

Past DSP Lab Projects

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Vulvovaginal Health and Hygiene Practices and the Vaginal Microbiome

Scientists have long realised the importance of microbial communities in the maintenance of genital/vaginal health. However, very little is known about the cultural, social, and psychological factors that influence these microbial communities. More specifically, we know very little about the types of vulvovaginal health and hygiene-related products and practices that women use and engage in that may affect women's health. This project is part of a larger team of scientists, clinicians, and researchers (the VOGUE team) studying the vaginal microbiome (read more about the [VOGUE Research Team](#)).

To learn more about Canadian's vulvovaginal health and hygiene practices, we conducted the following studies:

1. Women participating in biological studies as part of the larger VOGUE project completed a behavioural survey exploring their use of vaginal health and hygiene-related products, such as douches, wipes, and probiotics, and their experience with various vaginal practices.
2. A nation-wide online survey exploring the use of vaginal health and hygiene-related products, experience with various vaginal practices, vaginal health history and experiences, and sexual health history and experiences. Participants received a [summary of the survey results](#). The main findings are presented in [Crann et al. \(2018\)](#). See [Wood et al. \(2017\)](#) for findings related to sex toy use among Canadians.
3. Two qualitative studies (one in Southwestern Ontario and one in British Columbia) were conducted to learn more about the social, cultural, and motivational influences for vulvovaginal health and hygiene-related practices, such as using vaginal hygiene products like douches, wipes, or deodorant sprays, or engaging in particular vulvovaginal practices such as hair removal and cosmetic surgery. See [Crann et al., \(2017\)](#) and [Jenkins et al. \(2017\)](#) for main findings.

Inflammatory Bowel Disease and the Involvement of Children in Health Research

Similar to the Cystic Fibrosis study (below), this project also looks at children's experiences of participating in biomedical research. The main focus is on the social and ethical implications of large long-term research studies, in which children are enrolled at an early age. Although there is evident benefit to society from these children's involvement in the research, the ethical implications are not clear, as children are enrolled before they are old enough to meaningfully provide informed consent. Interviews with children who have participated in such research will help us to learn more about their experience as a research participant, their process for deciding whether to participate, their interpretations of the risks and benefits of participating, what participating in research means to them

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and the role that they and their parents took in the decision process. Our current project, in collaboration with clinicians and researchers at the Children's Hospital of Eastern Ontario in Ottawa, focuses on the experiences of children with Inflammatory Bowel Disease (IBD) who have participated in health research. Participants received a [summary of results](#).

Inflammatory Bowel Disease (IBD): is a debilitating gastrointestinal disorder affecting a wide population of children, adolescents and adults in Canada. IBD describes a group of conditions including Crohn's disease (CD) and ulcerative colitis (UC), both of which result in an inflammation of one's gastrointestinal tract. There are almost 301,000 Canadians living with IBD: 113,000 with CD and 88,500 with UC. The burden of IBD on patients are thus a significant source of being able to give a patient's different and equally important perspectives pertaining to the ethics of children's research involvement.

Cystic Fibrosis and the Involvement of Children in Health Research

This project looks at children's experiences of participating in biomedical research. The main focus is on the social and ethical implications of large long-term research studies, in which children are enrolled at an early age. Although there is evident benefit to society from these children's involvement in the research, the ethical implications are not clear, as children are enrolled before they are old enough to meaningfully provide informed consent. Interviews with children who have participated in such research will help us to learn more about their experience as a research participant, their process for deciding whether to participate, their understanding of the risks and benefits of participating, and the role that they and their parents took in the decision process. This project, in collaboration with researchers at SickKids Hospital in Toronto, focuses on the experiences of children with Cystic Fibrosis who have participated in health research, though future work will examine the experiences of children with other diseases. Participants received a [summary of results](#).

Cystic Fibrosis: Cystic Fibrosis (CF) is the most common fatal genetic disease among individuals of European descent. One out of every 2500 babies are born with the disease, and 1 of 25 individuals carry a recessive CF allele. The most common cause of death for CF patients is due to respiratory problems associated with repeated episodes of bacterial infection of the airways. Our project is part of a collaboration with natural scientists who aim to characterize the composition and dynamics of the microbial communities found in the CF lung with the long-term goal of establishing guidelines to assist clinicians in the design and selection of therapies tailored for individual patients. However, even the beneficial outcomes of this research come with difficult ethical and social challenges. Particular issues that need to be addressed include how informed consent is managed, as it is generally provided by parents on behalf of their children, and how incidental findings are managed (for example, information identified about patients during their participation in research may later lead to them to be denied a lung transplantation). This research project will therefore engage with the CF patient community, in particular children or young adults who were enrolled in research as children, documenting their experiences and providing a conceptual analysis of the social and ethical implications of medical research in this area. It is hoped that this project will lead to improved policies in CF research and child enrollment in medical research.

