
- Accessioning specimens
- Processing specimens
- Cell counting
- Automated fractionation of blood
- Secure storage of specimens
- Collection of clinical data to associate with specimens
- Regular reporting of specimens collected for PI



# Facilitating Major Research Projects

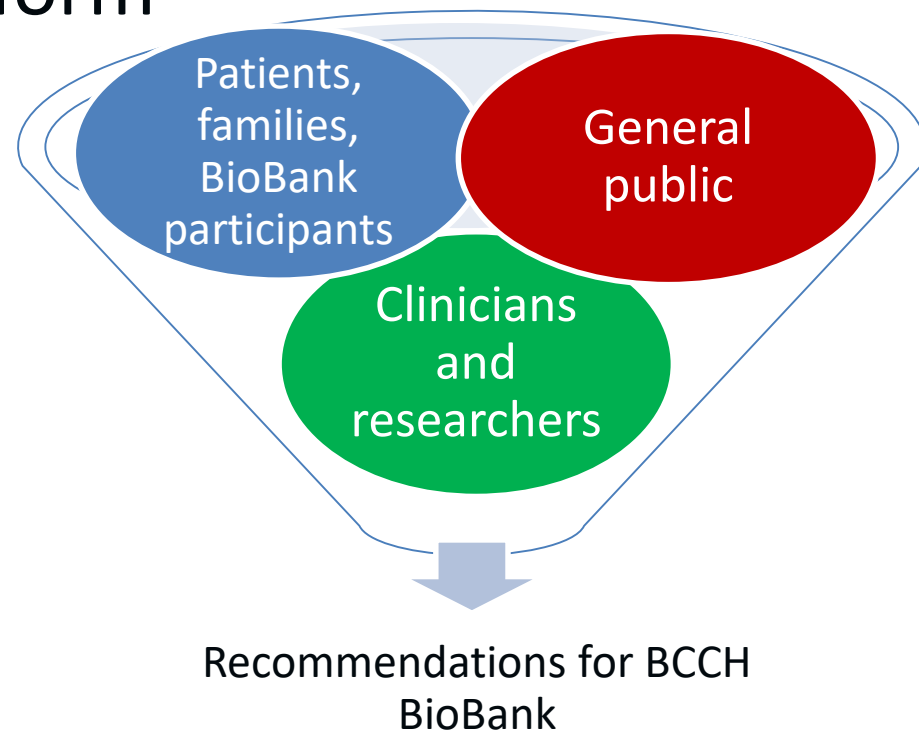
- Canadian Traumatic Brain Injury Platform
- Profyle: Precision Oncology for Young People
- CDTRP: Canadian Donation and Transplantation Research program
- COVID-19 collections in collaboration with the BCCH COVID BioBank Network
- POPCORN: **P**ediatric **O**utcomes im**P**rovement through **C**oordination of **R**esearch **N**etworks
- CBS: Collection of normal cord blood

# Consenting and Pediatric Biobanking

- Parents often make decisions/consent for their children
- Assent children 7 years and older
- Reconsent at age of majority
- Capacity to consent

# Patient Engagement and Education

- Focus groups with stakeholders
- Education in schools
- Electronic consent platform



# Giving patients and healthcare providers a voice in pediatric biobanking

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



Strategy for Patient-Oriented Research

**SPOR**

*Putting Patients First* 

# 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.**

# Research participants

Patients  
n=46

Adults

Teens 14-17 yr

Kids 11-13 yr

Public  
n=25

Adults

Teens 14-17 yr

Kids 11-13 yr

Healthcare  
providers  
n= 22

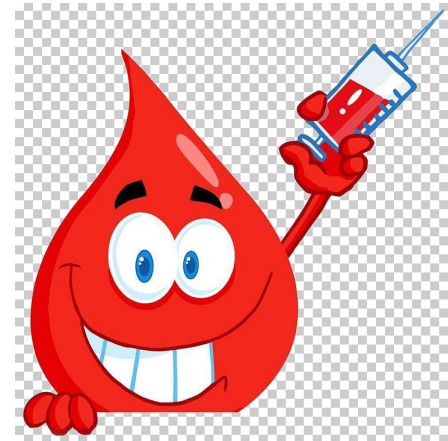
Doctors

Researchers



# Patient/Public Concerns

- Lack of awareness
- Timing of Consent
- Length and language of consent (not fun!)
- Privacy
- Extra pokes





BC Children's Hospital BioBank Information and Consent Form

COLLECTION AND BANKING OF BIOLOGICAL SPECIMENS AND CLINICAL DATA FROM PERSONS SEEKING MEDICAL CARE AT BC CHILDREN'S HOSPITAL

Principal Investigator: Dr Suzanne Vercauteren UBC Department of Pathology and Laboratory Medicine Children's & Women 604-875-2939

BioBank Administration: (604) 875-2939 biobank

Emergency Telephone Number: (604) 875-2939 Toll Free Number (BC only): 1-888-322-2239

If you are a parent or legal guardian, you must have permission from you and the assent (agree say "you" or "your" in this consent form) of the doctors and other staff.

Introduction Doctors and Scientists at BC Children's Hospital BioBank (hereafter collect samples and clinical data from children and families, with the ultimate goal of improving health outcomes for children and families.

The BioBank is governed by the ethical committees (UBC) / Children's and Women's (REB) as well as the governing bodies of the donating samples to the BCCHB are protected standards that govern the operation of biobanks.

This consent form is to help you decide if BioBank staff will be happy to answer all your questions if you sign this consent form, you are consenting to research projects, which as of now, are under review.

What is BioBanking? BioBanking is the collection, storage, and use of biological samples for research. The BioBank at BC Children's Hospital is a research facility, across Canada, and around the world.

The amount of sample taken will be any harm to you. If you are testing for medical care, the amount of sample taken will be any harm to you.

Because certain demographic information is collected, there is a risk of this. In addition, if your demographic information is collected, there is a risk of this. In addition, if your demographic information is collected, there is a risk of this.

There is also a small possibility of harm to your health. The C&W Research Ethics Board to you. If the findings are discussed with your health care team will discuss.

What are the benefits of donating? You will probably not derive any medical point of view. We will be used in the future to be used to develop new treatments that the results of the research discussed above.

you do not agree to the closure plan you will have the opportunity to request that your samples and electronic documentation be destroyed.

What will donating to the BioBank cost me? You will not incur any expenses as a result of donating samples to the BioBank. You will not be paid for donating samples for research purposes. You will not financially benefit from discoveries or commercial products developed from samples you have donated.

Privacy policy of the BioBank The BioBank acts according to the Personal Health Information Act of British Columbia as well as the "Freedom of Information and Protection of Privacy Act of British Columbia." These acts protect your privacy and give you the right to access your information.

Who do I contact if I have questions about donating to the BioBank? If you have any questions or would like to have more information about donating to the BioBank you can contact the BioBank Director and Principal Investigator at 604-875-2939, or the BioBank Administration at (604) 875-2000 extension 6423.

Who do I contact if I have questions or concerns about my rights in relation to donating to the BioBank? If you have any concerns or complaints about your rights as a research participant and/or your experiences while participating in the BioBank, contact the Research Participant Complaint Line of the University of British Columbia Office of Research Ethics by e-mail at R3IL@ors.ubc.ca or by phone at 604-822-8598 (Toll Free: 1-877-822-8598).

Signing this consent form in no way limits your legal rights against the investigators, or anyone else involved in the BioBank. If you are interested in participating in the BioBank, please go to the next page for a description of the types of sample that the BioBank is interested in collecting.

transferred to a private facility of your choice or you have the option to store them in the BioBank for research. In the event that an abundant stem cell collection occurs and there are more cells than are medically required as per your doctor and apheresis director, some may be given to the BioBank provided you have agreed.

Buccal (Inside of your cheek) cells or saliva A buccal smear is obtained from the painless brushing of the inside of the cheeks to collect cells from the lining of the mouth that are normally shed and grow again. If you have mouth sores you can agree to do a mouth rinse and we will collect the discarded rinse in a container. In some situations we may ask for saliva instead of a buccal smear and this is simply collected as a result of "spitting" into a tube.

Excretory products Urine or feces specimens may be collected for the BioBank. These samples may be requested at the time of medical collections but there is the possibility of additional collection of these sample types, purely for the BioBank. Parents of infants or children using diapers may be asked for the used diapers, in order to obtain these samples.

Old samples If you had a previous procedure at BC Children's Hospital or BC Women's Hospital there may be old (archived) samples related to that time that are still stored in the Department of Pathology and Laboratory Medicine. Sometimes these are no longer required for medical purposes; we ask your permission to donate some of these old (archived) specimens to the BioBank if enough of this specimen is secured for potential future diagnostic purposes.

What other samples may be collected? You may be asked about other samples that are not covered by this list. If this list is not complete, the sample type and collection procedure will be clearly outlined to you and in the consent form.

How to use this consent form. Please fill out the check boxes below so that the BioBank staff has the information you are willing to donate for research purposes. Please understand that medical information will be collected with these samples as outlined on the consent form.

Form with checkboxes for sample donation options and initials.

How to use this consent form. Please fill out the check boxes below so that the BioBank staff has the information you are willing to donate for research purposes. Please understand that medical information will be collected with these samples as outlined on the consent form.

Peripheral blood stem cells or bone marrow harvested stem cells for a stem cell transplant for yourself or for a family member and the transplant does not take place are cells left-over after treatment, and your doctor has determined they are not needed for treatment they will be discarded or you can arrange to have them.

# Health-care providers Concerns

- **Barriers**

- Lack of research culture
- Time
- Ethical barriers
- Length of consent forms
- Unaware of studies/biobank
- Unethical circumstances to consent (capacity, rare disease, erosion of informed consent)
- Small window of opportunity to consent diagnostic samples



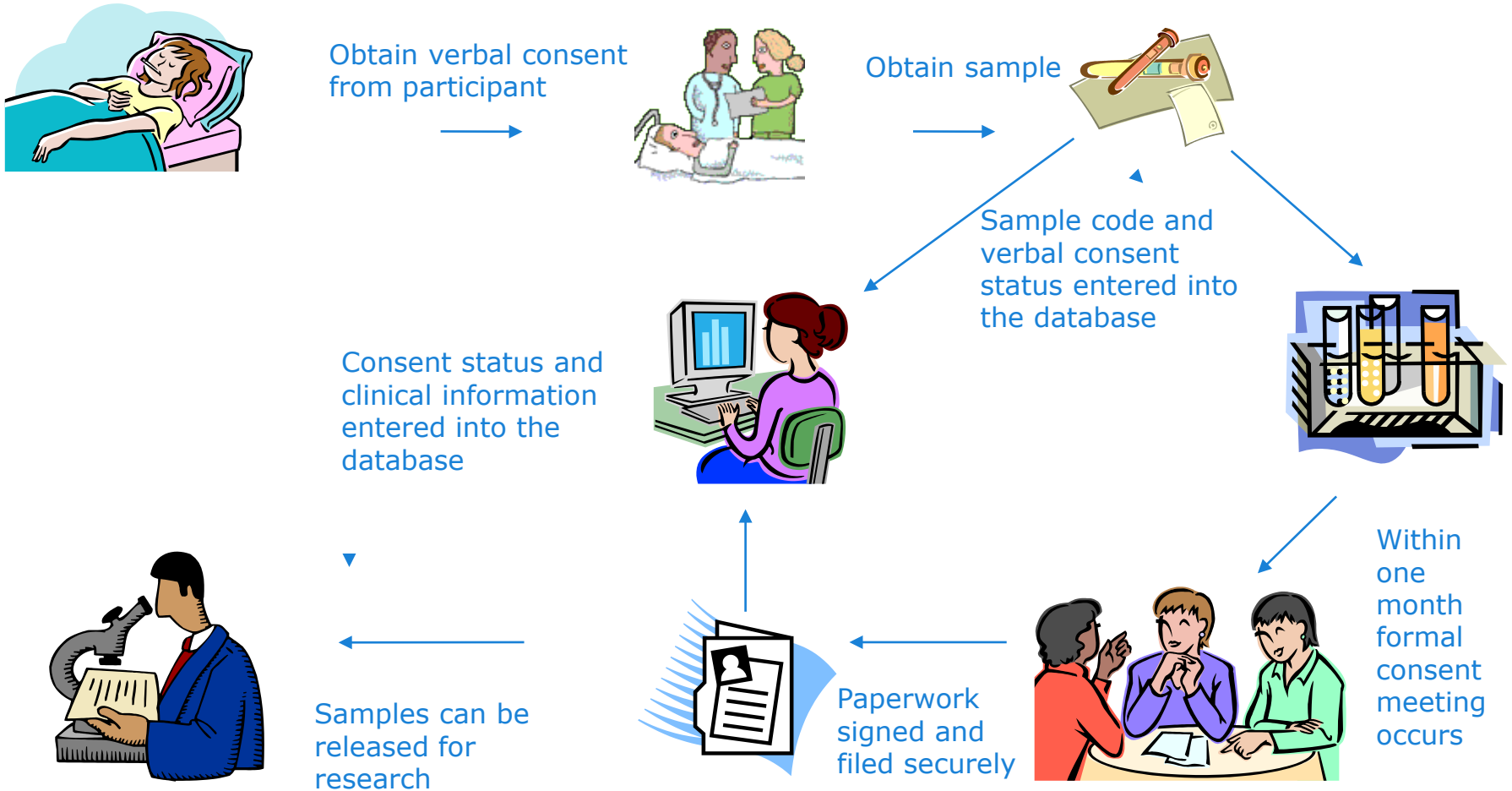
# Researchers concerns

- Lack of samples
  - Several initiatives fail due to lack of samples -> need for control samples
  - Competing with pharmaceutical companies that pay more \$ for clinical trials
- Need for better consenting system including universal consent
- Knowledge Translation training needed
- Too many ethical regulations
  - Consent forms are too long, department has grown, too many regulations
- Prioritization studies with newly diagnosed patients



