TOMORROW'S NEWS

UPDATE ON ALBERTA'S TOMORROW PROJECT
ESTABLISHED IN 2000 TO LEARN MORE ABOUT CANCER AND CHRONIC DISEASE

ALBERTA'S TOMORROW PROJECT
Inspiring research for a healthier tomorrow

VOLUME 13 | ISSUE 1 | SPRING 2024

Letter from our Directors

Dear ATP Participants,

This last year we capped off our Survey 2023, and what a success!

- Over **21,000** of you logged on to complete Survey 2023.
- Over **14,000** also completed the optional diet and physical activity survey.

Thank you. This was the longest and most comprehensive survey we've ever done, and we know it was time-consuming. We appreciate your efforts to do this survey and we are paying attention to your feedback in planning for future surveys, which may be more focused.

In fact, we are already planning our next data collection activity (you can read more about how we develop our surveys), which will likely be about diet and physical activity. You may remember that we previously planned to do this, but it was put on pause in 2020 due to the pandemic efforts. We are excited to share that we are reviving this activity thanks to additional funding through a Canadian Institutes for Health Research grant led by Dr. Rachel Murphy (University of British Columbia) and Dr. Sharon Kirkpatrick (University of Waterloo), which will support data collection in ATP participants as well as participants in other provinces across Canada, who are also part of the national CanPath research platform.

More information will come, but the goal is to collect comprehensive information about your diet and physical activity over time. This will allow us to get the best data possible and enable research into how these activities influence cancer and chronic disease. Diet and physical activity are important for reducing risk of cancer and chronic diseases, as well as at every stage in the health or disease journey, for example they may influence how you respond to treatment. What we eat and how much we exercise are also impacted by many external factors (such as access, availability, your neighbourhood, cost, preferences, and social and cultural influences), which all need to be considered in the context of how these impact our health.

DR. JENNIFER VENA AND SHANDRA HARMAN
(photo by Leah Hennel)

We are also looking forward to moving into our new home at the Arthur Child Comprehensive Cancer Centre later this year, which will open for patient care in fall 2024. We are excited to be part of this amazing facility, which will co-localize research and patient care. Our offices and biobank will both be moving to the new centre (read more about ATP's biobank below).

ARTHUR CHILD COMPREHENSIVE CANCER CENTRE RADIATION THERAPY MACHINE

Letter from our Directors

(continued from page 1)

Now, we are often asked, how are the data and biological samples you have provided being used? Well, many researchers are making good use of it. In fact, to date there have been over **100 projects** using ATP participant data which has resulted in over **120 scientific papers** being published. In this newsletter you can read about Dr. John Lewis, a researcher using ATP data and biological samples, who is developing a new minimally invasive prostate cancer screening test.

We also share how ATP data is helping to support the next generation of researchers.

Finally, to help promote ATP and the valuable data you have contributed, we created three videos to showcase what ATP is and what we do, including: an overview of ATP, our data and biosample collections, and how researchers can request access to these resources. You can find these videos on our YouTube channel; feel free to subscribe and share them with family and friends!

Thank you again for your contributions to ATP—we couldn't do this without you, and we are continually grateful and humbled by your support and dedication.

Best in health,

DR. JENNIFER VENA,
Scientific Director

SHANDRA HARMAN,
Strategic Director

Alberta's Tomorrow Project ■

ARTHUR CHILD COMPREHENSIVE CANCER CENTRE EXTERIOR

Participant Feature: Lorna-Mae Reidy

Deeply moved by the painful loss of several family members to cancer, Lorna-Mae joined ATP in 2007. For the past 17 years she has been a dedicated participant, generously volunteering her time and completing numerous health and lifestyle questionnaires.

LORNA-MAE REIDY AND FAMILY

Lorna-Mae's interest in helping others lead a healthy life began when she was just seven years old. During a long-term hospital stay she developed a great fondness and respect for the nurses who cared for her, and she went on to be a nurse herself for an impressive 43 years.

We asked Lorna-Mae – what prompted her to join ATP? She said that it takes little time to fill out a survey and that she is happy to do so if it helps researchers looking at the causes of cancer and chronic disease.