Experiences of Research Participation of Adults who have Cystic Fibrosis

The purpose of this study is to understand the ethical and psychosocial aspects of long term involvement in biomedical research. Although ethics protocols have been developed to protect the rights of individuals participating in biomedical research, the changing landscape of this research (i.e., biobanks and long-term cohort studies) has raised new challenges with respect to the adequacy of these practices. Faced with these new advances, it is essential to conduct systematic studies into the lived experiences of populations participating in biomedical research in order for Research Ethics Boards to make informed decisions about the research involvement of such populations.

A key aspect of the proposed study is to gain an understanding of the perspectives towards research participation across the lifespan. This project will specifically focus on the remembered experiences of

adults with Cystic Fibrosis (CF) regarding their participation in research related to their illness when they were children. Individuals with CF are in a unique position of being able to give an account of different and equally important perspectives pertaining to the ethics of research involvement. Most patients with CF are involved in biomedical research from a very early age. Therefore, many patients with CF may be well aware of the burdens and possible risks of research participation. On the other hand, patients with CF may also be aware of the tremendous advances achieved through biomedical research because of the important impact the results of this research have had in extending their lives.

Disease Perceptions, Asthma, Antibiotics, and the Respiratory Microbiome

This project is about asthmatics' understandings and experiences of living with asthma and how these might change owing to developing medical knowledge on the human microbiome. A team of scientists in BC is currently investigating the link between asthma and use of antibiotics in early childhood. There is strong evidence that gut microbes are critical in the development of the human immune system, and growing evidence that they are linked to the potential development of asthma in particular. Currently neither expert medical nor lay understandings of asthma include consideration of a microbial component. As evidence is emerging for such a link, there are implications for how asthma is treated and how asthma sufferers experience and understand their illness. For example, will a microbial understanding of asthma lead patients to change their daily practices such as hand washing, house hold hygiene, and social interactions? Might a microbial etiology of asthma lead to the disease being viewed as infectious and lead to shunning or discriminatory practices? How might broader societal discourses of asthma be shaped by this new knowledge?

The psychosocial component of this project involves:

1. Theoretical and empirical work on the social construction of asthma (i.e., how the symptoms of asthma are interpreted according to dominant understandings that are historically and culturally situated). Currently, we have collected 102 years of newspaper articles (1910-2012) from The Globe and Mail. Using qualitative methods, such as thematic analysis and discourse analysis, we are examining various social representations of asthma (e.g., constructions of causal reasoning models relevant to the etiology of asthma) and asthmatics (e.g., portrayals or stereotypes of asthmatics)
2. The lived experience of asthma sufferers and their care givers. We have conducted interviews with asthmatics and caregivers of children with asthma about their experiences with and understandings of asthma. Qualitative analysis of this data is informing conference presentations (e.g., poster on the stereotypes and stigmatization of asthmatics) and publications (e.g., a theoretical understanding of asthmatics' process of monitoring their asthma).

Direct to Consumer Genetic Testing and Privacy Concerns

Direct to consumer genetic testing (DTCGT), or online genetic testing, allows people to order genetic tests directly from a company to learn more about their ancestry, asses a wide array of potential diseases and health issues, or determine the chances of their children inheriting a genetic disorder. As a result, people now have access to health relevant genetic information without the aid of a physician, though the quality of this health information is largely unregulated. While much of the research on DTCGT focuses on the health risks and healthcare burden of such practices, little research has examined the privacy risks associated with entrusting private companies with one's genetic material. Research that explores the ethical and privacy implications of biobanks tends to focus on publicly funded biobanks, many of which are embedded in the existing health system. Discussions have only just begun to turn to the additional privacy concerns that arise from private companies having access to, storing, and conducting research with genetic samples and information provided by their customers.

In order to fill this important gap in the literature regarding knowledge of the privacy risks of engaging with private companies for genetic testing, we conducted a review of the websites of DTCGT companies

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to determine what information they communicate about the way they handle people's private information. We then surveyed customers to learn more about their experiences with DTCGT and to see how they interpret the privacy information. We also provided recommendations of best practices for DTCGT companies in presenting privacy information to consumers, offered some considerations for regulation of DTCGT companies, and created a guide to consumers in considering the purchase of a DTC genetic test. To read more about this project and the findings, please download our [final report](#), delivered to the Office of the Privacy Commissioner of Canada, who funded this project under their Research Contributions Program.

Biobanks and Biomedical Data Sharing

Biobanks are large collections of human biological tissue specimens. The use of biobanks for medical research promises faster discoveries, for better diagnostic tests and more personalised treatment options. However, biobanks come with many ethical challenges, and complex social and cultural implications. This aspect of DSP research consists of several projects with different collaborators. In addition to biobanks, a related focus concerns the ethical, legal, social implications (ELSI) of data sharing in large scale genetic and genomic studies. Increasingly, there are pressures on scientists conducting genetic research to share their data, which is then made available to other scientists via electronic platforms. However, the implications of these practices for research participants are not clear. How do they feel about this? What are the implications for privacy and insurance? Could law enforcement or immigration agencies gain access to these data?

For a public deliberation project on biobanks conducted with collaborators in British Columbia see <http://biobanktalk.ca/>

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