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*Alberta's*  
Health  
**INFORMATION**  
Act

**Online Training**

**Collecting and Using Health Information**

Department of Medicine  
University of Alberta

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## Use vs. Disclosure

- **Use** implies access and sharing of information among custodians and affiliates within an office/organization for a purpose.
- **Disclosure** refers to sharing information with someone **outside** of the custodian's organization.

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# Collecting Health Information

When collecting health information, the *Custodian* must:

- Collect only essential information, i.e. only the amount of information necessary to carry out the intended purpose.
- Collect with the highest degree of anonymity possible.
- Ensure that their affiliate(s) must only collect information that is needed to carry out their responsibilities (need to know principle).
- Identify the authority that they have to collect the information.

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# Identify Authority to Collect Health Information

- The custodian must take reasonable steps to inform the individual
  - Of the *purpose* for which the information is being collected;
  - Of the specific *legal authority* for the collection, which is the Health Information Act [Section 20(b) to be precise]; and
  - Of the title, business address and business phone number of an affiliate (or the custodian him or herself) who can answer questions about the collection.

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- These steps can either be done:
    - Verbally; or
    - By way of a poster in a patient area.

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- If patients fill out forms, the authority to collect health information should be specified at the top or bottom of each form or put on a separate sheet or in a brochure accompanying the form.

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# Collection of Health Information Directly from the Individual

- Health information must be collected directly from the individual *unless indirect collection is authorized.*
- You may collect health information indirectly from someone other than the individual...

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- When the person authorizes collection from someone else.
  - When the information is collected from the person's representative (eg. from the guardian of a person under 18 or in cases of powers of attorney, etc.).
  - Where collecting from the individual is not reasonably practical (e.g. the person in unconscious).



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- Where the information is available to the public.
  - Where a disclosure would be allowed under the Act (see the Section on Disclosing Health Information).
  - When the custodian believes, on reasonable grounds, that collection from the individual would result in the collection of inaccurate information or would prejudice:
    - The interests of the individual;
    - The purposes of the collection; or
    - The safety of another individual.

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- When the custodian is assembling a family or genetic history for providing a health service.
  - When conducting research or performing data matching.
  - When the collection is for determining and verifying the person's eligibility to participate in a program or receive a benefit (e.g.: Homecare).

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# Authorized Uses of Health Information

The following are authorized uses of health information:

- To provide health services.
- To determine eligibility for a health service.
- Health service provider education.
- Research or data matching.
- To comply with another piece of legislation.
- To manage internal operations (billing, quality control).

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# Use of Health Information for Research

## *Ethics:*

- Ethics committee approval is required, and conditions imposed by the committee must be adhered to; and
- Consents from individuals must be obtained if required by the ethics committee.
- Additionally, an agreement must be made between the researcher and the custodian **prior to** the custodian disclosing individually identifying health information.

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# Agreement Between Researcher and Custodian

The Researcher must agree to:

- Abide by the Act and any conditions imposed by the custodian to safeguard the health information.
- Only use the information for the proposed research.

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- Pay the costs incurred by the custodian for preparing the information or for obtaining consents.
  - Allow the custodian to inspect researcher's premises to ensure information is safeguarded.
  - Not contact subjects for additional information unless the custodian obtains consent first.
  - Make sure that the identities of the people involved cannot be ascertained by the resulting publications.

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## Last Slide in this Set

Congratulations! You can now move on to the next set of slides - ***Duty to Protect Health Information.***