**CONSENT**

# Verbal Permission for Biobanking





## Childhood Cancer Blood Research Program BioBanking Initiative

### Witness of verbal consent form

This form is to authorize collection of samples for the CCBR BioBank from

\_\_\_\_\_ 00 \_\_\_\_\_  
(Print patient's name) (Date)

Verbal consent was obtained from

\_\_\_\_\_  
(Print parent or guardian's name and relationship)

**Instructions for fellows or physicians: Please read the statements below and initial in the relevant boxes to indicate that you discussed these issues with the patient.**

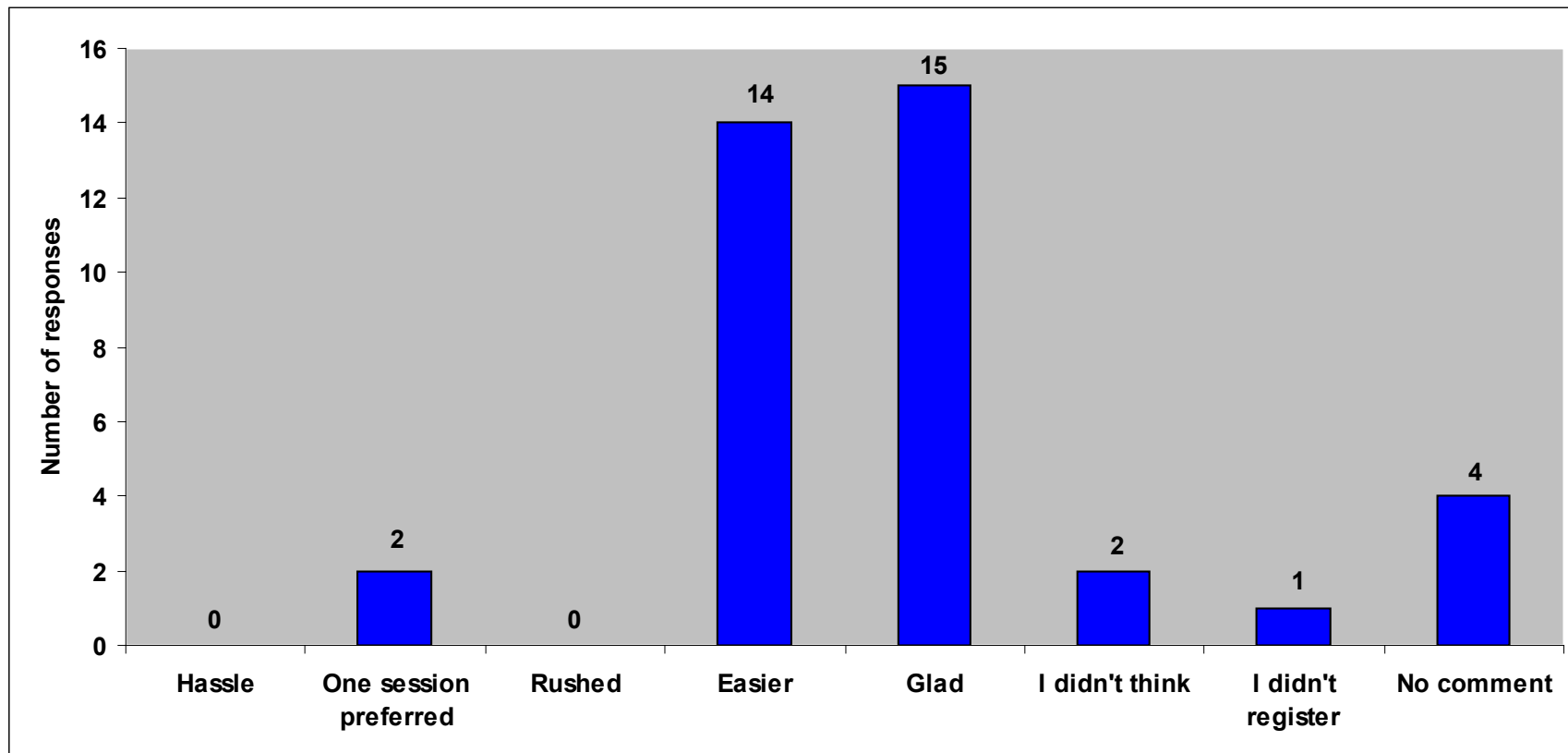
I state that the above patient was informed of the CCBR BioBank and agreed to an extra 2-5 mLs (approx 1 teaspoon) of bone marrow to be taken from their child for research purposes at the time of his/her bone marrow procedure.	
I have explained that this extra withdrawal will not affect their child.	
I have explained that the BioBank Coordinator will meet with me in the next 1-2 weeks to discuss the CCBR BioBank in more detail and give them the opportunity to ask any questions they may have. At this time a formal consent form will be signed, if applicable.	
The parents understand that their child's sample will not be used for research until they have met with the BioBank Coordinator and have signed the formal consent form.	
Should the patient be discharged from the hospital sooner than anticipated and before the BioBank Coordinator has managed to meet with them, the patient has agreed that the BioBank Coordinator can contact them by mail or telephone in order to follow up with the formal consent.	

\_\_\_\_\_  
(Signature of clinician or designate obtaining consent) (Print clinician's name or designate obtaining consent)

Please place addressograph sticker on this form.

**Attention: Please tube this form and the bone marrow requisition to HemPath (336)  
Please contact Tamsin Tarling, L6423, [tamsin.tarling@cw.bc.ca](mailto:tamsin.tarling@cw.bc.ca) with any questions**

The CCBR BioBank intentionally set up a process by which your initial contact with the CCBR BioBank was via your doctor who asked you for a verbal consent only. The BioBank Coordinator then followed up with you in the weeks after your diagnosis for a signed formal consent. Please tick the boxes that you agree with regarding your impression of this 2 stage process. You may tick more than 1 box.







## Verbal Permission to Obtain Clinically Urgent Bio-Specimens for a Paediatric Biobank

Tamsin E Tarling<sup>1,4,5</sup>, Caron Strahlendorf<sup>1,4,5</sup>, Kirk R Schultz<sup>1,4,5</sup>, Ruth Milner<sup>1,4,5</sup> and Suzanne M Vercauteren<sup>2,3,5\*</sup>

<sup>1</sup>Department of Pediatrics, University of British Columbia, Vancouver, BC, Canada

<sup>2</sup>Department of Pathology and Laboratory Medicine, University of British Columbia, Vancouver, BC, Canada

# Consenting for future and ongoing research projects

- BioBank consent form is for ‘yet undetermined research studies’
- Currently the culture is that you have to consent separately for studies that are ongoing
- One sample can go to many research studies



many consents

# Consenting for future and ongoing research projects

## **STUDY: Understanding the immunological basis for early-life infections in preterm infants**

### **Background & Purpose:**

Normal umbilical cord blood contains primitive blood cells. After your baby is born, the umbilical cord is cut and the placenta, or “afterbirth,” is delivered soon thereafter and usually discarded. However, at this time, the blood can be collected from the cord and then used for research. Understanding how normal blood cells are produced is important because it helps us better understand disease processes. For instance, from studying normal blood cells in healthy full-term infants we can detect vulnerabilities in a premature baby’s immune system, or learn how to better treat blood diseases, or improve transplant therapies

The goal of this project is to understand how the immune system of healthy babies born at term differ from babies born earlier or from healthy adults

**What’s required?** Umbilical cord blood.

**Who’s eligible?** Everyone.

**Principal Investigator:** Dr. Pascal Lavoie

**Co-Investigators:** T. Kollmann, K. Schultz, M. Levings

**Contact:** [plavoie@cw.bc.ca](mailto:plavoie@cw.bc.ca)

**Link for more information:** [\[WHRI link w/consent & contact info\]](#)

# E-Consent Platform

## The Team:

- Suzanne Vercauteren: PI, Director BCCHB
- Alice Virani: ethicist
- Holly Longstaff: privacy and regulatory expert
- Julie Robillard: patient experience scientist
- Elodie Portales Casamar: bio-informatician
- Ashton Ellis: BCCHB Research Coordinator
- Adam Velenosi: BCCHB Research Coordinator
- Michelle Dittrick: Research Manager Pathology & Laboratory Medicine C&W
- Ashley McKerrow: REDcap expert
- Augusta Lutynski: Graphic arts support , Emily Carr
- Katie Plain: C&W Patient & Family Engagement Advisor

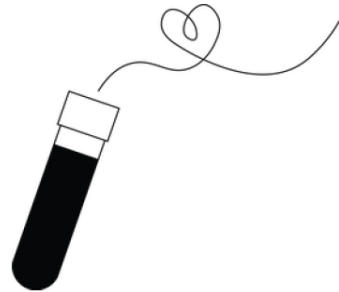
*Funded by BC Children's Hospital Research Institute,  
Clinical Research Development Award*



# E-Consent platform

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## Welcome to The DEMO BioBank e-Consent Platform



This electronic consent form to take part in the BC Children's Hospital BioBank (the BioBank) will take about 15 minutes. When you are able to understand all the risks and benefits and can agree without any help from anyone else this is called providing consent.

If you don't want to be part of the biobank that's okay. If you want to participate, this platform will lead you through the consent process first, followed by the assent, which is required for children 7 years and older. Adolescents (14-18 years) may be able to consent on their own if the biobank staff feels that you understand all benefits and risks. Your assent and consent matters!.

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[Save & Return Later](#)

<https://rc.bcchr.ca/redcap/surveys/?s=4ECKE9AKFA>

Exit

## About The BioBank

Advances in medical research have led to effective treatments for common conditions and conditions that were once life-threatening.

The BioBank collects samples for research to help understand the causes of disease in children and their families. In order to continue improving treatments and therapies, researchers need access to health information and biological samples, such as blood, from a wide variety of people.

A single sample collected at BC Children's Hospital or BC Women's Hospital has the ability to fuel numerous research projects, any one of which might lead to an important medical breakthrough.



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# E-Consent platform

## Who?

The BioBank is run by doctors and scientists at BC Children's and BC Women's Hospital. Scientists worldwide can apply to the BioBank to ask for samples and health information to use for their research. Samples and **de-identified** health information is only given to a scientist if the BioBank and **Research Ethics Board** confirm that the research is worthwhile and safe.



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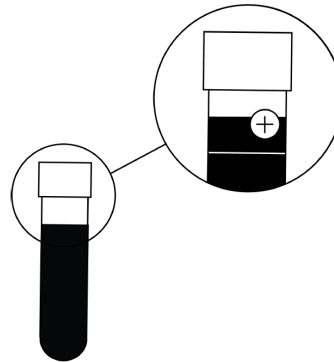
# E-Consent platform

## Extra Samples at the time of a medical procedure

There is the option of giving an extra sample to the BioBank at the time of a medical procedure. For example, if you are having a blood draw, and extra tube could be collected for the BioBank. Extra samples will only be collected if this is considered safe for you by your doctor, and we will always ask before we collect this extra sample.

