

## PRIVACY AND CONFIDENTIALITY

CATEGORY, SCOPE, AND AUTHORITIES		KEY DATES	
<b>Policy category:</b>	Governance	<b>Approval:</b>	2015
<b>Functional area:</b>	All areas	<b>Effective:</b>	2015
<b>Applies to:</b>	Staff, Board of Directors, volunteers, third parties	<b>Revision frequency:</b>	3 years
<b>Approval Authority:</b>	Board of Directors	<b>Last review:</b>	Oct. 2022
<b>Executive Champion:</b>	CEO	<b>Next review:</b>	2025

### I. RATIONALE

Ovarian Cancer Canada (OCC) recognizes an individual's right to privacy and is committed to maintaining the accuracy, confidentiality, privacy and security of the personal information in its custody. In pursuit of our mission, we pledge to treat everyone with respect and dignity and to protect their privacy. To demonstrate this commitment, the organization has developed policies and procedures about the collection, use and disclosure of information that align with the provisions of federal and provincial legislation and with industry standards. As recommended by the Office of the Privacy Commissioner, this policy is based on the 10 fair information principles outlined in the Personal Information Protection and Electronic Documents Act (PIPEDA).

### II. OBJECTIVE

This policy articulates OCC's privacy practices and standards about the collection, use and disclosure of personal information and personal health information during OCC activities. OCC will only collect, use and disclose personal information in accordance with this Privacy Policy.

All staff, volunteers and third parties who are given access to personal information or personal health information in OCC's possession are required to maintain the privacy and confidentiality of all personal information and personal health information in any and all formats, both while acting as an active volunteer or staff member and after they leave the organization and must uphold the principles and practices outlined in this policy and related procedures.

### III. SCOPE

This policy applies to **personal information** and **personal health information** provided to or collected by OCC through its website(s), social media, by email, facsimile, postal mail, hand delivered, verbally or any other means.

This policy **covers** the privacy of **all stakeholders**: staff, volunteers, board members, donors, fundraisers, program participants, service users, advocates, visitors to our websites and participants in OCC social media channels, and other methods of engagement under OCC umbrella.

This policy **applies to all staff, volunteers and third parties** who have access to OCC personal information or who collect, use or disclose personal information on behalf of the organization.

## IV. POLICY DETAILS

### 1. CORE DEFINITIONS

**Personal Information:** Any information, in any form, about an identifiable individual or that can be used to identify an individual, alone or in combination with other information. Personal information *does not* include information that is publicly available, such as business contact information that is collected, used or disclosed solely for the purpose of communicating with that person in relation to their employment or profession, or information found in a telephone directory.

**Personal Health Information:** OCC considers information about whether a person has ovarian cancer or is at risk of ovarian cancer to be personal health information.

**In this Policy, the term 'personal information' is inclusive of personal health information, unless the latter term is used exclusively. In that case, it applies only to personal health information.**

### 2. COMPLIANCE WITH FAIR INFORMATION PRINCIPLES

OCC adheres to the 10 Fair Information Principles set out in the Personal Information Protection and Electronic Documents Act (PIPEDA).

### 3. WHAT PERSONAL INFORMATION OCC COLLECTS

To achieve its mission, OCC collects certain personal information about its program participants, service users, donors, sponsors, fundraisers and other supporters, staff, and volunteers. OCC will only collect the minimum amount of information needed to achieve the purposes identified in this policy.

Subject to the application of the consent principle outlined in Section 4.3 below, personal information collected by OCC includes, but is not limited to:

- Contact and identification information, such as name, address, telephone number and email address.
- Ovarian cancer diagnosis or identified risk factors for ovarian cancer.
- Participation in OCC advocacy online campaigns, fundraising events, information, education and support programs, conferences and any other events led or facilitated by OCC.
- Financial information such as payment methods and preferences, billing and banking information (IP address, credit card number and expiry date or chequing account transit numbers which are required to process a donation).
- Donation information such as date of gift, amount of gift, the campaign to which one contributed.

