



University of British Columbia – Children's & Women's Research Ethics Board

**UBC C&W Research Ethics Board**

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RISe: <https://rise.ubc.ca>

## RESEARCH PRIVACY BREACHES

### **Purpose**

This guidance has been developed to provide clarity around considerations and process for Privacy breaches involving research participants in research settings.

### **Background**

Privacy breaches that occur within clinical research settings are connected but distinct from privacy breaches that occur outside research settings. Participation in research is voluntary, this needs to be accounted for in the risk/benefit assessment of any breach. Underscoring the voluntary nature participating in research, participants have usually signed a consent form. Further, consistent across research ethics standards and regulations, researchers have a duty to inform in a timely manner if new information that becomes available that may be relevant to the participants willingness to continue participating.

### **Assessment**

- Is the patient a research participant? Is the incident related to research activities?
- Is the data breach within PHSA or outside of PHSA?
- Any reason not to inform participant?
- Reasons to delay? (ie. Patient special circumstance In-patient status, current distress)

### **Steps**

1. Study team to analyse the situation.
2. Inform the participant unless justification to do otherwise.
3. Report
  - a. To C&W REB in RISe following [protocol deviation instructions](#)
  - b. **And** to PHSA Privacy following the [instructions on POD](#)

### **Contacts**

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### **Resources**

PHSA Research Privacy [guidance and instructions](#)

PHSA Privacy Breach reporting instructions on [POD](#)

UBC Clinical REB guidance on reporting [protocol deviations](#)