Consumer Representative Training Handbook

Government
of South Australia

SA Health

SA
Ambulance
Service

AKNOWLEDGEMENT OF COUNTRY

SA Ambulance Service acknowledges Aboriginal and Torres Strait Islander peoples as the Traditional Custodians of this land and waters. We pay our respects to Aboriginal and Torres Strait Islander Elders, past, present and future, and acknowledge the diversity and strength of Aboriginal and Torres Strait Islander peoples and communities today.

We recognise consumers and carers, and their expertise and lived experience. Consumers’ wishes, needs and aspirations are at the heart of our work at SAAS and their perspective is vital in helping us to define and achieve our goals. Further, their courage and tenacity inspires us and drives our work for all South Australians.

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Introduction and Background

SAAS are committed to working with consumers and health services to position consumers at the centre of care. Health consumers are people who use, or are potential users of health services, including their family and carers.

Our mission is to engage consumers and health services to achieve high quality, safe, consumer centred care for all South Australians. We seek to promote and strengthen the voices, wellbeing, rights and leadership of health consumers.

We believe that consumers have a powerful influence on the health services they pay for, use and expect to support the health and wellbeing of all South Australians. SAAS advocates for health and human rights for all South Australians; is informed by the lived experience of health consumers, carers and the community; provides evidence-based consumers representation in health policy and planning and works collaboratively with consumers and health service providers to build the capacity for meaningful consumer engagement. We work to ensure consumer centred policy and practice is embedded across SA Ambulance Service.

Consumer Engagement

National and local healthcare policy and standards require health services to partner with consumers in the governance and management of health services. The World Health Organisation Declaration of Alma Ata (1978) states that '*The people have a right and a duty to participate individually and collectively in the planning and implementation of their health care."*
Consumer engagement is underpinned by standards and policy including:

- ***Statewide Consumer and Community Engagement Strategic Framework (Department for Health and Wellbeing)*** o which ensures there are mechanisms in place to actively engage with consumers and the community in order to meet their needs preferences and values and develop appropriate services. The principles values recognise the importance of partnering with consumers and the community and maintaining high quality and efficient health services.

- ***National Safety & Quality Health Service Standards 2019 (Australia Commission on Safety and Quality in Health Care)*** o Which aims to protect the public from harm and to improve the quality of health service provision. In particular
o Standard 1 describes the systems and strategies to use clinical governance systems to improve safety and quality improvement and partner with consumers to set these priorities and
o Standard 2 describes the systems and strategies to create a consumer-centred health system by including consumers in the development and codesign of quality health care

Health services must be informed and influenced by all people with lived experience, especially the most vulnerable individuals and groups, consumer advocates and representatives and the general public. These partnerships must genuinely reflect the needs, preferences and values of the people who use them and the communities who fund them. Consumer Advocates play an important role in promoting consumer engagement in health services.

Who is a Consumer Advocate?

A **Consumer** is recognised as users or potential users of health services and includes their family, carers and other members of the person’s support network (as identified by the person) who have an important role in the person’s health care decision making and in care giving. In mental health, the definition of a consumer refers to the user or potential user of health services and does not include their family, carer or other support persons.

Consumers are commonly identified by health services as patients and/or clients. Consumer Advocacy organisations have moved away from using the term patient so as to eliminate any inherent idea of passivity and to recognise that ‘a patient’ refers to a person at the point of care.

A consumer is recognised as any person, whether a current or potential health service user, who is impacted by the decisions of the health service and therefore has a right to be involved in this decision-making. Changes in the use of terminology acknowledges and supports the cultural shift required to enable and empower health service users and the broader community to actively participate in health service planning, design, delivery and evaluation

A **Consumer advocate** is a person with lived experience who supports, promotes and defends the interests of consumers, carers and/or the community. They may support an individual or stand up for a just cause or a specific position. A consumer advocate is independent of the health service and is able to provide a unique perspective and experience of the needs, goals and expectations of the person or cause for which they advocate. Consumer Advocates should have access to training to support and underpin their capacity to both understand the role and the health system in which they participate as an advocate

A Consumer representative is a person who voices collective consumer or community perspectives and take part in decision-making as a representative of those consumers and communities. Representatives may be nominated and given authority by an organisation or group and be accountable to them. They have a responsibility to remain informed by and inform the organisation or group of discussions and issues arising from the representation.

Core Skills for Consumer Advocacy

When you apply for a job you usually have a resumé to showcase your knowledge, skills, abilities and experiences. When you apply for a consumer advocate role you will be asked to show why you are ideal for the role by listing information such as your lived health experience, interest in the project, your connections to the community and any experience you have had as a consumer representative.

You should list any training you have done and also conferences and forums you have attended or presented at. You can regularly update your skills and experience to include any the committees and groups you have been involved with and supported. You should also consider the following questions to help you identify your core skills:

- Which personal qualities do you have?
- Which qualities would you like to develop and learn to be a more effective consumer advocate?