- Personal information that OCC receives that was not requested but was voluntarily given to us (e.g., in emails, in support groups or other programs, comments in social media or on the website).
- Communication preferences for marketing purposes.
- Employee records.
- Employment history and background checks for volunteers and employees, including results of police records checks.
- Information provided while applying for OCC employment or volunteer work or during employment / volunteering.
- Images, including photographs and videos.
- Other personal information used for purposes that a reasonable person would consider appropriate in the circumstances.

#### 4. HOW OCC COLLECTS PERSONAL INFORMATION

OCC collects personal information in different ways, including:

- **Direct interactions:** individuals may voluntarily provide OCC with personal information by filling out forms; creating an account on our website; making a donation; applying to work or volunteer for OCC; registering to attend an event; requesting information to be sent to them; subscribing for OCC's publications; responding to OCC's direct mail or telemarketing campaigns; participating in an OCC event; posting comments on OCC's website or social media channels; or communicating with OCC face to face, over the telephone, by mail, by email, by text, through social media or through other means.
- **Automated interactions:** when someone uses its website, OCC may automatically collect technical data about their equipment and browsing history using cookies and similar technologies (See below for more information).
- OCC may collect personal information when someone interacts with its content on its website or on third-party sites or platforms, such as Facebook, Instagram, Twitter or You Tube. This may include data such as comments or feedback, "likes" or shares, profile data or the fact that someone viewed or interacted with OCC content.

OCC may receive personal information from third parties such as regulatory bodies, government agencies, or health professionals while providing its services.

#### 5. WITH WHOM DOES OCC SHARE PERSONAL INFORMATION

OCC may share personal information with the parties set out below for the following purposes:

- Service providers, such as those who provide IT and system administration services, fundraising services, telemarketing services, direct mail services, donor relations services, donation management services, database management services.
- Professional advisors, such as lawyers, auditors, bankers and insurers who provide legal, accounting, auditing, banking or insurance services.
- Government, regulatory authorities, law enforcement, dispute resolution bodies, courts and similar entities to comply with any legal or regulatory obligation, to detect and prevent crimes or to assert or defend legal rights and interests.

- Any persons or entities where OCC has a legitimate business reason for doing so, such as to manage risk, to process payments or to perform or carry out the terms of any contract.
- To the transferee if OCC transfers, sells or disposes of all or substantially all its assets or operations.
- To other third parties if OCC has told someone about them and they have given it their consent.
- OCC may provide restricted information (name, address, partial credit-card number) for administrative purposes to vendors located in the United States.

### **5.1 Treatment of donor information and donor lists**

OCC does not rent, sell, barter or trade donor lists.

### **5.5 Treatment of personal health information**

While OCC is not subject to legislation governing the privacy of personal health information, it has voluntarily adopted elements outlined in personal health information legislation as outlined in this policy.

## **6. THE PURPOSES FOR WHICH OCC USES PERSONAL INFORMATION**

The main purposes for which OCC generally uses personal information are:

- To manage, oversee and administer its operations
- To deliver its programs and services
- To conduct government relations and advocacy initiatives
- To deliver public education
- To conduct and facilitate fundraising appeals
- To administer gifts in accordance with donor wishes
- To process donations
- To manage its relationship with donors
- To conduct marketing efforts
- To undertake statistical reporting
- To meet funder requirements
- To comply with any legal regulatory requirements
- To maintain and manage relationships and provide customer service
- To identify and authenticate users in its information system and network
- To provide, administer and protect its website, information system and network
- To establish, manage and terminate (collectively, "administer") an employment or volunteer relationship
- For privacy and quality management audits and training
- To protect its rights, property or safety, or that of its employees, volunteers or any other person
- For other purposes to which individuals consent
- To fulfill other purposes permitted or required by law

## 7. OCC's PRIVACY AND CONFIDENTIALITY PRINCIPLES

### 7.1. Accountability

OCC is responsible for the personal information under its control. To this end OCC will:

- Designate an individual to ensure compliance with this policy ("Privacy Officer")
- Implement practices and procedures to carry out this policy, which may include:
  - Procedures to protect personal information
  - Procedures to receive and respond to questions or complaints from individuals regarding their personal information
  - Training and communicating to staff and volunteers about this policy and practices
  - Developing information to explain its privacy policy and practices to its stakeholders

### 7.2. Identifying purposes

OCC will identify the purposes for which personal information is collected. The identified purposes will be specified at or before the time of collection to the individual from whom the personal information is collected. When personal information that has been collected is to be used for a purpose not previously identified, we will communicate the new purpose to each individual and obtain their consent to use the information.

### 7.3. Consent

OCC only collects, uses and discloses personal information with an individual's knowledge and consent. Consent may be expressed orally, electronically or in writing, or it may be implied. OCC will obtain meaningful consent and use clear explanations and plain language to make sure that our consent processes are understandable and user friendly.

The knowledge and consent of the individual are required for the collection, use or disclosure of personal information, except where consent is not required for very specific reasons. It is anticipated that instances in which the knowledge and consent of the individual would not be required would be extremely rare and would include legal, medical or security reasons, which would have to be fully documented.

Consent is considered valid only if it is reasonable to expect that individuals to whom OCC's activities are directed would understand the nature, purpose and consequences of the collection, use or disclosure to which they are consenting.

7.3.1. Typically, OCC staff and volunteers will seek consent for the use or disclosure of the information at the time of collection. The form of the consent sought by OCC may be either **express** or **implied**, depending upon the circumstances and the sensitive nature of the personal information.

7.3.2. **Express consent** is required from an individual before OCC will disclose personal health information. Express consent can be provided verbally or in writing. For children under age 13, consent must be given by parents or guardians.

7.3.3. The provision of personal information to OCC constitutes *implied consent* to collect, use and disclose their personal information in accordance with this policy, unless an individual expressly instructs otherwise.

7.3.4. **No consent.** There are certain activities for which consent is not required to use or disclose personal information. These activities are permitted or required by law. For example, we do not need consent from individuals to respond to legal proceedings or comply with mandatory reporting obligations, investigations/fraud detection and prevention, witness statements in insurance claims, financial abuse, personal information produced in the course of employment, business or profession, or other as identified by law from time to time.

OCC may use or disclose an individual's personal information without consent where the organization believes, upon reasonable grounds, that it is necessary to protect the rights, privacy or safety of an identifiable group or person (including the individual in question) or the public.

7.3.5. **Withholding or withdrawal of consent.** If consent is sought, an individual may choose not to give consent ("withholding consent"). If consent is given, an individual may withdraw consent at any time by contacting OCC's Privacy Officer, but the withdrawal cannot be retroactive. The withdrawal may also be subject to legal or contractual restrictions and reasonable notice.

#### 7.4. Limiting collection

The collection of personal information will be limited to that which is necessary for the purposes identified by OCC. Information will be collected by fair and lawful means.

#### 7.5. Limiting use, disclosure and retention

Personal information will not be used or disclosed for purposes other than those for which it was collected, except with the consent of the individual or as required by law. Personal information will be retained only as long as necessary for the fulfillment of those purposes.

Whenever possible, **access to personal information will be limited to authorized users only.** Personal information may only be used within the limits of each staff and volunteer role. Staff and volunteers may not read, look at, receive or otherwise use personal information unless they have a legitimate "need to know" as part of their position.

When OCC discloses personal information to third-party service providers with whom it has a contractual relationship, the third-party providers will only be given access to personal information that is needed to perform the related function and may not use it for any other purpose. OCC requires all third parties to respect the security of personal information and to treat it in accordance with all applicable legal requirements. All third-party service providers are required to enter into contractual agreements with OCC that prevent them from using your personal information for their own purposes and require them to use personal information only for specific purposes in accordance with OCC instructions and all applicable legal requirements.