Last year, at the age of 81, Lorna-Mae completed her first online survey for ATP. "Computers are the wave of the future" she says, "plus it must be easier for ATP staff to collect the information that way". She admits she was a little apprehensive at first, but then she thought to herself, "why would I [give up] after all these years? Just bite the bullet". So, Lorna-Mae reached out to ATP where a Project Assistant who was "friendly and encouraging" was able to help her get set up to complete the survey online. Lorna-Mae's optimism is infectious, and she encourages others who are hesitant to take a stab at it and reach out to ATP staff if they are having trouble.

Lorna-Mae's optimism also extends to the research being done with ATP data and biosamples. She says research is how we have learned everything so far, so she is hopeful that someday ATP participants' contributions can be used to help make discoveries to prevent and treat cancer and other chronic disease.

When asked what she thinks ATP should focus on next, Lorna-Mae says she would like to see ATP ask questions about exercise and diet. Anecdotally, she has noticed a decline in physical activity and the eating of homecooked meals, and she wonders about the impact on people's health. Fortunately, ATP is in the midst of developing a plan to collect detailed diet and physical activity information from participants soon.

It's clear that Lorna-Mae lives a full and meaningful life. She had four daughters with her husband of 50 years, and she fills her time with a long list of activities such as baking, needlepoint, puzzles, and reading. She is also an avid sports fan (cheering on the Edmonton Oilers and Saskatchewan Roughriders) and adores babysitting her grandchildren.

Lorna-Mae is grateful for this full life and her health, especially considering she had a close call with a serious tuberculosis infection in her youth. Nowadays though, she is less worried about her own health. Instead, she says she is "at the age where I worry about my children and my great grandchildren" and ensuring that she does her part to improve the health of those future generations. ■

New Prostate Cancer Screening Test Offers Less Invasive Option

Prostate cancer is the most common cancer diagnosis in men, with one in six being diagnosed in their lifetime. Prostate cancer can either be localized or metastasized.

Metastasis means that cancer has spread to other parts of the body, and when this happens with prostate cancer it becomes an incurable disease. However, when the cancer has not spread it is a far more manageable disease. As Dr. John Lewis says, "no man has ever died of prostate cancer that stayed in the prostate". This is why early, and easy, diagnosis of prostate cancer is so crucial—to catch it before it spreads.

Dr. John Lewis is an expert in this area, serving as both a University of Alberta professor in the Department of Oncology and as the CEO of Nanostics (a medical device and biotechnology company). ATP interviewed Dr. Lewis on his use of participant data and biological samples back in 2014 and it is our pleasure to share some exciting developments that have emerged since then.

Technologies such as DNA sequencing now allow us to better understand how a person's genetics may affect their chances of developing aggressive prostate cancer and how they might respond to different treatments. Treatments have also improved, especially for aggressive prostate cancer, making it easier for doctors to identify and then eliminate specific cancer cells.

Even with these valuable advancements, screening is essential to catching prostate cancer before it spreads. Traditionally, this has been done using a prostate specific antigen (or PSA) test. Higher PSA levels can indicate an increased chance of prostate cancer – however, according to Dr. Lewis, a lot of the time the individual does not have aggressive cancer, which is a major limitation of this test. This means that doctors must verify these results through a biopsy, which is an invasive procedure that involves using a needle to take a tissue sample from the prostate. Due to these issues, use of the PSA test as a screening tool has been on the decline, but the flip side of this means that more high-risk prostate cancer cases are being missed.

Clearly, there is a need for a more accurate screening tool that can identify aggressive prostate cancer, and this is where Dr. Lewis and team come in. For the past 12 years, they have worked tirelessly to develop a new and improved screening test called ClarityDX Prostate. This is a simple and accessible blood test, which provides a risk score that predicts aggressive prostate cancer. This blood test makes it possible to avoid around 35% of unnecessary and invasive biopsies and helps men diagnosed with prostate cancer understand if they will benefit from certain treatments or not. Currently this test is available as a private pay test and can be ordered through a physician, but Dr. Lewis' team is working with Alberta Health and Alberta Health Services to have it paid for by the province.

