



## 8.2 Privacy and Confidentiality Policy

### A. Introduction

1. Health Care Consumers' Association (HCCA) is committed to handling the personal information of our members, consumer representatives, staff, volunteers and members of the public with openness, transparency and accountability. HCCA respects the right of privacy and protects personal information of any individual making contact with the organisation for any purpose.

2. We are committed to protecting personal information, including sensitive and health information, and ensuring its privacy, accuracy and security. HCCA handles personal information, including sensitive information, in accordance with the Australian Privacy Principles contained in the *Privacy Act 1988* (Cth), the *Privacy Amendment (Enhancing Privacy Protection) Act 2012*, the *Privacy Amendment (Notifiable Data Breaches) Act 2017* and the *Privacy Legislation Amendment (Enforcement and other Measures) Act 2022*. HCCA handles any health records in accordance with the privacy principles contained in the *Health Records (Privacy and Access) Act 1997* (ACT)

3. By using any of our services, visiting our websites, or giving us your personal information, you agree to your information being collected, stored, used and disclosed as set out in this policy and as required under law.

### B. Definitions

- **Personal information** is defined in the Privacy Act as "*information or an opinion about an identified individual, or an individual who is reasonably identifiable: a) whether the information or opinion is true or not; and b) whether the information or opinion is recorded in material form or not*" (*Privacy Act 1988*, s 6). "Identified individual" and "reasonably identifiable" are not defined in the Act.
- **Sensitive information** is defined in the Privacy Act as information about an identified individual's health, genetics or biometrics, or opinions, including:
  - racial or ethnic origin
  - political opinions
  - membership of a political association
  - religious beliefs or affiliations
  - philosophical beliefs
  - membership of a professional or trade association
  - membership of a trade union

- sexual orientation or practices
  - criminal record”
- A **health record** is defined in the Health Records Act as “*any record, or any part of a record... containing personal health information*” where a **record** is defined as “*a record in documentary or electronic form that consists of or includes personal health information in relation to a consumer (other than research material that does not disclose the identity of the consumer)*”.
  - **Personal health information** is defined in the Health Records Act as “*any personal information, **whether or not recorded in a health record** – a) relating to the health, an illness or a disability of the consumer...*” where personal information is defined as “*any information, recorded or otherwise, about the consumer where the identity of the consumer is apparent, whether the information is – a) fact or opinion; or b) true or false*”. A consumer is defined as “*an individual... in relation to whom a health record has been created...*”.

### C. Purpose

4. This Privacy Policy sets out:

- who HCCA collects personal information from
- what kinds of personal information we collect
- why we collect it
- how we protect it.

5. It also outlines how a person can access and/or update any personal information that HCCA holds about them.

6. This Privacy Policy does not apply to HCCA’s employee records. This is because the Australian Privacy Principles do not apply to employee records.

### D. Collection of Information

7. We collect the personal or sensitive information necessary for us to provide you with the services or information you have requested from us, to improve the services we provide, and to enable us to meet our legal and regulatory obligations.

8. Personal information normally collected by HCCA includes:

- a) Name, title, address, gender
- b) Telephone number
- c) Email address
- d) Cultural background and language

- e) Level of education
- f) Bank details only when HCCA needs to reimburse members for any expenses authorised by HCCA.
- g) Photos or videos of people participating in HCCA events where they have given permission for these to be taken.

9. We may also collect additional information on:

- a person's lived experiences of health issues and health care, and life experiences related to these health issues
- Information relevant to a specific membership or consumer representative opportunity

10. In some circumstances HCCA may be provided with personal information about a person from a third party, for example parents/guardians providing information about children, and carers providing information about the person they care for.

11. If HCCA receives unsolicited personal information, we will determine whether the information is reasonably necessary or directly related to one of HCCA's functions or activities. HCCA then:

- may collect the information if it is reasonably necessary for or directly related to one of HCCA's functions or activities
- will destroy the information if it is not reasonably necessary or directly related to one of HCCA's functions or activities.