[Learn more about the extra sample here](#)

Extra samples collected for research may be more valuable since they can be stored quickly in standard way



**Yes, I want to donate extra samples obtained at the time of a medical procedure to the BioBank**

**No, I do not want to donate extra samples obtained at the time of a medical procedure to the BioBank**

reset

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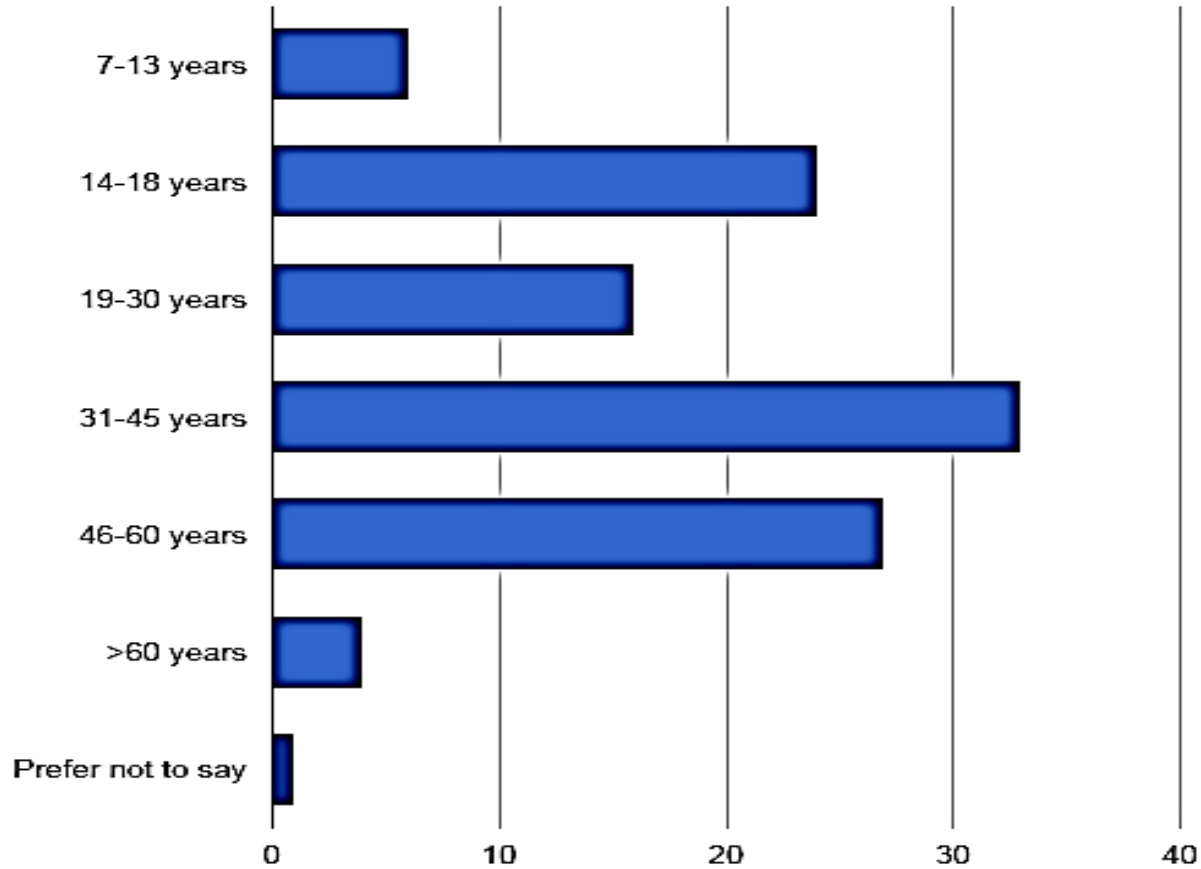
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# Stage 1: Survey Results

- Invitations sent out to previous BioBank participants & C&W Patient Experience Network
- Parents and children age 7 or older invited to view the prototype and complete an anonymous, online REDCap survey
- **Number of survey responses:** 113 (108 complete)
  - 29% of respondents were male
  - 69 % of respondents were female
  - 1% other
  - 1% prefer not to say

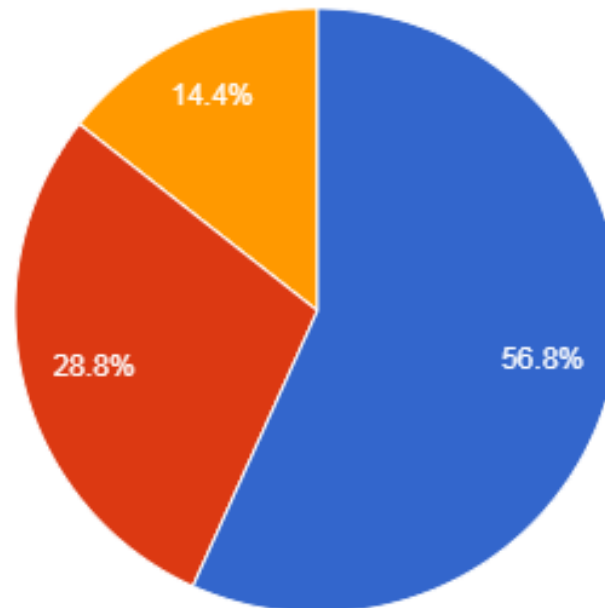
# Age Distribution:



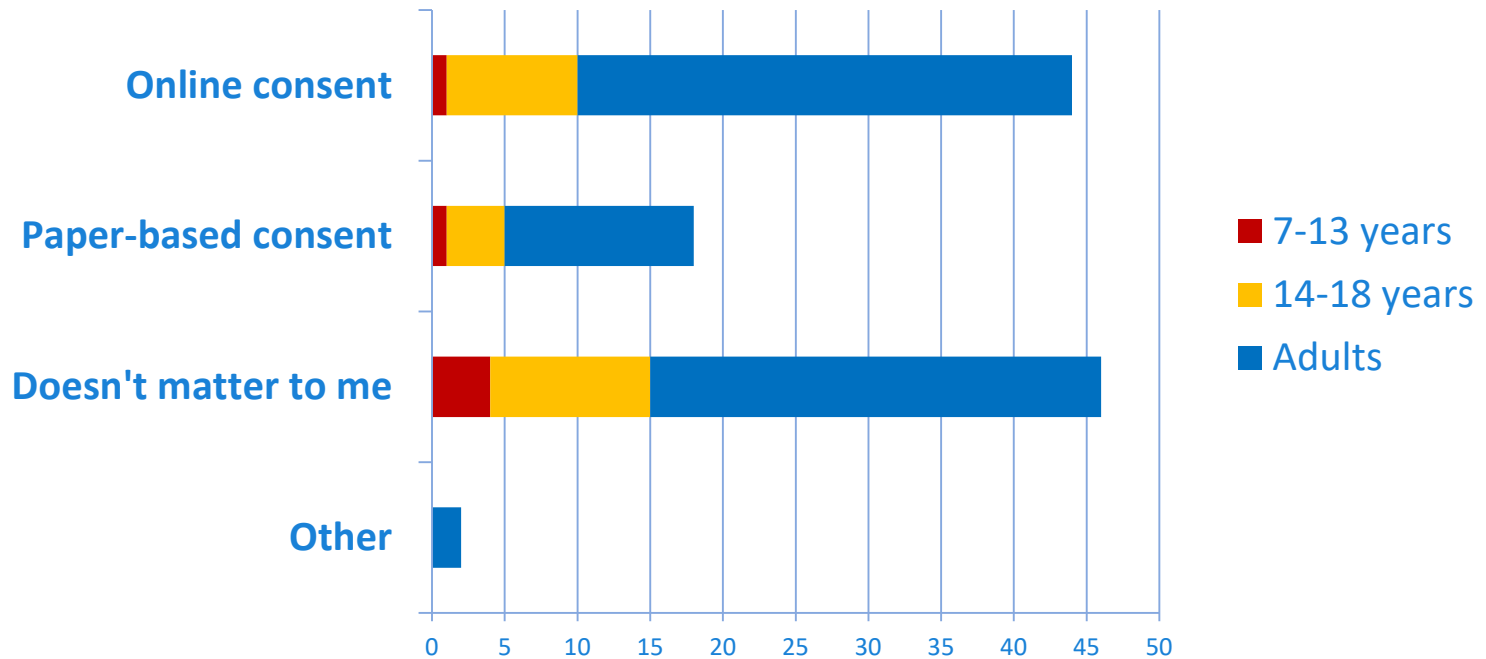
Number of patients

# Have you previously consented to the BC Children's Hospital BioBank?

- Yes: 63 (57%)
- No: 32 (29%)
- Don't recall: 16 (14%)



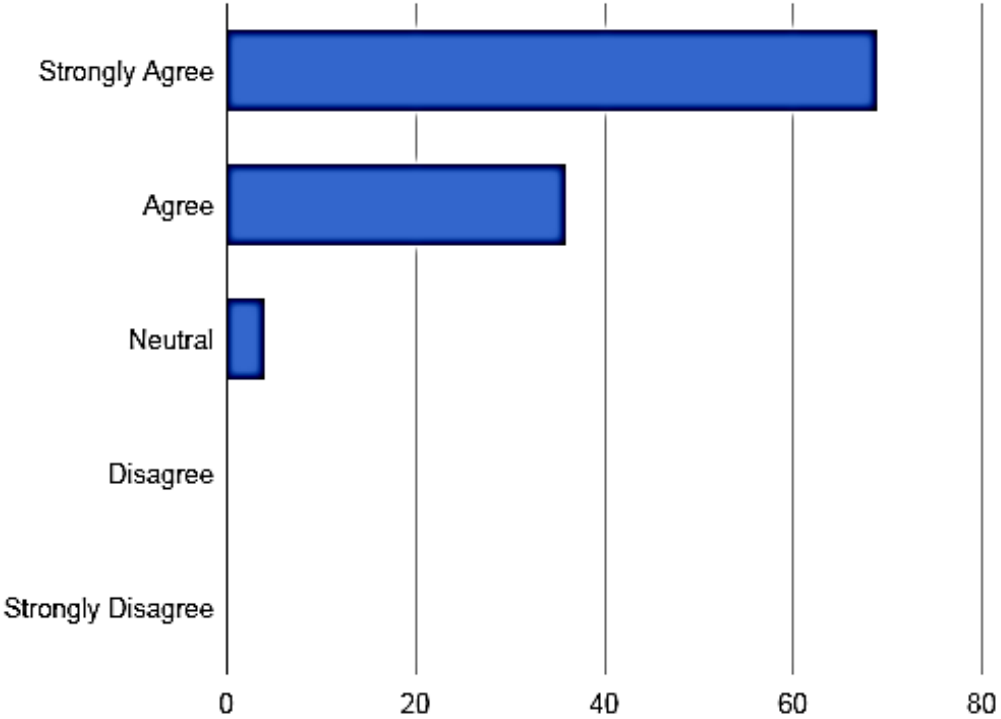
# If I had the choice of consenting method, I would choose:



\*Other:

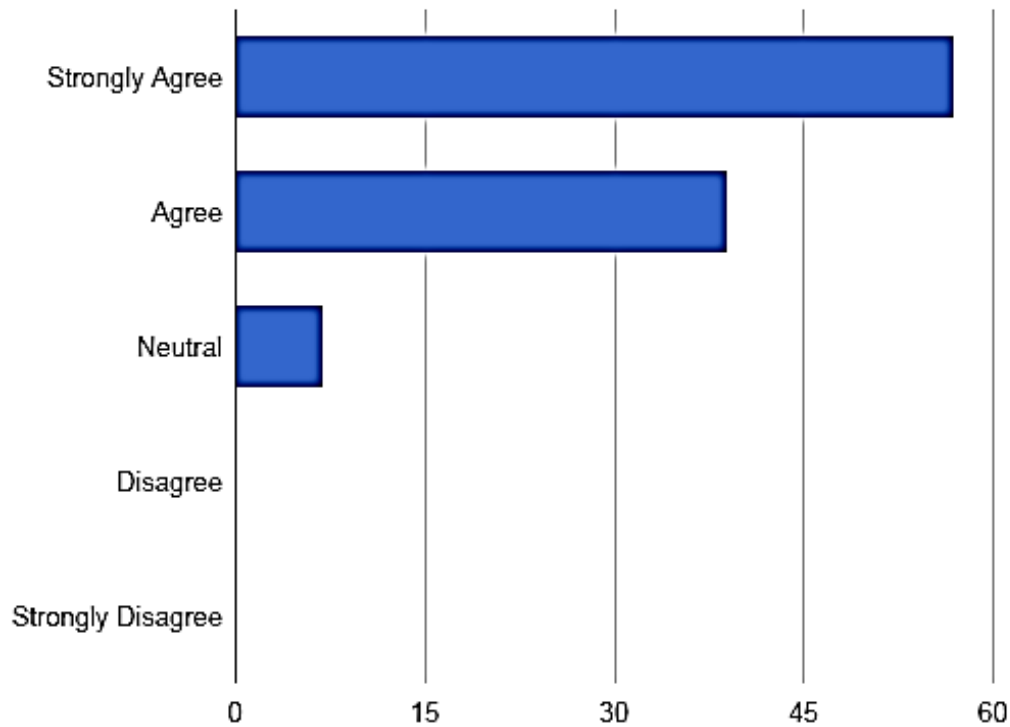
- *I like this on-line consent but I also like being able to ask a person questions*
- *Both*

