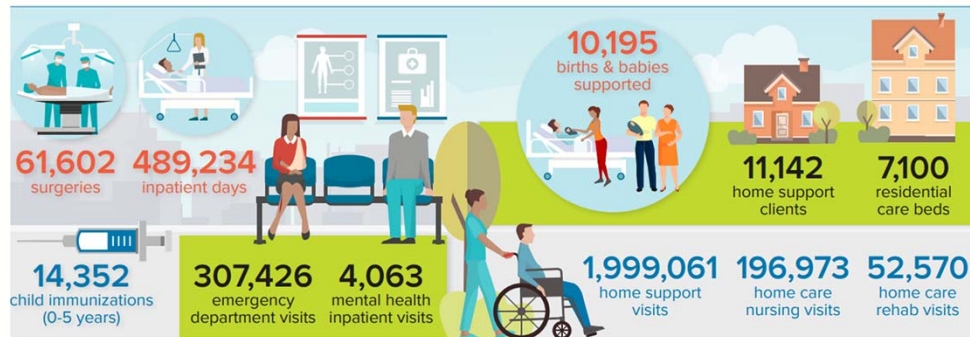


# What does Secondary Use mean at VCH?

Janine Johnston, Privacy Advisor, Research  
October 3, 2018



## VCH provides care and maintains services to support care...



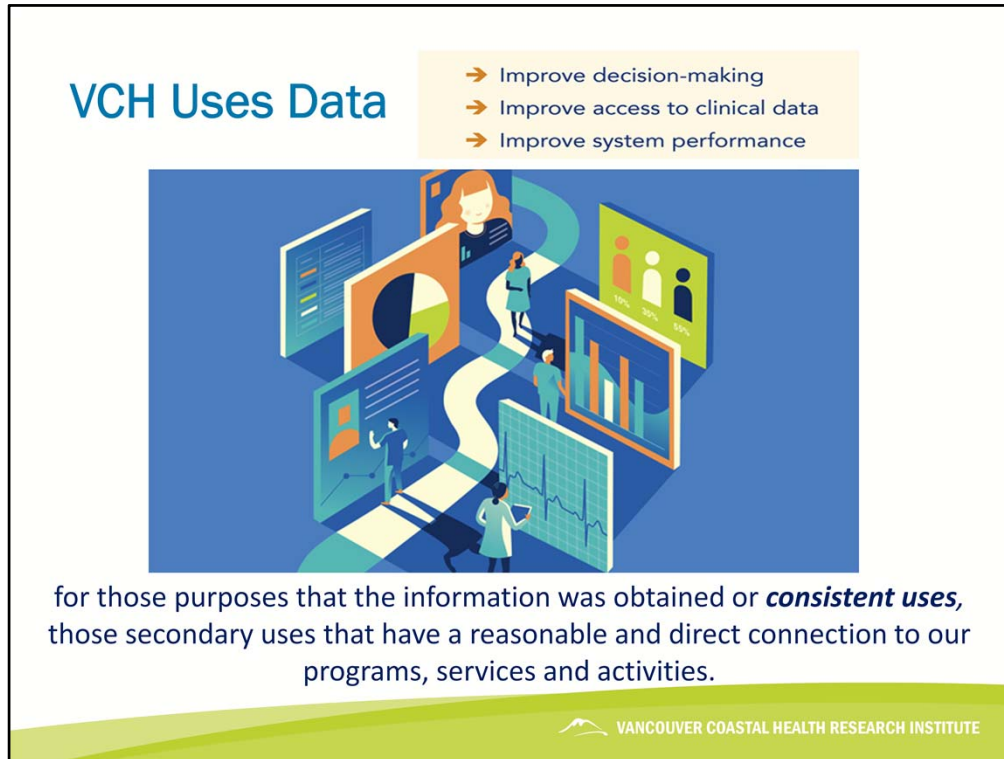
VCH collects information as it relates to our programs, services or activities.

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VCH Data is that data that has been collected by VCH in our systems, charts and other records in relation to our programs and services.

VCH typically collects personal information for the “primary purpose” of providing or supporting patient care. This information is captured at registration, clinical visits, and every time someone engages with VCH services.

VCH does not collect Personal Information specifically for QI or evaluation or research purposes.



VCH uses data to provide care, but also for consistent uses. *Consistent use* is a term in FIPPA and is often used interchangeably with secondary use, but it is a bit different.

Secondary use means a use other than the purpose for which the information was collected. Consistent use highlights that the purpose must have a reasonable and direct connection to the original purpose of collection.

If the use is considered a *consistent use*, the public bodies are authorized to use that information without consent.

Common consistent uses at VCH include:

- program planning, evaluation and monitoring, including quality improvement;
- system administration;
- privacy and security audits;
- medical education and training related to VCH programs;
- analysis, management and control of disease outbreaks and population health.