13. HCCA will not collect personal, sensitive or health information about an individual without appropriate legal consent.

### **E. Use of Information**

14. Personal information will, generally, only be used for the primary purposes of:

- a) Responding to individual's queries
- b) Processing HCCA membership forms
- c) Reimbursement and event sponsorship
- d) Distributing information and newsletters
- e) Providing training and events
- f) Research projects
- g) Recruiting and supporting consumer representatives
- h) Informing our systemic advocacy work, including developing position statements, policy submissions and consultation forums.
- i) Performing general administration, reporting and management functions

- j) Other purposes related to or in connection with our business, including meeting our legal and contractual obligations to third parties and for internal corporate governance purposes.

## **F. Storage and Protection of personal information**

15. HCCA stores information in different ways, including in paper and electronic form.

16. HCCA takes reasonable steps to protect the personal information it holds from misuse, interference, loss, unauthorised access, modification, or disclosure. These steps include physical security over paper-based and electronic data storage and premises; computer and network security measures, including use of firewalls, password access and secure IT environments.

17. HCCA's IT systems will be hosted by companies that keep HCCA's data inside of Australia. In exceptional circumstances an overseas provider may be used with approval from the Executive Committee.

18. In the unlikely event of a data breach HCCA will follow the data breach response requirements set out in the Privacy Act and HCCA's Data Breach Response Plan.

## **G. Destruction and Deidentification of Information**

19. HCCA will take reasonable steps to destroy, or permanently deidentify, a person's personal information (except records of a person's health information) once it is no longer needed for the purpose for which it was collected or for another legally allowed purpose. This includes destroying or permanently deidentifying any record (in written, audio or electronic format) containing personal information and all copies of those records.

20. HCCA will retain and destroy health information in accordance with the Health Records Act. HCCA will take reasonable steps to destroy, or permanently deidentify, records of a person's health information once they are no longer needed for the purpose for which they were collected or for another legally allowed purpose.

## **H. Disclosure of personal information**

21. HCCA will only disclose personal information:

- a) For the primary purpose for which it was collected
- b) Where the individual would reasonably expect us to
- c) Where the individual has consented.

22. Personal health information will not be disclosed by HCCA except where:

- the person has consented to the disclosure
- HCCA believes the disclosure is necessary to lessen or prevent a serious and imminent risk to life or health, or
- HCCA is otherwise legally required or permitted to disclose the information.

23. HCCA will not disclose personal information for any secondary purposes unless the individual's consent has been given or as required by law.

24. HCCA will not sell any personal information that it collects from an individual.

### **I. Anonymity when dealing with HCCA**

25. Individuals dealing with HCCA have the right not to identify themselves or use a pseudonym where it is lawful and practicable to do so.

### **J. Access and Updating of Personal Information**

26. HCCA will take reasonable steps to ensure the personal information it collects, uses or discloses is accurate, up-to-date, complete and relevant by updating its records whenever changes to information come to the attention of staff.

27. Under the Privacy Act and the Health Records Act, a person has the right to obtain access to any personal information which HCCA holds about them and to advise us of any perceived inaccuracy. There are some exceptions to this right set out in the applicable legislation.

28. A person can seek access to the information HCCA holds about them, and/or update their personal information by emailing [adminofficer@hcca.org.au](mailto:adminofficer@hcca.org.au). HCCA will require them to verify their identity and specify what information they require.

29. Although HCCA will not charge a person to access their personal information or make a correction, we may charge a fee to retrieve and copy material. In this circumstance HCCA will advise a person of the likely cost in advance.

### **K. Using our Websites**

30. HCCA's websites may record anonymous information such as IP address, time, date, referring URL, pages accessed and documents downloaded, type of browser and operating system. HCCA websites may contain links to or from other websites. HCCA is not responsible for the privacy practices of other websites. This privacy policy applies only to the information we collect on HCCA websites.