# Overall, the online consent clearly describes what a biobank is.



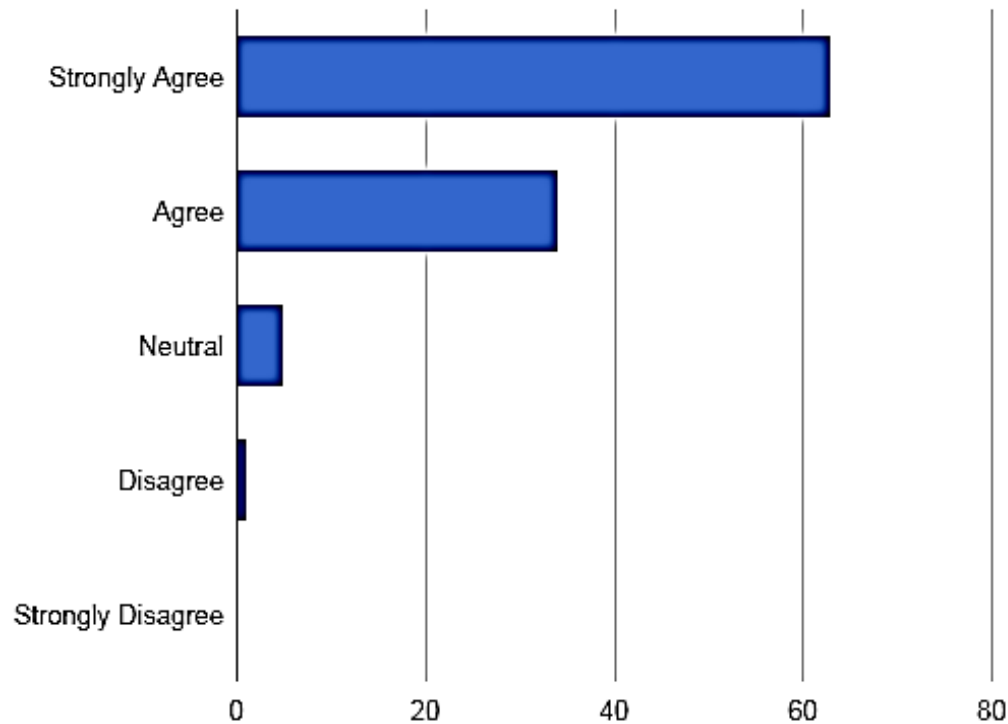
Strongly Agree: 69 (63%)  
Agree: 36 (33%)  
Neutral: 4 (4%)  
Disagree: 0 (0%)  
Strongly Disagree: 0 (0%)

# The risks of participating in the BioBank are well explained.



Strongly Agree: 57 (55%)  
Agree: 39 (38%)  
Neutral: 7 (7%)  
Disagree: 0 (0%)  
Strongly Disagree: 0 (0%)

# The benefits of participating in the BioBank are well explained.

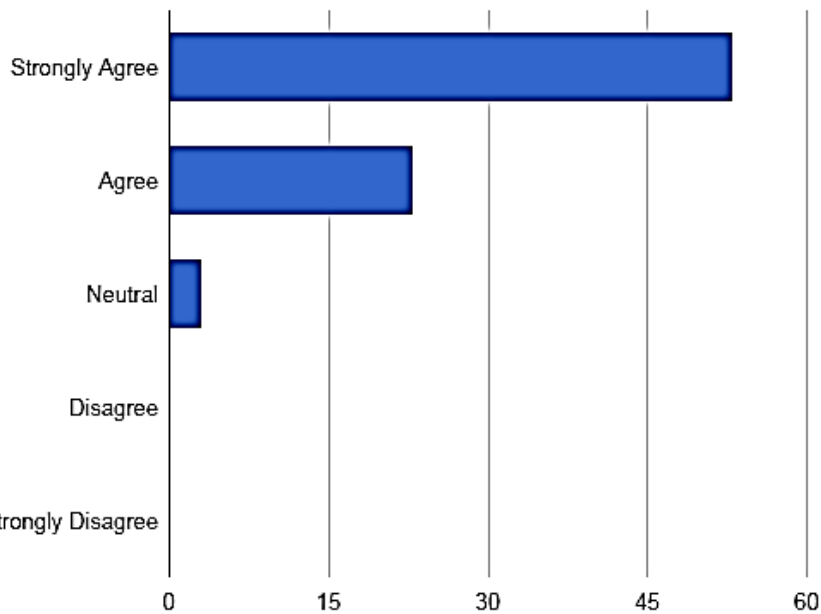


Strongly Agree: 63 (61%)  
Agree: 34 (33%)  
Neutral: 5 (5%)  
Disagree: 1 (1%)  
Strongly Disagree: 0 (0%)

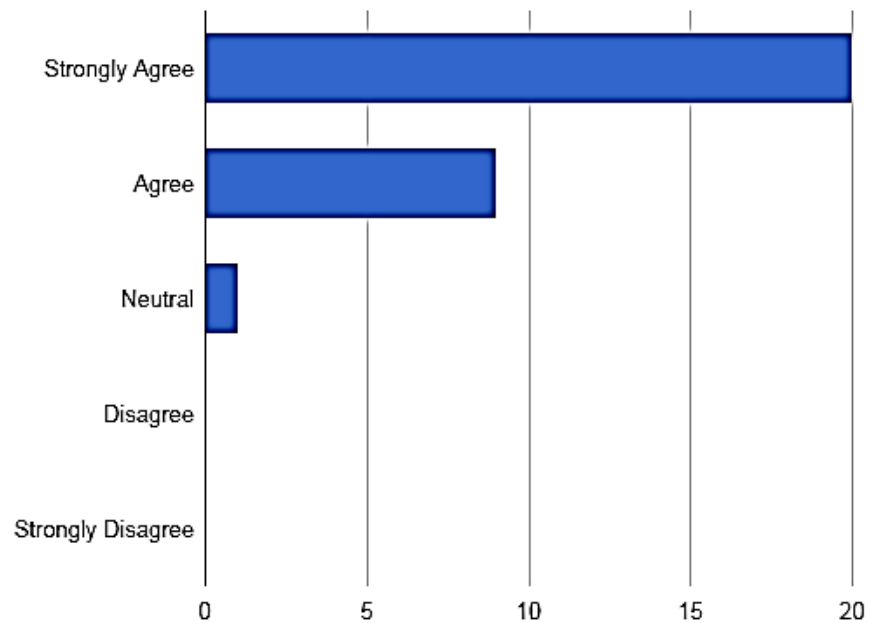
- Disagree comment: *"I think the benefits should be explained. Who benefits. Will big pharma profit?"*

# I understand that my participation is voluntary and that I can withdraw from the BioBank if I change my mind.

- **Adults n=79**

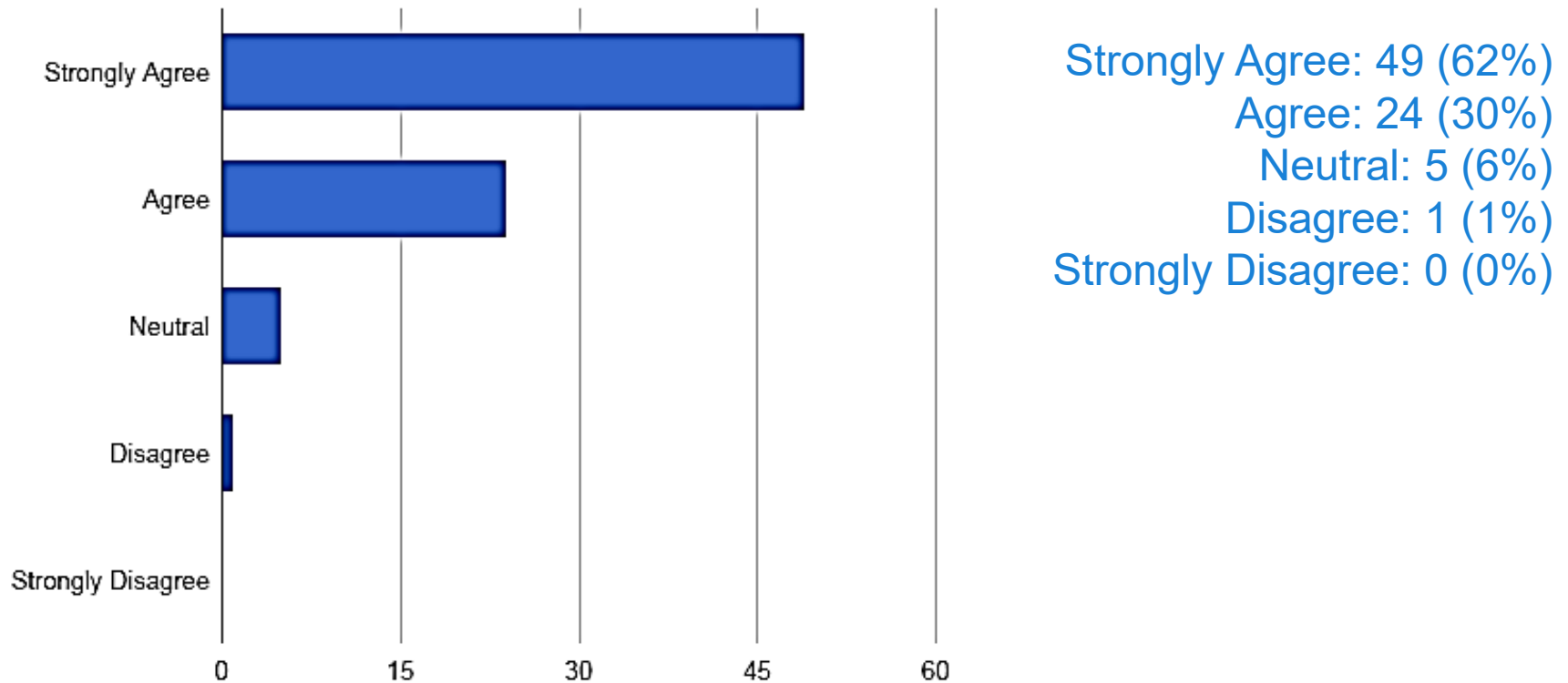


- **Kids n=30**

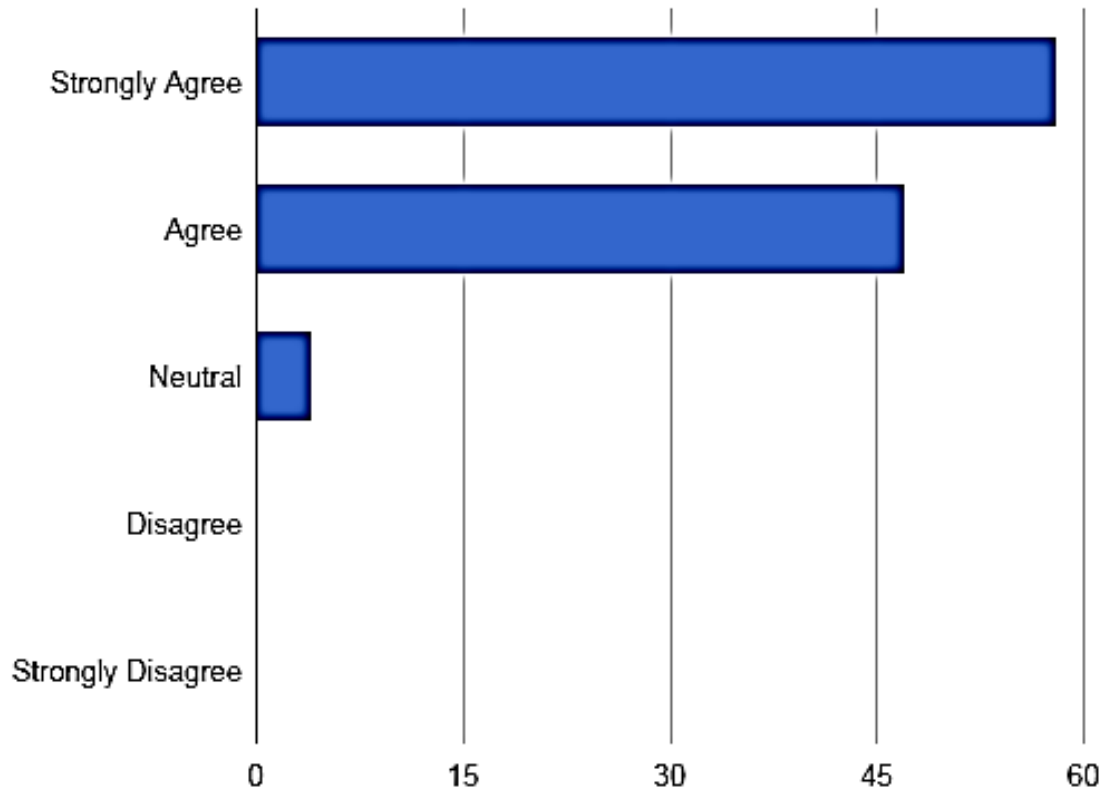




**It is clear to me that researchers need to get permission before they can get samples for their research from the BioBank.**