VCH staff can use data collected for these types of secondary uses as authorized under s. 32 (a) of FIPPA.



For most of our work, VCH collects, uses and shares data without patient consent. Collecting consent would be impractical and impede our ability to evaluate and improve on what we do.

As a publically funded organization, VCH cannot turn someone away if they refuse to allow us to use or share their information for the purpose we collected it or for a *consistent purpose*.

We do share information. We share it with our staff within in the Circle of Care - with specialists, nurses who will be involved in a patient's care, with lab staff who will test specimens to support diagnosis, but also the Health records folk who need to code information to ensure it is captured correctly in our systems, and our IT folk who store the information and manage our systems. We share information with the finance teams who ensure our services are adequately captured and billed to the Ministry.

We also disclose information, or share it outside of our organization. We share it with the Ministry of Health to help us ensure information about our patients is accurate, with a patient's GPs and where reasonable, with family members, where necessary to ensure the continuity of care. We share with our service providers and other Health Authorities who may provide connected or integrated services to ours.

We will also disclose to law enforcement as authorized by FIPPA and as outlined in our *Release of Information to Law Enforcement* policy.

## Caring for Your Information Notice to our Patients, Clients and Residents

### Collecting, Using and Sharing Your Personal Information

When you are receiving care, treatment and services at Vancouver Coastal Health Authority, our staff and physicians will collect personal information from you. Where permitted, we may ask your family, friends, or other organizations to give us information about you (e.g. copies of records, medication information or test results).

Your information may be entered into our electronic health information systems to assist authorized persons in quickly accessing pertinent information wherever you may be receiving care or services.

We collect, use and share your personal information under the primary authority of the BC *Freedom of Information and Protection of Privacy Act* ("FIPPA"). FIPPA and other legislations authorize us to use and share your personal information for these reasons:

- to identify you and keep in contact with you about your health care
- to provide ongoing care and support of care activities
- to help us plan, monitor, maintain and improve our care and services,
- for education and training (e.g. medical students) and to conduct research with consent or as permitted by law
- to know your eligibility for benefits and services and to arrange medical services billing
- to enable parties (e.g. Ministry of Health Services, Canadian Institute of Health Information) to confirm your identity, conduct planning and improvement activities, measure performance and fund healthcare
- to analyze, manage and control disease outbreaks and monitor the overall health of people
- as required by law (e.g. court order, reportable conditions) and as authorized by FIPPA

Your health information will be provided to your referring physician, other authorized health care professionals and their support staff, or health care agencies and facilities involved in your care to support continuous and consistent care and service. In some cases, these health professionals may look up your health information in our electronic health information systems in order to provide you with direct or supporting services.

If you are a patient in the hospital or residential care, we will provide your family or close friends who phone and ask about you with information confirming your admission and location. *If you do not wish us to release this information, please inform a staff member within Patient Registration or within your care area.*