This breakthrough would not have been possible without the use of data and biological samples donated by ATP participants. By combining large datasets from several prospective cohort studies, including ATP, Dr. Lewis's research team was able to implement advanced computer science techniques to develop the ClarityDX Prostate test.

DR. JOHN LEWIS

As for what lies ahead, Dr. Lewis believes that the future will be about personalization – understanding an individual's risks, how they respond to cancer treatments, and more. This will allow for personalized treatments and better outcomes. However, this can only be achieved if research teams have the appropriate and sufficient data to explore, which is precisely why the information ATP participants provide is so valuable. As Dr. Lewis explains:

"We simply cannot do what we do without information provided by ATP participants. It is absolutely critical to have real human experience and information to be able to test our ideas. Improved data collection over time will allow us to build better tools for diagnosing and treating cancers." ■

ATP Supporting the Next Generation of Researchers

ATP not only supports cutting-edge research led by established researchers such as Dr. Lewis, but we also help students and early career researchers on their journey to becoming the next generation of world-class scientists and health professionals.

ATP allows students to access participant health and lifestyle data under the supervision of a qualified researcher. One such supervisor, is Dr. Trevor Dummer; the National Scientific Co-Director of the Canadian Partnership for Tomorrow's Health (CanPATH) and formerly the Co-Scientific Director of BC Generations Project (BCGP). Under his wing, his students have been using information collected from ATP participants to investigate the connections between air pollution, neighbourhood walkability, and cancer diagnosis.

When asked why his students like to use ATP data for their projects, Dr. Dummer stated that it is because ATP "has been following up with participants over the course of two decades" making it a rich source of 'mature' or longitudinal data. Getting the chance to work with this sort of data prepares students for success in future research and healthcare roles. He also mentions that many student projects use both ATP and BCGP data, which allows for comparisons between the provinces.

The quality of ATP data was also echoed by Dr. Dylan O'Sullivan—a research scientist with the Cancer Epidemiology and Prevention Research department of Alberta Health Services, as well as Adjunct Assistant Professor at the University of Calgary in the Departments of Oncology and Community Health Sciences—who used ATP data during his PhD and postdoctoral training. He studied the association between time spent in the sun and non-Hodgkins lymphoma, as well as lifestyle behaviours and colorectal cancer risk. Dr. O'Sullivan is interested in using large cohort data to solve questions in public health.

DR. DYLAN O'SULLIVAN

Since completing his PhD, Dr. O'Sullivan has been developing a research program around "precision prevention and screening" (how do we personalize preventive measures and recommendations, such as improving how we identify the people who should receive cancer screening, and follow-up surveillance of cancer survivors for development of new cancers). He intends to use ATP data again, only this time he will be in the role of mentor at the University of Calgary, training the next generation of health professionals.

ATP also supports the next generation by hosting public health practicum students.

One such practicum student, Paige Zurbrigg, came to ATP from the Bachelor of Public Health program at the University of Lethbridge. During her time at ATP, she studied the patterns of cervical cancer screening over time and what factors are associated with meeting screening recommendations.

When asked why she chose public health as a degree, she stated that

"Public health focuses on prevention rather than the treatment-focused aspect that we see in acute-care settings".

While at ATP, Paige was able to expand her analytical abilities using ATP data and truly felt like a collaborator, an otherwise rare opportunity as a young university student. Since then, Paige has become a permanent staff member at ATP and she intends to pursue a Master's of Public Health where she hopes to investigate the overlap between health research, health policy, and how we can turn health research findings into meaningful changes that improve the health of Albertans.

One thing was abundantly clear when interviewing the students and scientists for this article: they all wish to thank ATP participants for contributing their time to ATP over the last 20+ years. As Dr. O'Sullivan put it, "the research [we] do is only as good as the data that [we] get".

By answering ATP's questions about your life and health and donating your blood (and other things we have asked for throughout the years!), you enable scientists, healthcare professionals, and students to conduct high quality research that helps improve the health of our friends, family, neighbours, and future generations to come. ■

Creating a Survey: From Start to Finish

Since the project began in 2000, ATP has collected close to half a million completed surveys. In the last year alone, over 21,000 dedicated participants logged on to take part in our most recent survey, Survey 2023.