# I understand all of the information given during the online consent process.



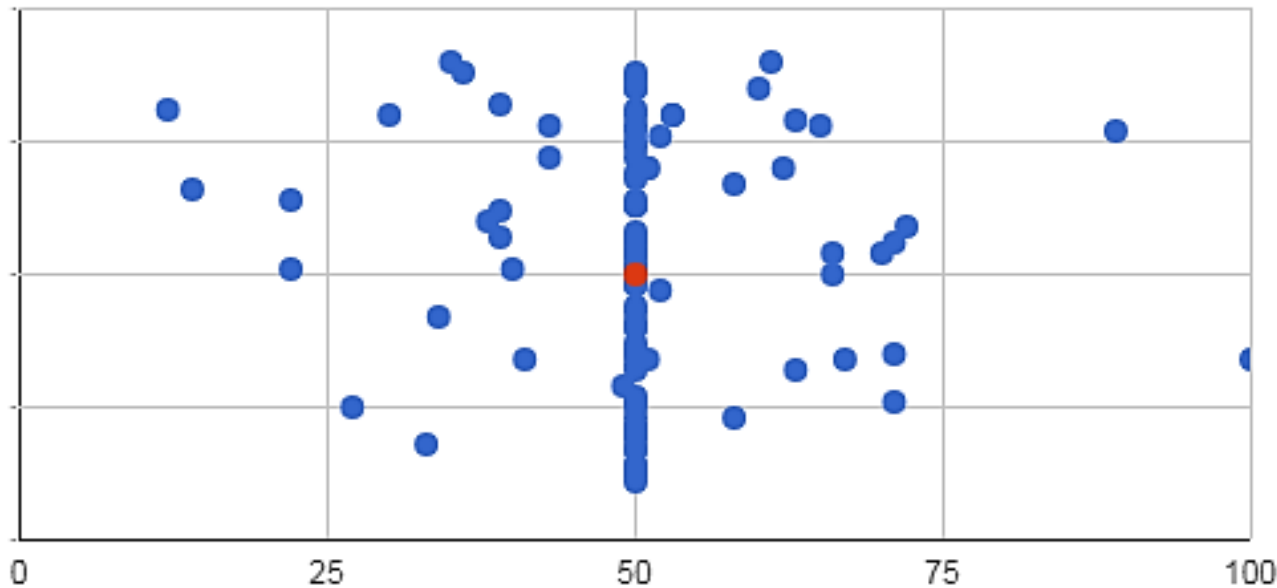
Strongly Agree: 58 (53%)  
Agree: 47 (43%)  
Neutral: 4 (4%)  
Disagree: 0 (0%)  
Strongly Disagree: 0 (0%)

# I feel the amount of information given is:

0=too little

50=just right

100=too much



**Median 50.0; Mean = 50.3**

Kids median: 51.5

Teens median: 50.0

Adults median: 50.0

## Other Feedback/Comments

- I am a parent of a child who has been diagnosed with a life-threatening disease and has been fighting for her life at BC Children's Hospital. I have a vague memory of two young ladies approaching us in the early days of our daughter's battle, explaining the BioBank program and requesting that we consider participation. At that point, we were **completely overwhelmed** with the recent discovery of our daughter's illness, traumatized by all she was being subjected to, and **in no condition to understand the complexities and implications of the BioBank program**, as presented in a few minutes by even well-meaning and articulate BioBank workers. **This online consent form is a far superior way to present the BioBank information to patients and their families. It allows for much-needed time for a gradual absorption of information as well as the time to make an informed decision about an important but delicate subject that carries enormous scientific and moral implications.**

# E-Consent Platform



## *Refining e-consent in REDCap*

### **Stage 2: Focus group**

- View the revised prototype and gather feedback through open discussions during user navigation.
- Identify words/phrases for clarification
- Discuss practical aspects (setting, timing, presence of BB staff)
- Assess appropriateness of quiz at end of consent form
- Attendance:

Adults:	9
Teens:	4
Children:	8

# Identify words/phrases for clarification

## Who?

The BioBank is run by doctors and scientists at BC Children's and BC Women's Hospital. Scientists worldwide can apply to the BioBank to ask for samples and health information to use for their research. Samples and **de-identified** health information is only given to a scientist if the BioBank and **Research Ethics Board** confirm that the research

 Speak the displayed text

A research ethics board is a group of people that review and monitor research involving human participants to make sure it is ethically acceptable



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Save & Return Later



# Practical assessment and quiz

- Practical assessment:
  - In person consenting:
    - Read aloud option added (kids)
    - 'Ask questions by email' box added
- Quiz:
  - Adults: No
  - Teens: Probably good but may not
  - Kids:
    - Mini game at the end
    - End with something fun



# Other Considerations

## PDF emailed to participant after completion

Displayed below is a read-only copy of your survey responses. Please review it and the options at the bottom.

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**BioBank e-Consent Platform** Page 1

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This electronic consent form to take part in the BC Children's Hospital BioBank (the BioBank) will take about 15 minutes. When you are able to understand all the risks and benefits and can agree without any help from anyone else this is called providing consent.

If you don't want to be part of the biobank that's okay. If you want to participate, this platform will lead you through the consent process first, followed by the assent, which is required for children 7 years and older. Adolescents (14-18 years) may be able to consent on their own if the biobank staff feels that you understand all benefits and risks. Your assent and consent matters!

I certify that all the information in the document above is correct. I understand that clicking 'Submit' will electronically sign the form and that signing this form electronically is the equivalent of signing a physical document.

If any information above is not correct, you may click the 'Previous Page' button to go back and correct it.

<< Previous Page

Submit

Exit

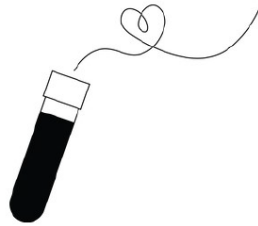
Save & Return Later



# Other considerations

To allow linking, consent will be obtained first followed by assent

## Welcome to The BioBank e-Consent Platform



This electronic consent form to take part in the BC Children's Hospital BioBank (the BioBank) will take about 15 minutes. When you are able to understand all the risks and benefits and can agree without any help from anyone else this is called providing consent.

If you don't want to be part of the biobank that's okay. If you want to participate, this platform will lead you through the consent process first, followed by the assent, which is required for children 7 years and older. Adolescents (14-18 years) may be able to consent on their own if the biobank staff feels that you understand all benefits and risks. Your assent and consent matters!

\*THIS IS A PROTOTYPE AND NOT THE FINAL PRODUCT\*

Next Page >>

Save & Return Later



Thank you for completing the consent!

Agreement (assent) from children age 7 and older is also required.

If you are a child 7 years or older we would like you to review the assent form to let us know if you agree to be part of the BioBank.. Your assent matters!

Please select age group below:

Kids (7 - 13)

Teens (14 - 18)

I'm all done!

Submit

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# E-Consent Platform

## Stage 3: Implementation

- Choice of consenting via either e-consent, or traditional paper-based forms for new BCCHB participants.
- Track uptake, including demographics
- User survey to assess comprehension and satisfaction

# Youth-Friendly Assent Form

## BC Children's Hospital BioBank Adolescent Assent Form Age 14-18

## Common Questions and Answers

### The Goal

The BioBank samples used in research are to understand the causes of disease in children and their families. **Our goal is to improve treatment and to prevent those diseases for the future benefit of people.**

### Who?

The BioBank is run by doctors and scientists at BC Children's and Women's Hospital. Scientists from around the world may apply to the BioBank for samples to be used in research. If their study is approved the samples will be shared.

### What?

The BioBank collects tissue, blood, DNA, urine, stool, fluid, and bone marrow samples as well as patient information such as date of birth, diagnosis, date of diagnosis, and treatment. This information is used for research.

### When?

**You are being invited to donate and it is your choice to participate.** If you choose to donate samples to the BioBank, it will be during your procedure or visit, for as long as you are receiving medical attention at BC Children's Hospital.

### Where?

The BioBank samples are taken at BC Children's Hospital. Samples are processed in the BioBank laboratory which is located in BC Children's and Women's Hospital and stored in a secure area in the Research Institute.

### Why?

The scientists and doctors are collecting the BioBank samples and information from youth and families to create a bank of samples and data to use in medical research.

**Q.** What if I'm scared of the procedure I'm going to have (eg. taking blood, surgery)?

**A.** Your doctors and nurses at the hospital will try their best to make your procedure comfortable. Let them know what your concerns are and they may have solutions. For example, if you feel needles are painful, we have emla cream which will help numb the area.



**Q.** Will I have to give any extra samples?

**A.** For most procedures, you will not have to give any extra samples. In many cases, there are leftover samples, which are usually thrown away, but instead will go to the BioBank if you choose to donate. However, there are a few exceptions where your doctor may ask if you would like to donate another sample (eg. an additional vial of blood). This will be your choice.



**Q.** By donating, will I get better?

**A.** Most likely, you will not medically benefit from donating to the BioBank. If something is found from your samples through research, you will be contacted.



**Q.** If I don't want to donate, will I get in trouble?

**A.** No, you will not get in trouble. If you do not wish to donate to the BioBank, your care will not change. There is no difference in treatment between those who wish to donate and those who do not wish to donate.



**Q.** If I have more questions who should I contact?

**A.** You can contact the BioBank at **604 875 2000 ext. 6423**

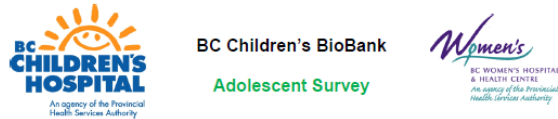


# **BIOBANK SURVEYS**

# 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!



Thanks for participating in our survey! This survey should take 5-10 minutes to complete, and responses are completely anonymous, nobody will know which survey was completed by you. The data from this survey may be published in a scientific journal or presented at a scientific meeting. By completing this survey you are giving your consent that you agree to this possibility.

Age:	Gender:	First 3 digits of postal code:
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Where are you doing this survey?

- School: \_\_\_\_\_
- BC Children's Hospital
  - Oncology Clinic
  - Cardiology Clinic
  - Orthopedics Clinic

- 1) Before participating in this survey, had you heard of a BioBank before?  
 Yes     No     Uncertain
- 2) If you answered "Yes" or "Uncertain", what did you think a BioBank was?
- 3) Do you have any chronic medical conditions, for which you see a doctor on a regular basis?  
 Yes     No     Uncertain
- If so, what medical condition? (optional):
- 4) Are you currently taking any doctor-prescribed medications?  
 Yes     No     Uncertain

BioBanking is the collection and storage of human samples, such as tissue, blood, bone marrow, DNA and others for research purposes. These samples are stored anonymously, and used by health researchers in their studies. The ethics board at BC Children's Hospital monitors the proper use of these samples and the studies they are used in.

5) With which of the following statements do you agree/disagree? (Please circle)

	Strongly agree	Somewhat agree	Neutral	Somewhat disagree	Strongly disagree
I would be willing to give an EXTRA tube of blood or similar sample for research purposes if I was <u>already</u> having a tube of blood (or similar) taken for medical reasons.	1	2	3	4	5
I would be willing to have an EXTRA procedure performed (e.g. a poke to take a tube of blood) for research purposes even though I did not need this procedure for medical reasons.	1	2	3	4	5
I would be willing to give any samples, such as blood that are left over from medical tests for research purposes.	1	2	3	4	5

Comments:

6) The genetic code for some diseases is embedded in a person's DNA. DNA can be extracted from samples such as blood. Would you be willing to donate DNA to the BioBank?

- Yes     No     Uncertain

Right now, anyone under age 18 can donate a sample if their parent/guardian gives consent (permission) to the BioBank. Often, samples are taken because the child is already sick (for example, has cancer) and the parents consent to an extra research sample being taken while the child is getting a medical test.

If the child is old enough to understand, they are also asked for their permission to have the sample taken. This permission is called "assent".

7) If you were <18 years of age, would it be important for you to be included in the agreement process and asked for assent?

- Yes     No     Uncertain

8) At what age (under 18) do you think it is appropriate to ask for a child's assent?

- Age: \_\_\_\_\_  
 None, I think parental consent is sufficient.

9) If you had a sample taken when you were a child (<18 years of age), how important is it to you that the BioBank contacts you after you turn 18 to obtain your permission (consent) for the continued use of your sample in research? This process is called re-consent. (Please circle the most applicable response).

Very important	Important	Neutral	Of little importance	Not at all important
1	2	3	4	5

10) If the BioBank was unable to contact you for your re-consent at the age of 18, would you still want your childhood sample to be used for research?