31. The personal information we collect through our website includes: names, e-mail addresses and phone numbers.

32. We only collect personal information by lawful and fair means. We usually collect personal information via our websites through:

- a) Use the Contact Us form
- b) Registration to receive our newsletter
- c) Forms when nominating to a committee vacancy or providing an update on committee work

#### **L. Google Analytics**

33. We use Google Analytics software to gather and temporarily store a variety of information about use of our websites. This information cannot be used to identify an individual.

34. We use aggregate data from all visits in order to improve our website and provide a better user experience to our visitors. The aggregate data is available only to HCCA web managers and other designated staff who require this information to perform their duties. You can review the [Google Analytics Privacy Policy \(link is external\)](#) for more information.

#### **M. Direct Marketing**

35. HCCA may use personal information for the purpose of advertising HCCA events, such as consumer representatives training, health issues groups, HCCA health forums and HCCA workshops.

36. If people do not want to receive this type of information they can request that we delete their contact details from HCCA distribution lists.

#### **N. Consumer representatives: Communication with community members on general principles and issues**

37. Asking consumer representatives to observe the confidentiality and privacy of information will not prevent them from communicating with other community members on general principles and issues.

38. If a consumer representative is unsure about any information they receive and how to store or record it, it is important that they check and seek clarification from the chairperson of the committee that they are a part of or HCCA's Executive Director.

#### **O. Case Studies**

39. HCCA may develop and publish case studies, write submissions and deliver presentations. In using personal stories in advocacy and training, HCCA staff shall:

1. Obtain written permission from the person concerned to use their experience.
2. Make every effort to de-identify the record of the experience.

40. In the event a person agrees to reveal their identity in a case study, HCCA staff shall make every attempt to ensure that the person's decision is an informed one. The person will have sufficient time to make the decision and will not be under pressure when making the decision. HCCA will also suggest the person discusses the decision with an appropriate third party, for example an advocate, family member or solicitor.

#### **P. Whistle-blower protections**

41. If HCCA is approached about fraudulent or negligent practice the Executive Director and the President will convene a meeting of the Executive Committee to decide on the organisation's response.

#### **Q. Complaints**

42. If a person would like further information about this Privacy Policy or has any concerns or complaints related to HCCA's collection, storage, use or disclosure of personal information, they should contact HCCA's Executive Director Darlene Cox by:

- email: [adminofficer@hcca.org.au](mailto:adminofficer@hcca.org.au)
- telephone: 02 6230 7800
- writing to: HCCA, Executive Director, 100 Maitland Street, HACKETT ACT 2602.

43. They will need to provide details of their complaint, as well as any supporting evidence and information. We will review and respond to all complaints received.

44. If a person is not satisfied with our response, they can refer their complaint to the Office of the Australian Information Commissioner by:

- online form at: <https://www.oaic.gov.au/about-the-OAIC/contact-us>
- telephone: 1300 363 992
- fax: +61 2 6123 5145
- writing to: Office of the Australian Information Commissioner, GPO Box 5288, SYDNEY NSW 2001.

## **R. Quality Assurance**

45. HCCA regularly reviews its operational procedures to ensure they comply with our obligations under the Australian Privacy Principles contained in the Privacy Act 1988 (Cth) and related legislation and the Health Records (Privacy and Access) Act 1997 (ACT).

46. This policy will be reviewed every 3 years, or earlier if required following changes in legislation.

47. HCCA provides new employees with training on how to handle personal information appropriately in accordance with this policy and associate procedure. A copy of this policy and the associated Privacy and Confidentiality Procedure is included in new employee induction packages.

## **S. Relevant policies**

1. HCCA Data Breach Response Plan
2. HCCA It Security Policy

## **T. Relevant legislation**

1. Privacy Amendment (Enhancing Privacy Protection) Act 2012
2. Privacy Act 1988 (Act)
3. Australian Privacy Principles contained in the Privacy Act 1988 (Cth)
4. Health Records (Privacy and Access) Act 1997 (ACT)
5. Privacy Amendment (Notifiable Data Breaches) Act 2017
6. Privacy Legislation Amendment (Enforcement and other Measures) Act 2022