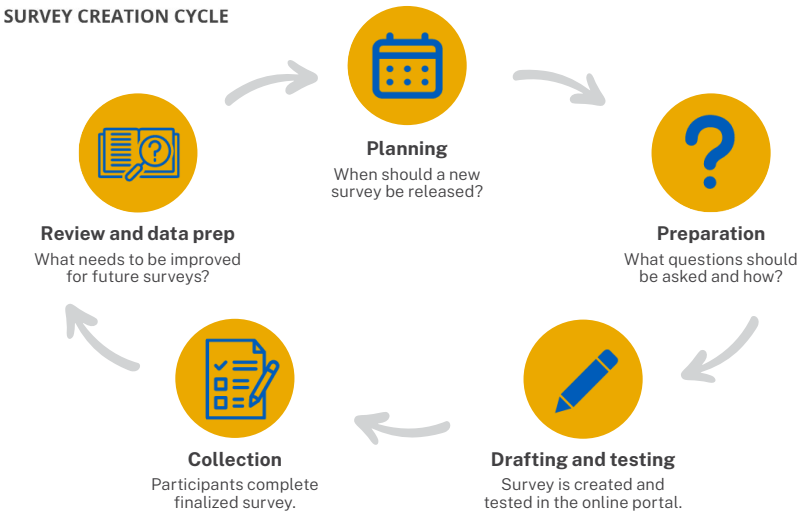
While participants see the surveys in their final form, the process leading up to a survey launch can be complex. So, what really goes into the development of a new survey? From the early stages of brainstorming to the final product, the ATP team explains our process!

The first major consideration that goes into launching a new survey is timing. ATP's Scientific Director, Dr. Jennifer Vena, says there is a fine balance to strike when considering how often to collect data from participants.

"We want to make sure you are not asked to complete surveys too often, but we also want to ensure we are interacting with you regularly to keep you involved with the study and that we are capturing how health and lifestyle changes over time".

So, ATP aims to release a new survey every few years.

The next step is brainstorming which topics and questions to include. ATP staff review scientific literature and previous surveys to see what was asked and to determine what is valuable to ask again. We also explore adding new and emerging topics through consulting with researchers from a variety of fields. Once the sections have been finalized, the team begins drafting the questions. As Dr. Vena mentions, "one of the big strengths of ATP is that we try to collect information from participants in the same way over time" which allows researchers to track changes in lifestyle, health conditions, and outcomes. This is why some questions might seem familiar – repeating them allows researchers to see how things have changed (or not).



After all questions have been created, the drafted survey undergoes extensive review by ATP staff, the Participant Advisory Committee (a group of ATP participants that provide feedback on surveys and more), and external researchers and knowledge users. This thorough review is to ensure quality and clarity. The final phase is for ATP's Data Analysts to build the survey that you see online. Once the survey has been successfully created in the participant portal it goes through further rounds of testing to eliminate as many errors and bugs as possible and to improve flow.

Before a survey is launched to all ATP participants, it is first circulated to a small group of participants as a test-run to catch any remaining errors and to make final improvements. Even after the survey has been released, ongoing improvements are made using feedback from participants who call or email us. Sometimes this might mean fixing technical bugs or adding more instructions. If you have ever provided suggestions to ATP, we want you to know that we track all of this and use it to inform future projects. For example, during Survey 2023 we heard that shorter surveys are preferred, which is valuable feedback as we plan for the future.

All stages of survey development involve immense effort and collaboration from a variety of individuals. Even after the survey closes, the ATP team must prepare the data for use by researchers and create resources for them to understand it. At the end of it all, data collected through these surveys provides researchers with more pieces of the puzzle to better understand cancer and chronic disease and will allow for personalized treatments and better outcomes. ■

ATP Staff Highlight: Wendy Powell, Bioresource Advisor

Between 2008 and 2015, more than 30,000 ATP participants came to one of our study centres and donated their blood, urine, and/or saliva.