- Yes     No     Uncertain

11) Any further comments about BioBanking:

# Survey Demographic

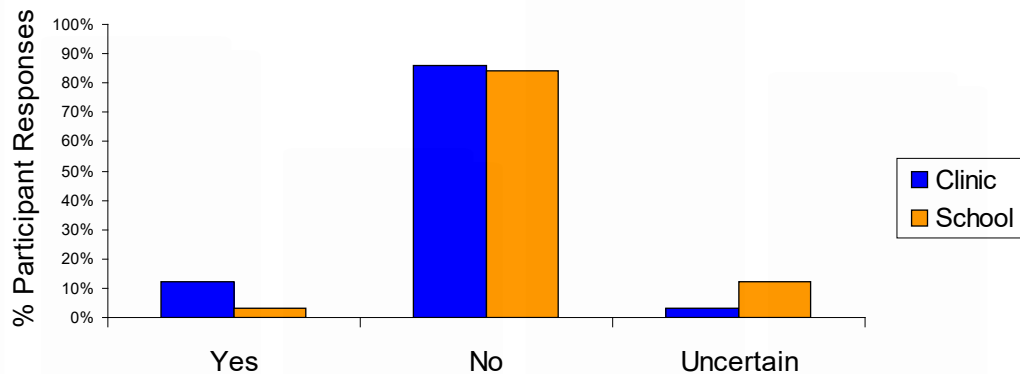
- Male:Female ratio of respondents ~1:1

BCCH CLINIC COUNTS	Adolescent surveys	Parental surveys
Oncology clinic	31	19
Cardiology clinic	31	30
Orthopedics clinic	49	43
Subtotals	111	92

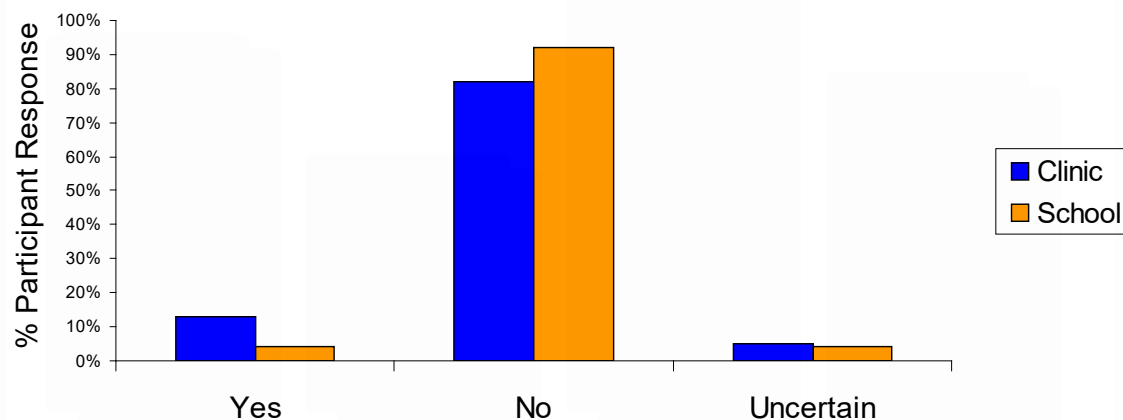
SCHOOL COUNTS	Adolescent surveys	Parental surveys
School 1	34	23
School 2	56	62
School 3	26	19
Subtotals	116	104

# Have you ever heard of a biobank?

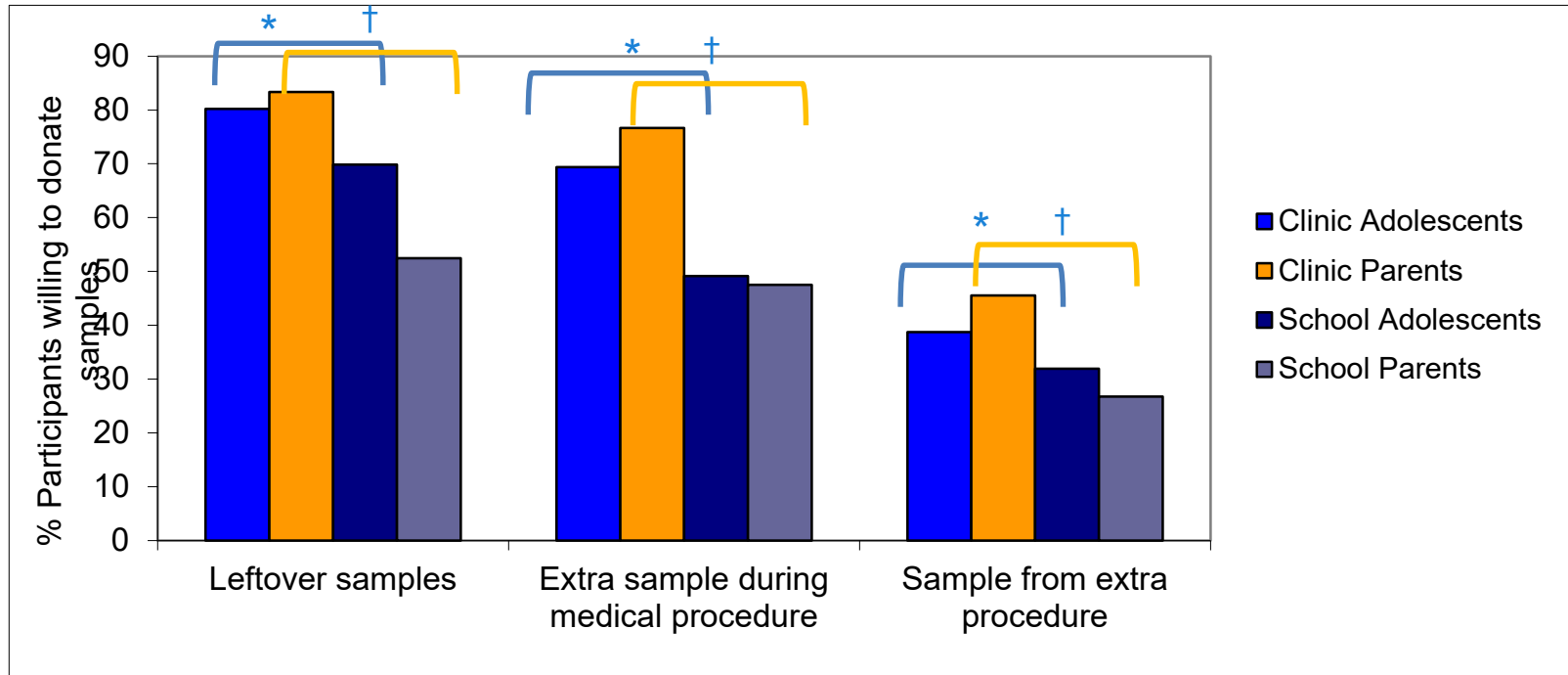
**Adolescents: Have you ever heard of a biobank before?**



**Parents: Have you ever heard of a biobank before?**



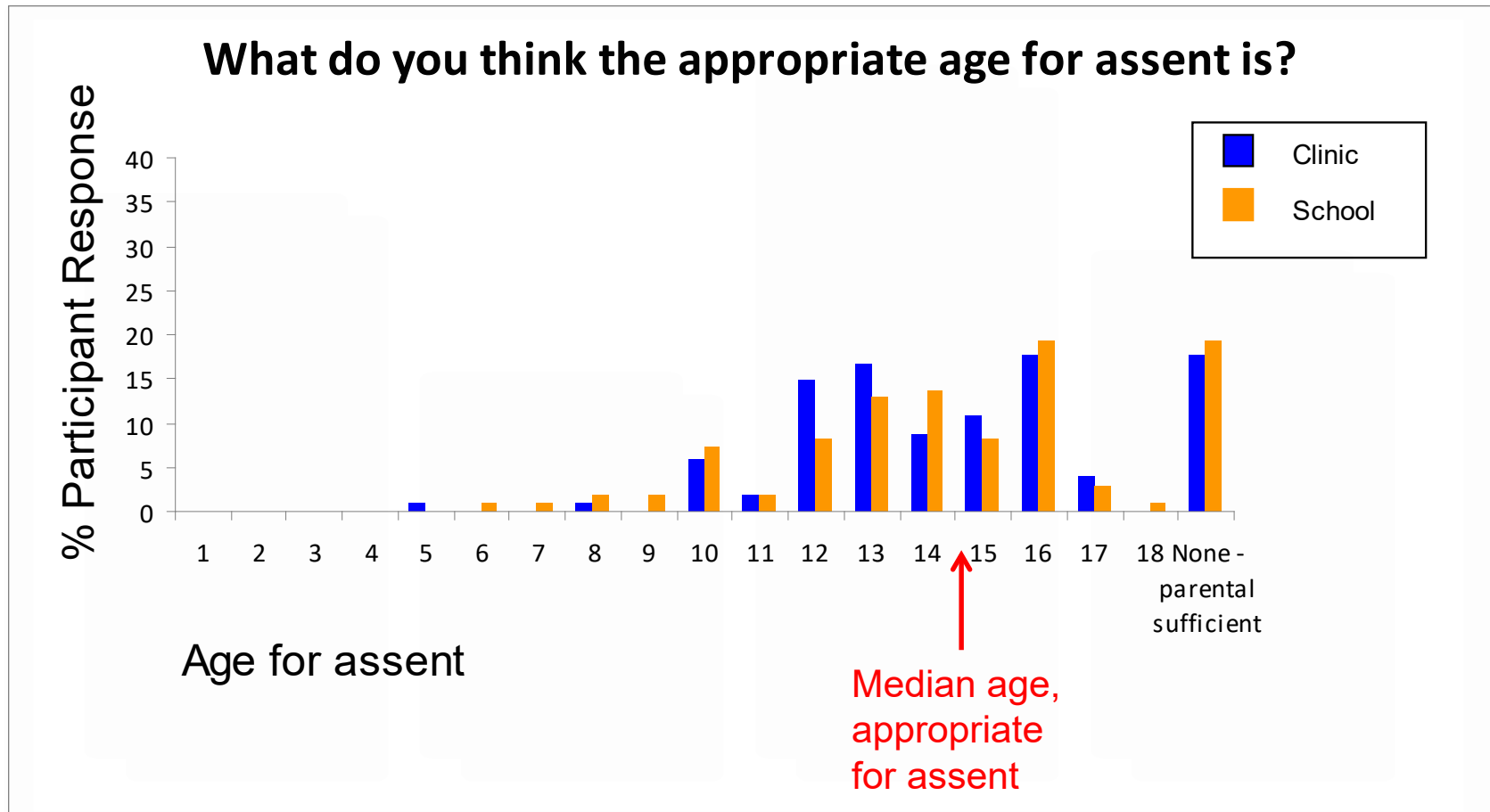
# Would you be willing to donate samples to a biobank?



