

A survey of pregnant women and new moms regarding their opinion of research, biobanking, and the consent process

Ashton Ellis^{1, 2}, Paige Muir^{1, 4}, Qudrat Aujla¹, Pascal M. Lavoie^{3, 5}, Michelle Dittrick² and Suzanne Vercauteren^{1, 2, 4, 5}

¹ BC Children's Hospital BioBank, Vancouver, Canada, ² Department of Pathology and Laboratory Medicine, University of British Columbia, Vancouver, Canada ³ Division of Neonatology, Department of Pediatrics, University of British Columbia, Vancouver, Canada, ⁴ Faculty of Medicine, University of British Columbia, Vancouver, Canada, ⁵ BC Children's Hospital Research Institute, Vancouver, Canada

Introduction

- The BC Children's Hospital BioBank (BCCHB) recruits patients of BC Women's Hospital (BCWH) to donate maternal samples such as placenta, cord blood and maternal blood.
- Recruiting maternity patients to take part in research can be challenging as it is highly dependent on appropriate timing.
- Ideally, consent is obtained well before delivery, though this necessitates confirmation of consent closer to delivery to verify continued agreement.
- In addition, there may be numerous research projects relevant to each patient. As a result, they may be approached multiple times for research participation.

Hypothesis

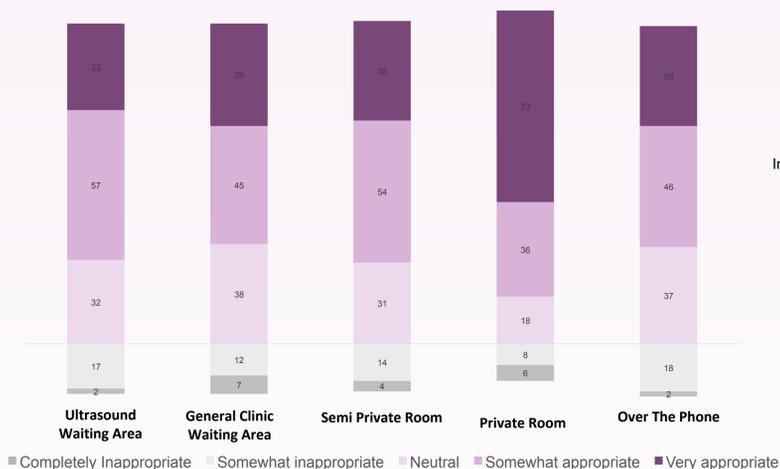
- Pregnant women and new mothers are interested in participating in research but are not provided the opportunity.**

Methodology

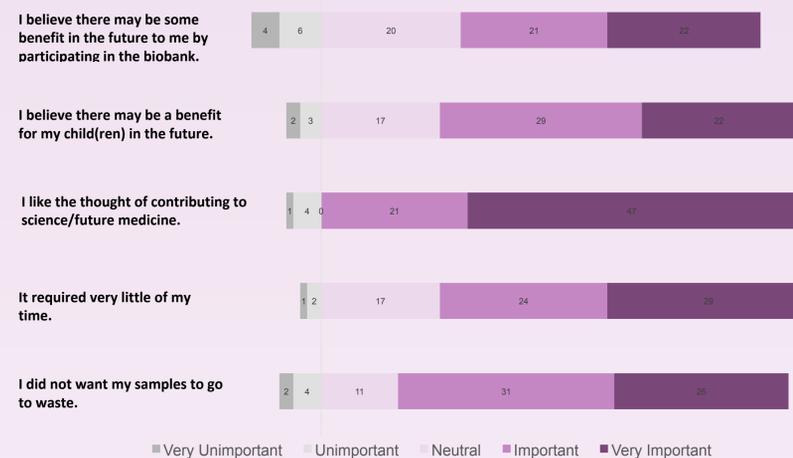
Maternity patients were invited to complete an online survey. Survey links were distributed through social media channels and to current BCCHB participants. The survey consisted of 24 questions with Likert scale for assessment. Only completed surveys were analyzed.

Results

Appropriateness of Care Areas for Consenting

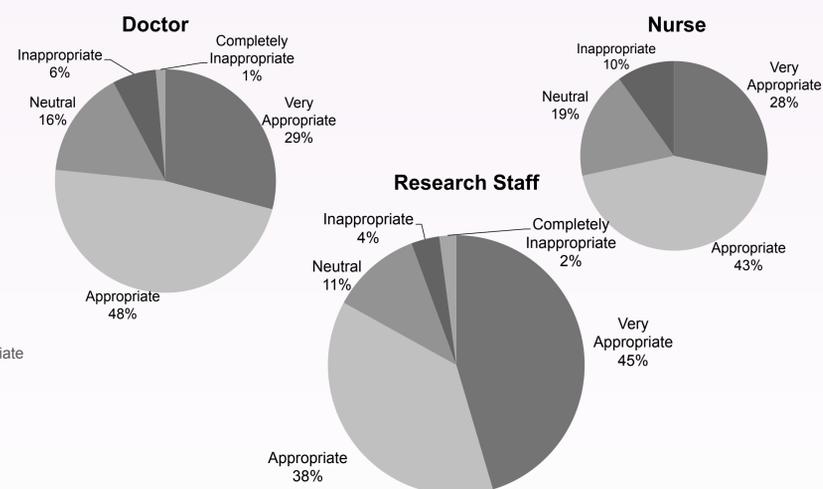


Why Some Participants Agreed to Participate in the BCCH BioBank



- Respondents were between the ages of 19 and 47, and 50/141 of participating women had previously consented to the BCCHB.
- 91% of women agree on the importance of research at BCWH but over half have not been asked take part in research.
- Similarly, 90% of mothers believe it is important that BCWH supports a biobank of premature births, yet 67% have not heard of the Premie BioBank, Canada's first biobank of this type.
- 87% of respondents would agree to donating leftover biological samples to a biobank.
- 70% of responders would prefer a single overarching consent either with or without a summary sheet if several studies are conducted at the same time.
- 80% of women indicated they would prefer to have BCCHB staff administer the consent form, but 83% of participants would like the concept of the BioBank to be introduced to them by someone in their circle of care first.

The Most Appropriate Person for Consenting



Conclusion

- The majority of pregnant women or new moms are supportive of research and are willing to donate samples to research.
- Increasing awareness may facilitate increased participation and stakeholder engagement in research.
- Implementing a single consent covering the BCCHB as well as other research studies is an acceptable method which may aid recruitment while decreasing patient burden.

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References

- Nam, Hye-Young, et al., 2011, Pharmacogenomics. doi:10.2217/pgs.11.24
- Critchley, Christine R., et al., 2012, The European Journal of Public Health. doi:10.1093/eurpub/ckq136
- ISBER, <http://www.isber.org/>. Accessed 8 April 2020.
- World Medical Association Declaration of Helsinki: Ethical Principles for Medical Research Involving Human Subjects, 2013, JAMA. doi: 10.1001/jama.2013.281053
- The Belmont Report: Ethical Principles and Guidelines for the Protection of Human Subjects of Research, 1979, PsycEXTRA Dataset. doi:10.1037/e301872003-001