### ***7.5.1 Personal information collected through OCC website(s)***

OCC may use automatic data collection technology and services that record and collect information that identifies users' computers, tracks use of the websites and collects certain information about users and their surfing habits. This data collection technology may include cookies, web beacons and other similar devices on OCC websites to enhance functionality and navigation for visitors of OCC websites.

A cookie is a small data file that is placed on the hard drive of a user's computer so that their computer will "remember" information when visiting a site. Web beacons and tags are small strings of code that are used in conjunction with a cookie and allow OCC to record activity on the websites. Internet tags, graphic tags and similar web beacon type functions allow OCC to count the number of users who have visited a particular web page or to access certain cookies. OCC may use web beacons on their websites to count users and to recognize users by accessing cookies. Being able to access cookies allows OCC to personalize the websites and improve individuals' experience. OCC may also include web beacons in HTML-formatted e-mail messages that are sent to determine which e-mail messages were opened.

OCC collects information from users at several different points on its website. Information tracked through these mechanisms includes but is not limited to: IP address; the type of web browser and operating system being used; the pages of the website a user visits; and other sites a user visited before visiting OCC websites.

Individuals can reject or disable cookies by managing their browser. Cookies and web beacons do not collect or contain personal information. IP addresses are not linked to personally identifiable information.

### ***7.5.2 Links to Other Websites***

Our website contains links to other sites. Clicking on those links may allow third parties to collect or share information about users. OCC is not responsible for the privacy practices of other such sites. OCC cannot control these third-party websites and is not responsible for the actions or policies of such third parties. Users should check the privacy policies of third parties when visiting their websites or when providing any personal information to them.

OCC may collect personal information when someone interacts with its content on third-party sites or platforms, such as Facebook, Instagram, Twitter or You Tube. This may include data such as comments or feedback, "likes" or shares, profile data or the fact that a person viewed or interacted with its content. If someone voluntarily posts or submits any information on these platforms, their personal information may be automatically included in the posting and may be collected and used by others.

### ***7.5.3 Third Parties Outside Canada***

OCC may use service providers, data processors and other third parties ("Third Parties") to perform services on its behalf. These Third Parties may store, process and transfer personal information on servers located outside of Canada in jurisdictions whose data protection laws may differ from those of Canada, which may include the United States of America. As a result, personal information may

be subject to access requests from governments, courts, or law enforcement in those jurisdictions according to the laws in those jurisdictions. For example, information may be shared in response to valid demands or requests from government authorities, courts and law enforcement officials in those countries. Subject to applicable laws in such other jurisdictions, OCC will use reasonable efforts to ensure that appropriate protections are in place to require third parties to maintain protections on personal information that are equivalent to those that apply in Canada.

#### **7.5.4 Targeted advertising**

As users interact with OCC websites, third party advertising partners may use cookies that are placed on users' computer, tracking pixels, web beacons and similar technologies to identify users as a visitor to the websites, and present users with targeted ads to help promote OCC. Users can opt-out of the use of information for select ad targeting by visiting this site: <http://youradchoices.ca/choices>, and also by setting up "Do Not Track" options available through their browser. OCC also occasionally provides personal information to trusted advertising partners for the purpose of presenting the user with targeted ads on behalf of OCC. Users can request that their personal information not be shared with advertising partners by contacting OCC's Privacy Officer.

#### **7.5.5 Google Analytics**

OCC's website uses Google Analytics, a web analytics service of Google, Inc. ("Google"), or comparable technology. Google Analytics uses "cookies", which are text files stored on users' computer, to analyze how they use the website. The information generated by the cookie about use of the websites (including IP address) is sent to a Google server in the U.S. and stored there. Google will use this information to evaluate use of OCC website, compile reports on website activity for website operators and to provide other site activity related to internet services. Additionally, Google may transfer this information to a third party when required by law or in the case of a third-party processing information on Google's behalf. In no case will Google use users' IP address in connection with any other information held by Google. Users can set their internet browser to prohibit the installation of cookies, although some features and functions of the website will then be unusable. By using OCC website, users consent to the processing of user data collected by Google in the manner described and for the above-mentioned purpose. The consent for collection and storage of data can be withdrawn at any time in the future by clicking on the following link: <https://tools.google.com/dlpage/gaoptout?hl=en>. OCC website uses the "Anonymize IP" function of Google Analytics which works with a shortened form of IP addresses to avoid direct personal identification.