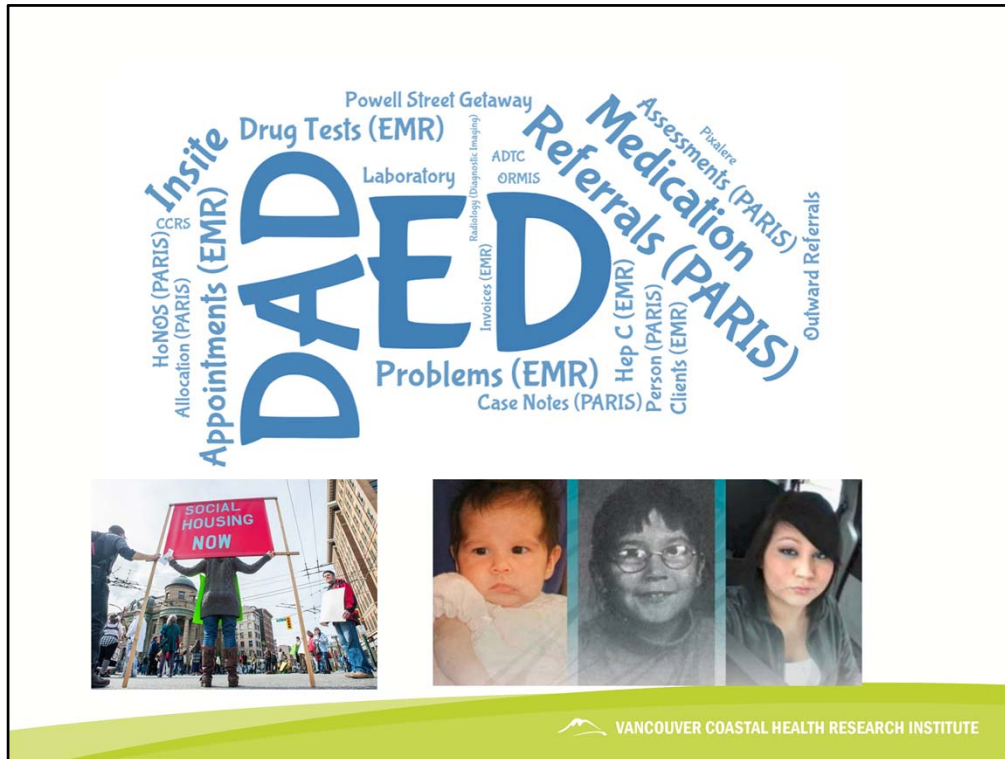
### eHealth and Your Information

eHealth is a provincial initiative that allows certain aspects of your health information to be accessed by authorized health care professionals throughout the province and not just within a particular region. Each Health Authority sends specific health information to a province-wide electronic information system, where it is stored with strict protections and used for limited and authorized purposes. For more information about eHealth, please visit the government eHealth website at <http://www.health.gov.bc.ca/ehealth>.

### For more information

If you have any questions about this Notice and the protection of your personal information please go to [www.vch.ca](http://www.vch.ca), search for "your privacy" and click on the link provided or contact the VCH Information Privacy Office at (604) 875.5568 or email: [privacy@vch.ca](mailto:privacy@vch.ca).

We rely on patient notification at our clinics and registration sites to highlight how we collect, use and disclose information.



Not all of our tools and systems are created from collect data directly from patients. Many systems and tools leverage data we already have in the health authority.

## What Systems are available for research?



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Technically all of our data sources are available for quality improvement and research. We may provide data for research through a data extract or allow a researcher to collect data directly from our electronic charts.

However, not all systems are available to be accessed directly by researchers.

Most systems were designed specifically to facilitate care. They have open access models, meaning all users can search for all patients across the system, and have access to most of the patient chart.

Not all systems would be reasonable to access directly for the purpose of a chart review. Some systems act as a viewer, and are not the source of truth for the information. Such systems may be useful help to identify cohorts for a research purpose, but they might not be the most accurate source of information for a chart review.



**VCH makes research happen**

- We facilitate research grants and awards
- We provide secure research networks, and facilities
- We support staff and physicians leading research at our sites.
- We direct Medical Staff and Department Heads to identify areas of research need.

**I am Iqbal. I do research.**

To Iqbal Ahmed, respirologist and clinical associate professor, research is an extension of patient care. "Questions come up all the time – for which there are no good answers. Setting up a study is intellectually stimulating as it brings together diverse people. It is a thrill to complete the research study and use the answers to improve patient care," says Dr. Ahmed.

**Health research changes lives.**

Be part of the discovery.  
**vchri.ca**

**Vancouver Coastal Health Research Institute**

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VCH Research Institute can be considered a program of VCH and VCHRI provides services to our researchers to make research research happen. Research is an activity that VCH staff engage in....

From a legal perspective, we see the undertaking of the actual REB approved projects as an external activity...

## We Disclose Data for Research

- All Principle Investigators require an academic affiliation.
- REB approved research projects are academic investigations.
- VCH Staff undertaking research are understood to be working in their academic capacity when doing research.
- All investigators apply to do research through VCH Research Institute
- This is necessary for research independence.
- This ensures research is treated consistently.



VCH discloses for research projects under section 33.1(1)(b) of FIPPA, with consent as documented in the REB approved Informed Consent Form. We also release information for REB approved projects where consent has been waived. We release these under s. 35 of FIPPA.

Disclosure in the context of FIPPA means to *make information known*. It does mean a loss control of that information.

Where VCH discloses information with under s. 33.1(1)(b), with agreement that the information is provided only for the purpose of that consent. When we disclose under s. 35, without consent, we also stipulate the terms of the disclosure.

The terms of disclosure is documented in the VCH-PHC Data and Research Access Terms and Conditions. See: [https://www.vchri.ca/sites/default/files/vch-phc-data\\_and\\_research\\_access\\_terms\\_and-condition\\_27march2018\\_final.pdf](https://www.vchri.ca/sites/default/files/vch-phc-data_and_research_access_terms_and-condition_27march2018_final.pdf)

## Disclosure under s. 35, without consent

- Identifiable data is necessary
- Data linking is in the public interest
- With a comprehensive Data Access Agreement stipulating:
  - conditions related to security and confidentiality
  - subsequent use of disclosure must be with express authorization of VCH
  - Researchers remove identifiers at the earliest reasonable time;



## When it Isn't Research...



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Just because a project isn't considered research, does not mean it is Quality Improvement. VCH would only consider the project QI or evaluation if:

- The project is undertaken on behalf of Vancouver Coastal Health and clearly approved and supported by a VCH operational lead, to ensure the results can be addressed operationally.
- The results of the project must be relevant, measurable and actionable by VCH.
- The project cannot interfere with the delivery of care, services or other activities taking place at VCH;
- A QI project cannot start collecting new prospective clinical data collection outside what is currently collected as part of the current standard of care.