It was at this time that Wendy Powell joined the ATP team. With a Master's in Physiology and previous experience running a research lab, Wendy was able to help plan the collection of biological samples and physical measurements from ATP participants across the province. For the last several years, she has been ATP's Bioresource Advisor, the in-house subject matter expert who helps look after your precious biosamples.

When asked why ATP sought to collect these samples, Wendy says, "we did that so that there could be future research on participants' samples... it's fascinating, because we have in fact captured a snapshot in time. It's a little window into the past".

These "windows into the past" are a valuable resource, and the fact that ATP began to collect samples for the purpose of future research over 15 years ago is quite remarkable considering, as Wendy notes, that this practice (known as biobanking) was relatively new at the time.

ATP's Bioresource Advisor is tasked with ensuring that participant samples are being used by researchers, but not in unnecessarily large quantities. Wendy likens the role to that of Goldilocks selecting porridge: she works with researchers to make sure that they only receive what is needed for their research, not more or less, but an amount that is just right. This is so the samples can be used for as many research projects as possible.

Another key part of Wendy's job is to work with ATP's research staff and other experts to make sure samples are released for rigorous projects that are aligned with ATP's goal of improving our understanding of the causes of cancer and chronic disease.

Lastly, the Bioresource Advisor can be thought of as guardian of the samples ATP participants so generously donated, which are held in a private and locked location that is only accessible to ATP's highly trained lab staff. The quality of the samples is ensured by storing them in ATP's freezers which run 24 hours a day with backup generators in place in case of a power outage. Wendy explains that these are not your ordinary household freezers, "while your freezer can keep things cool at -20°C, our freezers are at a whopping -80°C". ATP has 23 of these impressive freezers, each of which can hold between 80,000 and 90,000 samples!

FREEZERS WITH BIOSAMPLES IN ATP'S BIOBANK

WENDY POWELL IN ATP'S BIOBANK

When we asked Wendy to reflect on what working for ATP has meant to her, she shared,

"I have a family member with stage four cancer, and I have thought of her every day I've come into work. It's just so wonderful to have been part of this project where both staff and participants are working towards preventing this from happening to other people".

After 16 years at ATP, Wendy will be retiring this spring and passing on the baton to Gillian MacNevin, who has a Master's in Biology and has been working in research labs with a focus in biochemistry and molecular biology for over 15 years. Gillian is excited to step into the role of Bioresource Advisor and shares that she is "inspired by the dedication and commitment of ATP participants, and the passion and innovation of the ATP team and researchers". We wish Wendy a wonderful retirement and thank her for being an important part of ATP's legacy. ■

National Research Project Updates

Making strides toward a healthier tomorrow, together:

More than two-thirds of ATP participants are part of CanPath—the Canadian Partnership for Tomorrow's Health—Canada's largest population health study. Over the past year, CanPath, together with ATP and six other regional studies, has made significant strides to enhance and accelerate research for a healthier Canada.

Here are a few stories from this past year:

- Healthy Future Sask launched in February, representing Saskatchewan as the newest regional study addition to CanPath and completing the provincial map. Healthy Future Sask is actively recruiting participants.
- In June, the pan-Canadian team came together in Halifax for the Canadian Society for Epidemiology and Biostatistics Conference where ATP and our study colleagues from Atlantic PATH, CARTaGENE, the Manitoba Tomorrow Project, and the Ontario Health Study showcased groundbreaking research that was done using the data and biosamples you have contributed to health researchers.
- Last summer, at the University of Toronto's Artificial Intelligence (AI) for Public Health (or AI4PH) Summer Institute, students and early career researchers had the opportunity to use CanPath's Student Dataset, which mimics real data from participants but has been modified enough to protect the privacy of participants.
- CanPath (including ATP) contributed to the first publication of COVID-19 antibody testing data pooled from studies across Canada through the COVID-19 Immunity Task Force. Studies like this give us an idea of the spread of COVID-19 in the Canadian population throughout the pandemic. Thank you to the participants who took part in the ATP and CanPath antibody testing studies!
- In November, the regional studies came together in Halifax again for the Canadian Cancer Research Conference. CanPath Executive Director Dr. Jennifer Brooks co-chaired a CanPath session with a patient partner and Atlantic PATH participant, Pauline McIntyre. Four researchers using CanPath and regional study data presented their latest findings, including chemical exposures in the workplace and cancer risk, changes in cancer screening during the pandemic, risk factors for early-onset colorectal cancer, and an AI-based public health platform to predict cancer. ■