- \*P < 0.01
- †P < 0.001

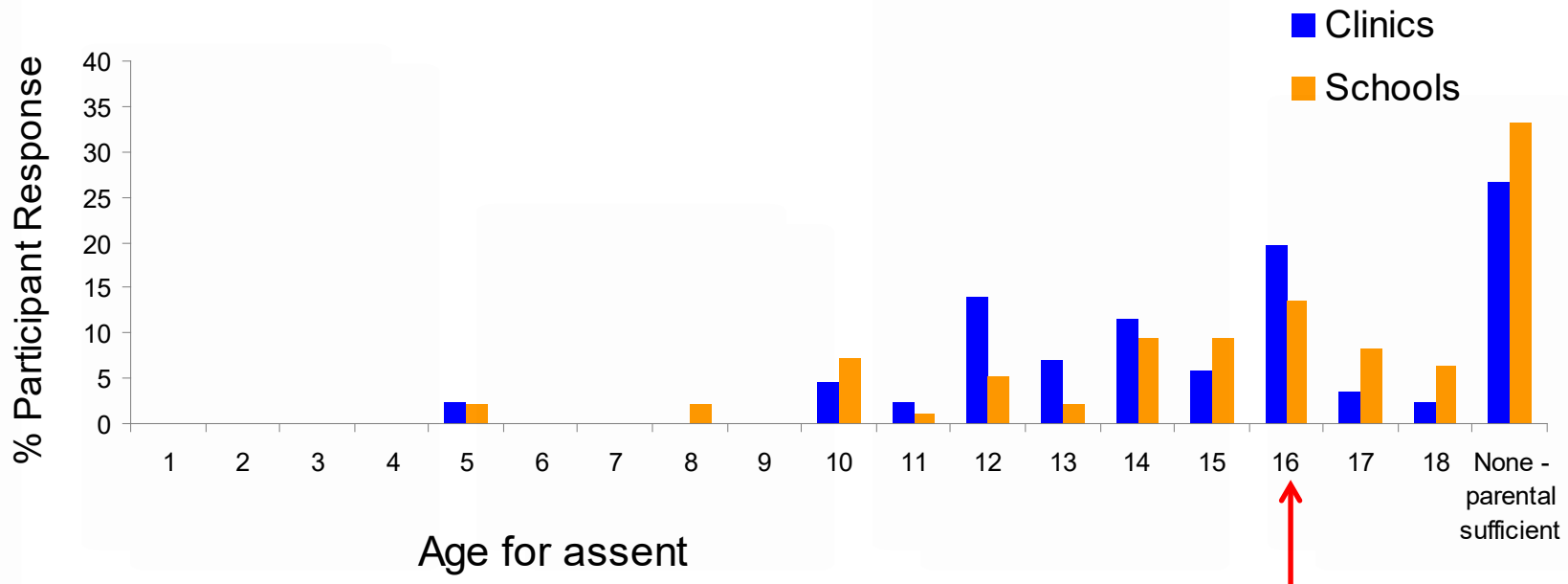


# Age of Assent-Adolescents



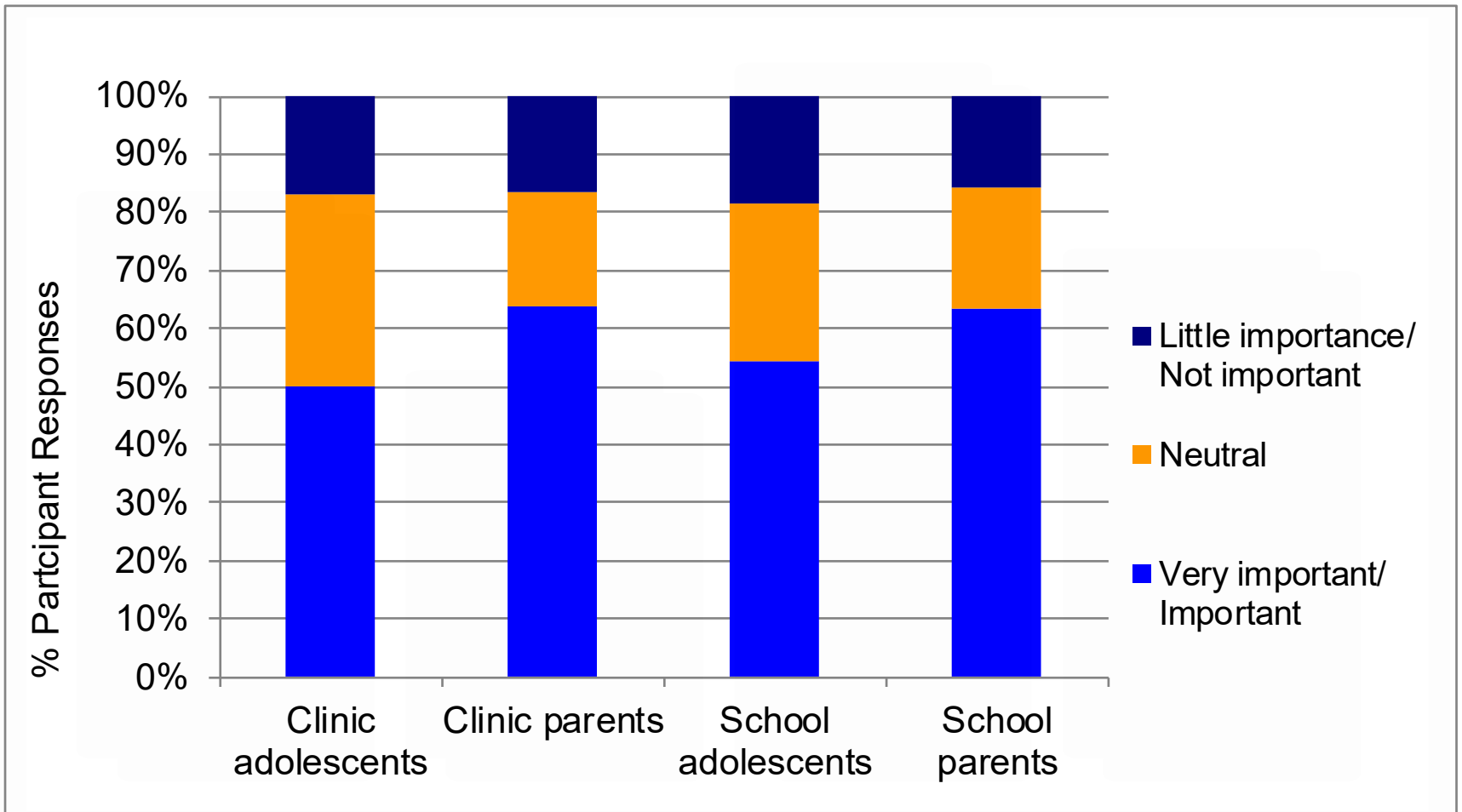
# Age of Assent- Parents

What do you think the appropriate age for assent is?

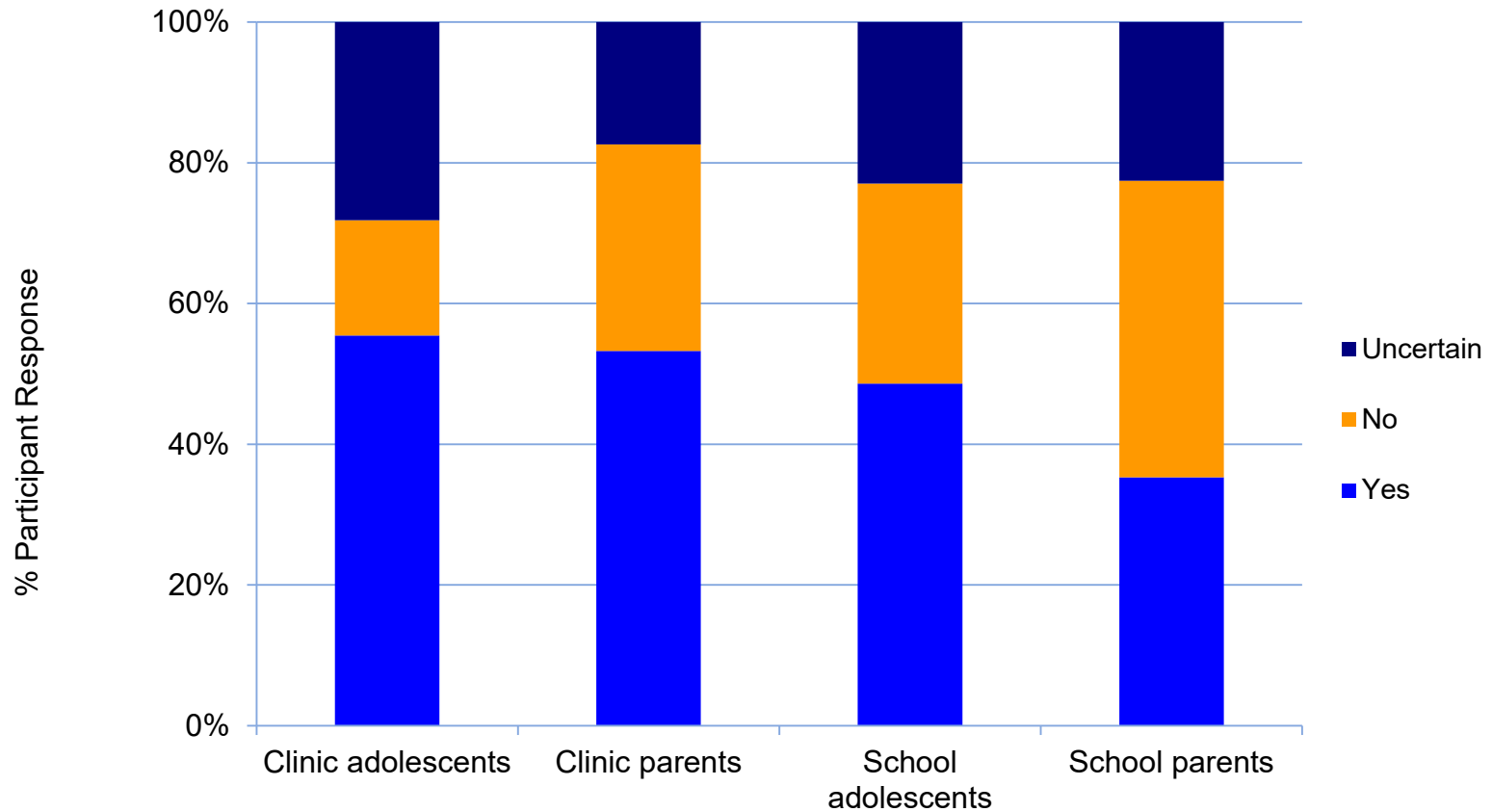


Median age,  
appropriate  
for assent

# Importance of re-consent



# Continued use of specimens in absence of re-consent



# 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

# Conclusions cont.

- The appropriate age for assent is lower for adolescents (14.5 years) compared to parents (16 years) but higher compared to the assent age used in most institutions.
- Re-contact for re-consent was considered important by the majority of all participant groups.
- The continued use of samples in the absence of re-consent was considered acceptable by the majority of participants

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HEALTH

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Original article

Opinions of Adolescents and Parents About Pediatric Biobanking



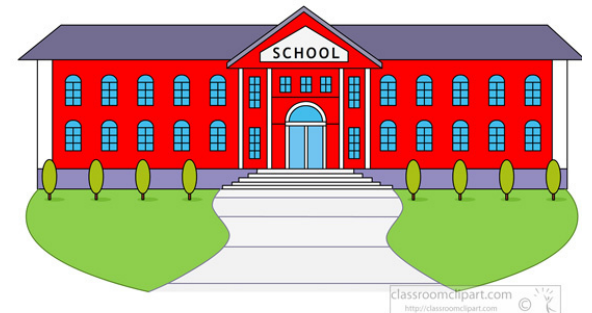
Cynthia C. Kong, M.D.<sup>a</sup>, Tamsin E. Tarling, M.Sc.<sup>b</sup>, Caron Strahlendorf, M.B., B.Ch.<sup>a,b,c,d</sup>,  
Michelle Dittrick<sup>e</sup>, and Suzanne M. Vercauteren, M.D., Ph.D.<sup>a,d,e,f,g,\*</sup>

<sup>a</sup> Faculty of Medicine, University of British Columbia, Vancouver, British Columbia, Canada

*Kong et al, J Adolesc Health. 2016 Apr;58(4):474-480*

# Extended school survey

- Would education about biobanks
  - change how school adolescents and parents respond to survey?
  - Increase willingness to participate
- Surveyed adolescents in high schools after giving them a 15 minute education session (BCCH BioBank video plus power point) about biobanking
- Surveyed parents of high school students having asked them to watch out BioBank video