OCC uses cookies to carry out frequency assessments, page usage assessments and marketing assessments. For the aforementioned assessments, OCC utilizes this cookie information without a link to users' personal information.

#### **7.5.6 User Content in Comments, Chat Rooms, Teleconferences, Message Boards, Social Media**

OCC may collect personal information voluntarily disclosed on OCC message boards, chat rooms, comment boxes, social media channels or other interactive services or programs as outlined in this policy. Users should be aware that personal information disclosed on these channels can be



collected and used by other internet users. This may result in unsolicited messages from other posters or parties. OCC undertake no obligations as to the security of information voluntarily posted in chat rooms, on message boards, in comment sections of the website or in other interactive features of OCC website.

#### **7.6. Accuracy**

OCC will take reasonable steps to ensure that personal information in its custody is accurate, complete and up to date as is necessary for the purposes for which it is to be used. We will not routinely update personal information, unless such a process is necessary to fulfil the purposes for which the personal information was collected. Individuals can always ask OCC to update their personal information by contacting the Privacy Officer.

#### **7.7. Safeguards**

OCC will use appropriate security safeguards (depending on the sensitivity of the information) to protect personal information against loss or theft, as well as unauthorized access, disclosure, copying, use, or modification, regardless of the format in which it is held.

Safeguards will include physical safeguards (such as locked filing cabinets and rooms, clean desk policies); administrative safeguards (such as permitting access to personal information by staff on a "need-to-know" basis only); and technological safeguards (such as the use of password protocols, encryption software, routine updates of our software and audits).

OCC requires that any individual or third-party who collects, uses or discloses personal information on behalf of the organization complies with the provisions of this policy. This will be done through the signing of confidentiality agreements, privacy training and other contractual means. We require all third-party service providers to enter into contractual agreements that require them to respect the security of users' personal information and to treat it in accordance with all applicable legal requirements.

OCC will securely destroy personal information so that reconstruction is not reasonably possible to prevent unauthorized parties from gaining access to the information.

While it uses appropriate safeguards, OCC cannot guarantee the absolute security of the personal information in its custody, and we cannot ensure or warrant the security of any information provided to us. Individuals can reduce the risk to their own personal information by using strong passwords, keeping passwords confidential and following other personal information security best practices.

#### **7.8. Openness**

Information about OCC's privacy policy and practices relating to the management of personal information will be available to the public, including:

- Contact information for our Privacy Officer, to whom complaints or enquiries can be made ([info@ovariancanada.org](mailto:info@ovariancanada.org))
- The process for obtaining access to personal information held by OCC and making requests for its correction.

- A description of the type of personal information held by OCC, including a general account of our uses and disclosures.
- A description of how an individual may make a complaint to OCC; and
- Copies of any materials or other information that explain the OCC's policies and procedures.

#### **7.9. Individual access**

If an individual requests it, OCC will inform them of the existence, use, and disclosure of their personal information. The individual will be given access to that information, will be able to challenge the accuracy and completeness of the information and have it amended as appropriate.

In certain situations, OCC may not be able to provide access to all the personal information it holds about an individual. Exceptions to the access requirement will be limited and specific. The reasons for denying access will be provided to the individual upon request. Exceptions may include information that is prohibitively costly to provide, information that contains references to other individuals, information that cannot be disclosed for legal, security, or commercial proprietary reasons, and information that is subject to solicitor-client or litigation privilege.

#### **7.10. Challenging compliance**

An individual will be able to raise concerns about OCC's compliance with its own Privacy and Confidentiality Policy to the Privacy Officer.