CanPath
Canadian Partnership for Tomorrow's Health

CCRC CONFERENCE, SHOWING DR. ELLEN SWEENEY (ATLANTIC PATH, DIRECTOR OF RESEARCH), DR. SARA NEJATINAMINI (ATP, RESEARCH ASSOCIATE), DR. TRAVIS HRUBENIUK (MTP, PROJECT LEAD), DR. JENNIFER VENA (ATP, SCIENTIFIC DIRECTOR), DR. RACHEL MURPHY (ASSOCIATE PROFESSOR, UBC; SENIOR SCIENTIST, BC CANCER), DR. JENNIFER BROOKS (CANPATH, EXECUTIVE DIRECTOR)

FAQs

What happens if I move outside Alberta?

You are still considered an active participant! ATP continues to follow participants even when they relocate out of the province or country. We simply ask that you contact tomorrow@ahs.ca and provide your up-to-date contact information such as mailing address, phone number(s), and email so we can continue to reach you.

What happens after I turn 85?

After you turn 85, you will no longer be required to complete our health and lifestyle surveys. We do this because ATP is a 50-year undertaking and since our youngest participants were 35 when we started, it makes 85 years the natural endpoint. This does not mean that you will no longer be contributing to ATP though! We will still receive updated health information for you each year through data linkage with hospital and medical records (if you consented to this when you joined the study), which will continue to support cancer and chronic disease research. After 85 you can also expect to continue to receive these annual newsletters!

I missed Survey 2023. Does this affect my participation going forward?

You remain an active and valued participant in ATP, even if you miss a survey for any reason (for example, Survey 2023 was only available online). There will be plenty more opportunities to participate in future surveys, which we aim to release every 2–3 years. Your continued participation is important!

How is participation post-cancer diagnosis helpful?

Every year since ATP began in 2001 there are more participants who receive a cancer diagnosis, even when they have been trying to 'do everything right' to live a healthy life. What can be learned going forward?

ATP was created to better understand cancer and chronic disease. Understanding how to prevent disease is of course important and is what we'd like to achieve in an ideal world. Equally important however, is understanding how we can have better outcomes throughout the entire cancer or chronic disease journey. This includes determining how we can develop better ways to identify who's at risk, figuring out the right treatments/interventions (and combinations) based on your situation, understand what you need after treatment is done, and more. In addition, many of the health/lifestyle aspects we associate with being good for preventing cancer or chronic disease (like eating well, exercising, and not smoking) are also important when managing, treating, and recovering from disease. To move the needle forward and better understand how disease evolves over time, responds to treatment, recovery and so on, we need to continue capturing information even after someone is diagnosed with cancer or chronic disease – it's just as, if not even more, important! ■

LAND ACKNOWLEDGEMENT

Alberta's Tomorrow Project acknowledges that our work takes place on historical and contemporary Indigenous lands, including the territories of Treat 6, Treaty 7 & Treaty 8, as well as the homeland of the Métis Nation within Alberta and 8 Métis settlements. We recognize the enduring presence and stewardship of Indigenous peoples on this land, which we all share, celebrate, and care for. By making this acknowledgement, we hope to illustrate our commitment to reconciliation.

Have you moved, changed your email address or phone number?

Please let us know if you have new contact information — we want to stay in touch!

HERE'S HOW TO UPDATE YOUR SECURE FILE

Contact the ATP call centre:

- Send us an email at tomorrow@ahs.ca
- Call the toll-free line 1-877-919-9292

Log in to the ATP participant portal:

- If already connected, go to myatphub.ca
- Log in with your Alberta.ca Account. Once logged in, click "Address Update" menu on left

CONTACT US

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Canada

For more information visit: myATP.ca

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