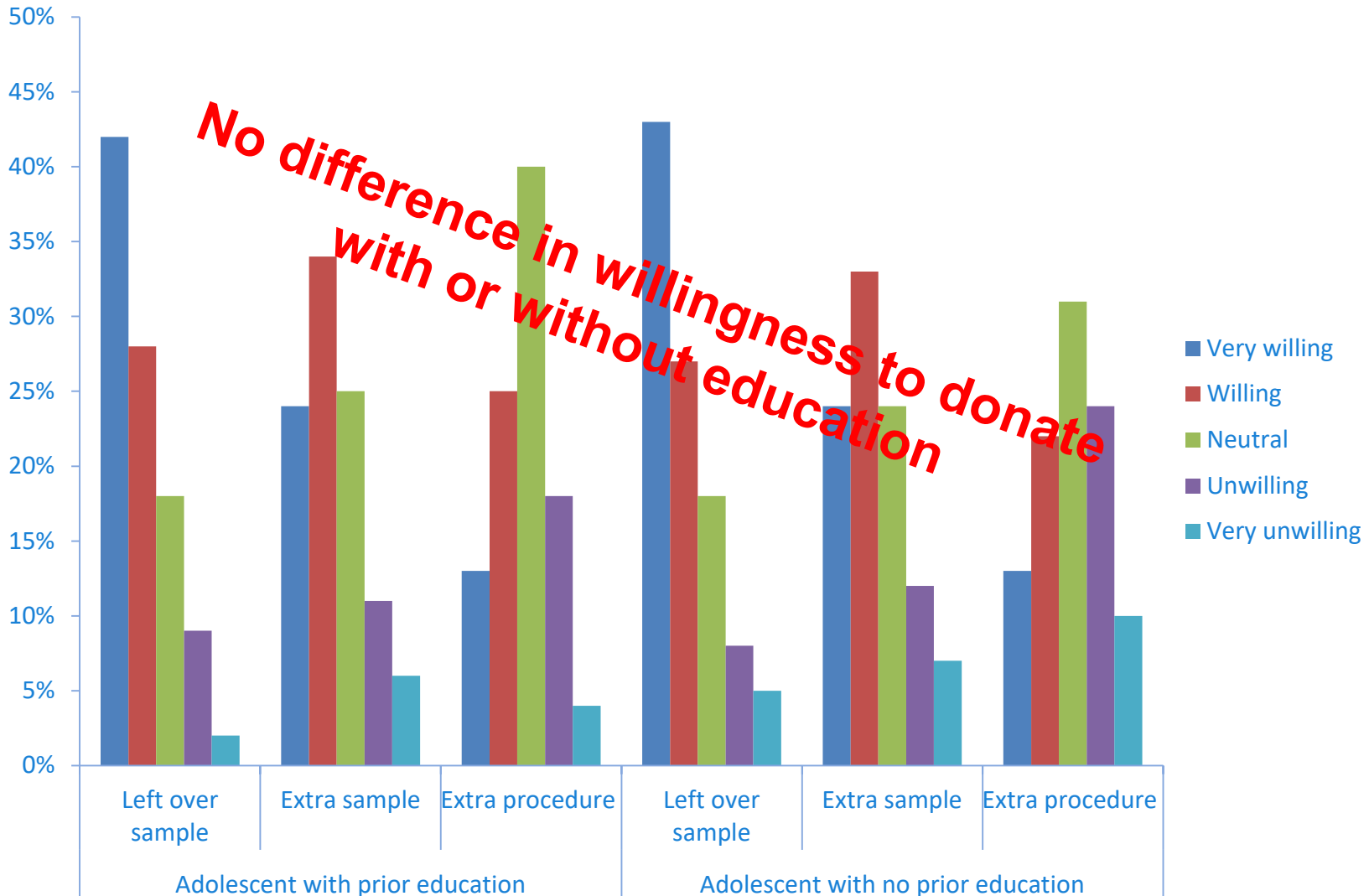


# School Survey Demographic

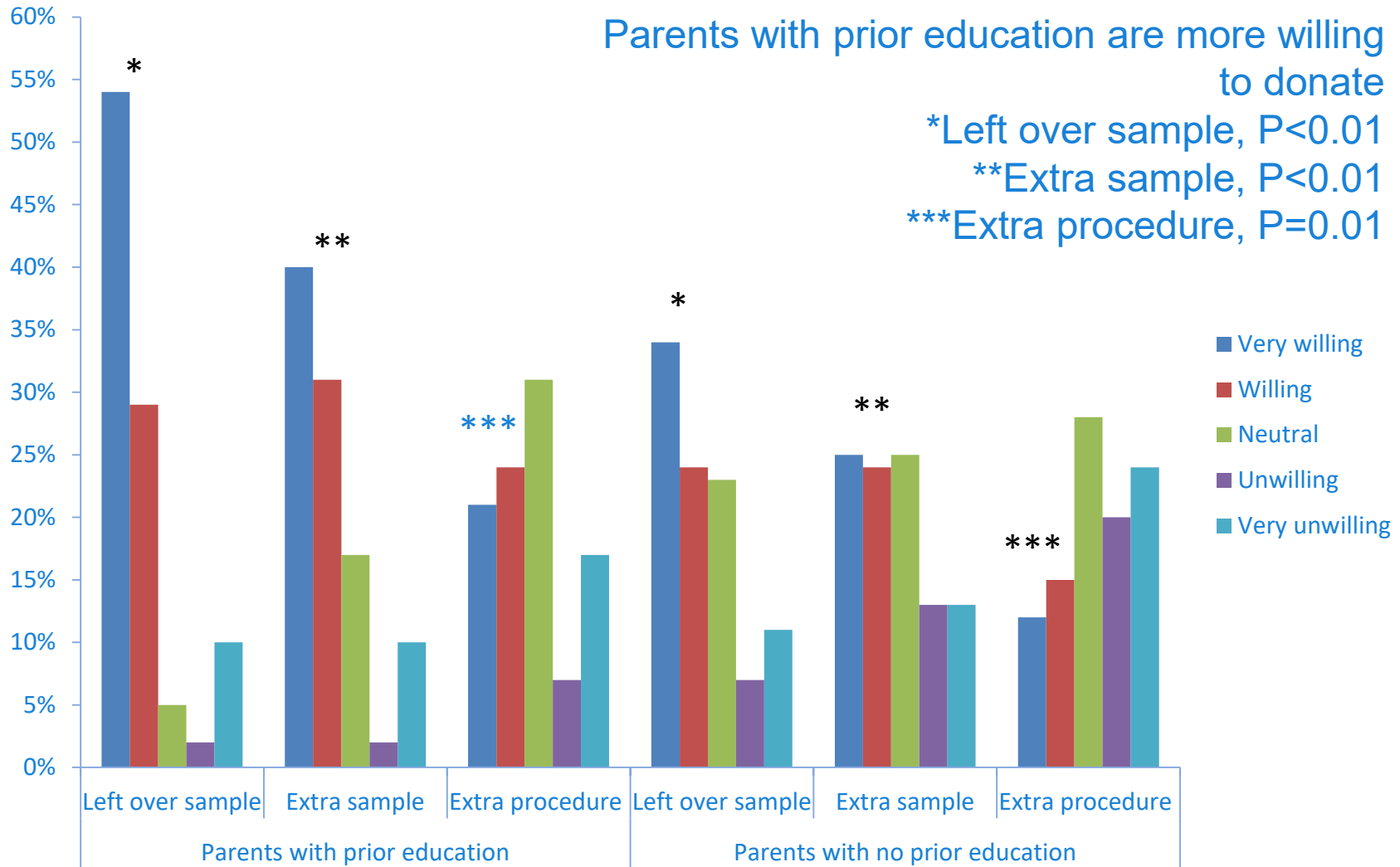
	Adolescents	Parents
# responding to survey with no prior education session	219	176
# responding to survey with 15 minute education session	106	44
Total	325	220



# Willingness to donate samples under various conditions - Adolescents

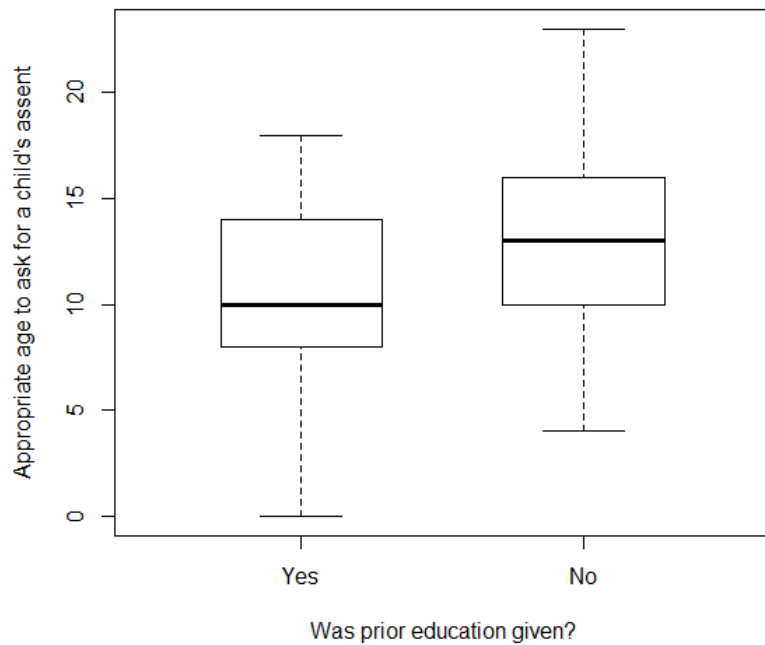


# Willingness to donate samples under various conditions - Parents



# Appropriate age of Assent

## Adolescents

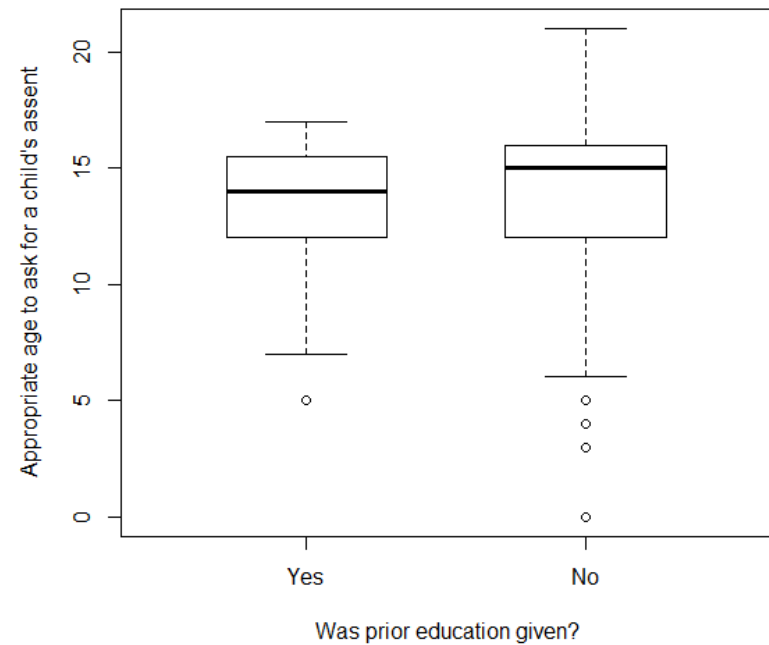


$P < 0.01$

Median age with education = 10

Median age without education = 13

## Parents



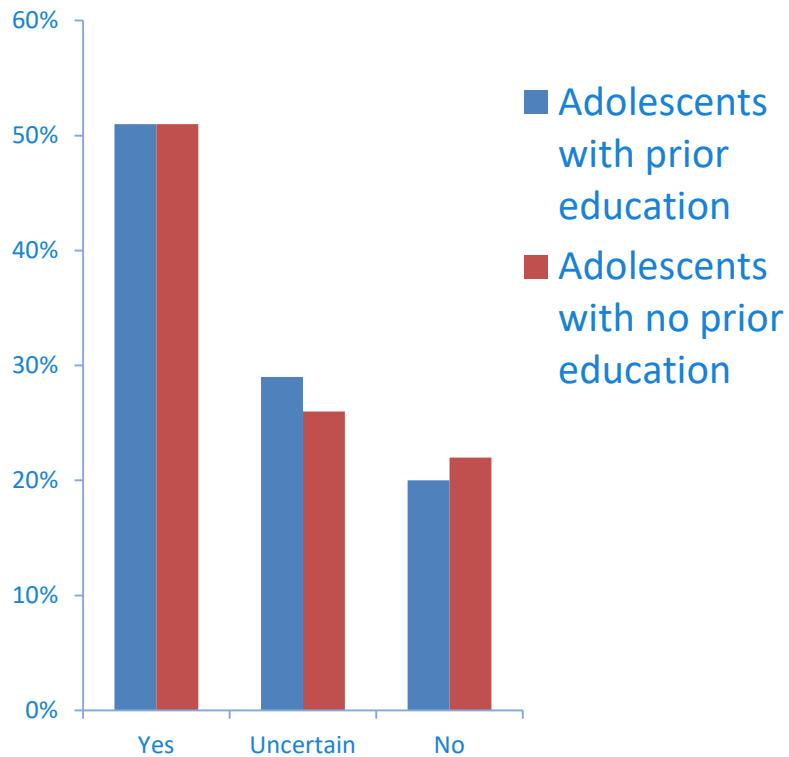
No significant difference

Median age with education = 14

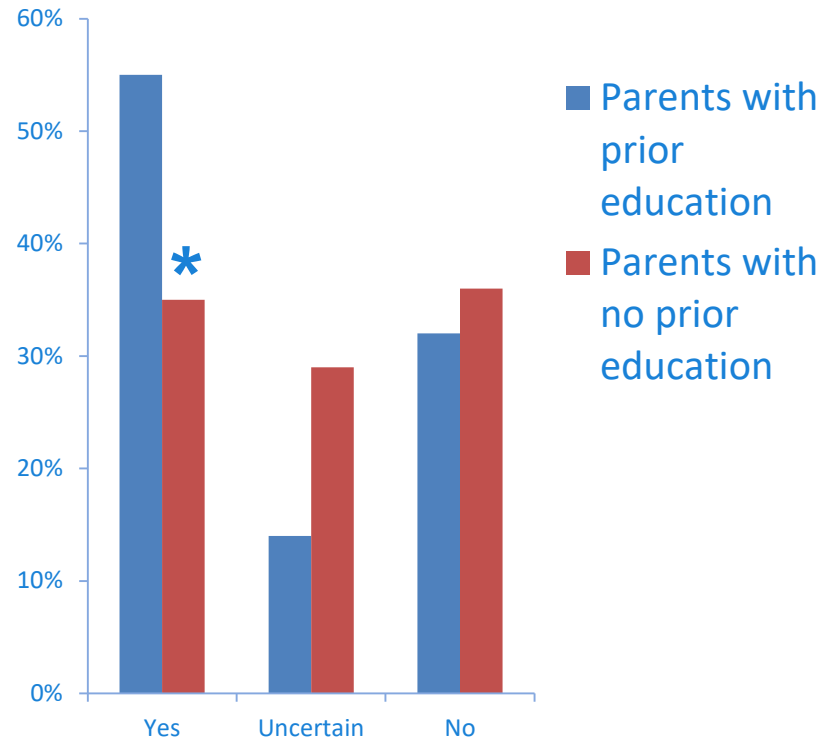
Median age without education = 15

# In absence of re consent, can your sample be used?

- Adolescents



- Parents



\* P = 0.03

# Conclusions

- Willingness to donate did not significantly change in adolescents after education
- Parents willingness to donate their child's samples increases with education
- Adolescents opinion on age of assent is lower after education

# Further work

- COVID 19 survey in BC public schools (Grade 8-12)
- Objective:
  - To see whether opinions on participation in medical research among adolescents has changed since the COVID-19 pandemic
  - To determine opinions of adolescent about vaccinations including barriers and benefits
  - 15 school districts are participating
  - 500+ completed surveys

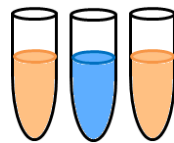
# Equality, Diversity and Inclusion

- Currently we are not collecting data with regards to gender, ethnicity, minority populations for BioBank participants:
  - How can we do this in a cultural appropriate/safe manner
- We are in the process of translating our BioBank video in two other languages (common Chinese and Punjabi subtitles)
- Inclusion of patient partners
- Information about biobank participation in a cultural sensitive manner

# Questions

## Thank you:

- Jonathan Bush, Co-Director
- Ashton Ellis
- Veronica Chow
- Vi Nguyen
- Qudrat Aujla
- Many people who have helped the BioBank including clinicians and researchers
- Special thank you to Tamsin Tarling



CHILDREN'S HOSPITAL  
**BC BioBank**

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