The Privacy Officer will receive and respond to complaints or enquiries about organizational policies and practices relating to the handling of personal information. They will inform individuals who make enquiries or lodge complaints of other available complaint procedures.

OCC will investigate all complaints. If a complaint is found to be justified, OCC will take appropriate measures to respond.

## **V. RELATED DOCUMENTS**

The following internal and external documents support the application of this policy:

- a. Procedures, forms, guidelines, and other resources:
  - Privacy Breach Procedure
  - Privacy Forms and Statements
    - i. Privacy and Confidentiality Agreement for staff and volunteers
    - ii. Consent Form: Image, Text and Identification
    - iii. Sample privacy notices
- b. Related organizational policies
  - Whistleblower Policy
  - Complaints Policy
- c. Applicable legislation and regulations:
  - [How PIPEDA applies to charitable and nonprofit organizations.](#)
  - [PIPEDA fair information principles](#)

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## DEFINITIONS

**Privacy:** The fundamental right of an individual to control information about themselves (including the collection, use and disclosure of and access to that information).

**Confidentiality:** An obligation to protect personal information, to maintain its secrecy and not misuse or wrongfully disclose it.

**Personal information:** Personal information is any information about an identifiable individual, other than an individual's business title, address or telephone number. Examples of personal information are name, home address, age, health and financial information. It does not include information that cannot be tracked back to a specific individual. In addition, information that is publicly available, such as a telephone book listing, is not considered to be personal information. The history of an individual's donations is personal information.

**Personal health information:** Personal health information is defined to mean, with respect to an individual, whether living or deceased:

- a. Information concerning the physical or mental health of the individual.
- b. Information concerning any health service provided to the individual.
- c. Information concerning the donation by the individual of any body part or any bodily substance of the individual or information derived from the testing or examination of a body part or bodily substance of an individual.
- d. Information that is collected in the course or providing health services to the individual; or
- e. Information that is collected incidentally to the provision of health services to the individual.

**Leadership Team (LT):** The most senior level of staff leadership within OCC comprised of the Chief Executive Officer (CEO), VP Finance and Administration, VP Marketing, Communications and Development, and VP Policy and Programs. The CEO may alter the composition of the LT as required from time to time. One person may hold more than one position. Titles may change at the discretion of the LT or the Board.

**Executive Champion:** A member of the LT with overall responsibility for an assigned policy including: drafting, carrying out appropriate consultations / assessment, evaluating implications of the policy including risks and costs and seeking legal advice where necessary, developing and carrying out the communication, change management and implementation plan, writing any related procedures, standards or guidelines, monitoring compliance through regular reviews of the policy and reporting to the approval authority on compliance with the policy. The Executive Champion may designate a delegate, who must be named.

**PIPEDA:** The Personal Information Protection and Electronic Documents Act (PIPEDA) is the federal act that sets the ground rules for how private-sector organizations collect, use, and disclose personal information in the course of for-profit, commercial activities across Canada. PIPEDA applies to organizations that collect, use or disclose personal information during commercial activities. **Non-profit organizations are usually not subject to PIPEDA** because they do not typically engage in commercial activities. This includes most charities, community groups and advocacy groups. The

following activities are not considered commercial and are not subject to PIPEDA: collecting membership fees, organizing club activities, compiling a list of members' names and addresses, mailing out newsletters, fundraising.

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**POLICY HISTORY**

Below is a record of all changes to the policy and their approval dates.

<b>Date</b>	<b>Type of review</b>	<b>Comments</b>
July 2015	Policy first approved	
Feb 2019	Policy revised and approved by Board of Directors	
Oct. 2022	Major revision	Integration of three privacy policies in one single policy document: (1) employee privacy policy, (2) privacy policy and (3) website privacy policy. Development of privacy breach procedure and revision of privacy notices, acknowledgement and release forms. Approved by the Board of Directors on Oct. 24, 2022.