Understanding your own strengths and areas for improvement can help you to become a more effective advocate

Personal Qualities and Skills

- Consumer focused
- Assertive
- Sees the big picture
- Is responsive & prepared
- Strong negotiation skills
- Outcome focused
- Critical thinking
- Culturally aware
- Proactive
- Resilient
- Sense of humour
- Self-reflective
- Persistent
- Organised
- Empathetic
- Positive
- Listener

Working on Committees

During your time as a consumer advocate you will work on many committees. The role and functions of a committee will depend on its purpose (the work it will do), but some functions include;

- Advising an organisation on consumer issues
- Completing a set project or program
- Reviewing policy and advising on new policy
- Overseeing on issues of safety and quality
- Identifying gaps in program delivery
- Providing advice and direction on new or existing programs
- Making recommendations about how well an organisation is doing its work

There are many types of committees all with different roles and functions

- Advisory committees- a group of people that share their experience & views
- Reference groups – a group of people to compare thoughts, ideas, values with
- Steering committees – decided on priorities in how things will be done
- Governance groups – ensures things are being done appropriately and safely
- Project committee – oversee, guide and support the work of a specific project
- Working party – a group who study, report & make recommendations on a specific question

Terms of Reference (TOR)

A committee is guided by the Terms of Reference. These are a written set of rules for the committee to understand it role and what it wants to achieve. The TOR outlines the purpose, role, function, duties, membership, reporting and objective of the committee. The TOR acts as a road map for the committee and outlines how the committee is organised, who is on the committee and the expectations of the committee members along with their power and decision-making capacities. The TOR will also include timelines of the committee, with meeting arrangements, resources and budgeting, what they have to deliver and how their work will be reviewed.

Expectations for Consumer Advocates

There are a number of things that will be expected of you as a consumer advocate on a committee. You will be expected to attend all meetings where possible and be prepared for meetings (including reading any and all papers and minutes), you will also be expected to be actively involved in discussions and providing your views, suggestions, ideas and providing feedback throughout the meeting in an open and honest way.

There are also expectations you should have as a committee member, these include;

- To be treated with respect and as an equal member of the committee
- To be heard, listened to and understood by the committee
- To be able to ask for clarification and more information, especially where specific language or words are used that you do not understand
- To be given all relevant information and an agenda for the meeting. The information should be provided in a format you can read and understand and in a way that you want to receive it (eg online, in hard copy, large print, no abbreviations etc)

Skills for Meetings and Minutes

Some people can find meetings intimidating in the beginning. Often you may be the only consumer advocate on the committee, and anywhere from 5 to 10 health professionals or other staff. Often the committee has been running for some time and the other members already know each other. This can be hard at first for consumers who do not have the experience on committees that others might. It is important to remember that as a consumer advocate, you are there as an equal partner.

The committee needs your lived experience as a consumer to help them understand the goals, needs, issues and preferences of consumers. The other members of the committee do not know what you know about these issues. While others in the room can speak from a health service point of view, none of them are there as a person who uses the service.

Prior to your first meeting you should;

1. Be provided an induction/orientation with the service

2. Receive information about the organisation any forms your need to sign and any policies that relate to you and your role for example:

- Policies that relate to you (Work Health and Safety, Confidentiality and Privacy, Organisation Structure, Consumer Engagement Strategies)
- Contact information sheet for you and your emergency contact
- Information regarding sitting fees, travel allowance and other reimbursement including the reimbursement and sitting fee policy and forms
- Terms of Reference
- Background information and previous minutes
- Time and location information for future meetings

3. Had some contact with the chairperson and/or consumer engagement manager, either via email, phone or in-person to welcome you and ensure you have everything you need before you begin in your role. These staff are also there to support you in your new role.

If you have not received any orientation or information of this nature, ask for this to occur before your first meeting.

Preparing for a Meeting

Before your first meeting it is important to understand where the committee fits within the organisation or department and the wider system – if the organisation has a website it's a good idea to review this before the meeting . Make sure you have read through your induction information; TOR, previous meeting minutes, background papers and completed any administrative paperwork that is required.

Prior to meetings you should receive a pack of papers for the upcoming meeting (via email or hard copy if that is your preference) which will include the meeting agenda (the summary of things that are to be discussed at the meeting), previous minutes (short report on the things discussed at the last meeting) and any related papers. It is expected that you will have read through this before the meeting so that you can fully contribute to the meeting. Your preparation and reading time should be included in your sitting fees.

It might be helpful to make some short notes of thoughts or questions you have relating to the agenda. Having those questions and notes prepared prior to the meeting will give you more confidence so that you are not having to prepare all your thoughts during the meeting

During Meetings

During your first meeting, you should be given an opportunity to introduce yourself and meet your fellow committee members. Provide a brief outline of why you have been invited to join the committee and what has brought you to the role – this is part of your expertise and the value of consumer advocates on a committee. Take the time to note the names and roles of other members of the committee, if you are unsure of people’s names you can suggest that name tags are worn in initial meetings (or ongoing).

Follow along with the agenda throughout the meeting, if you are unsure of anything or need clarifications – address your questions to the chairperson of the meeting or the person presenting the item. If there are only a small number, or one, consumer on the committee – sit closer to the chairperson or the consumer engagement manager (or other support person), this is one method to ensure your voice is heard throughout the meeting. Your perspective as a consumer is important. Health practitioners and health service staff can often make assumptions consumers understand medical language, words and abbreviations. Your questions and feedback can highlight and help them understand about how to make information more accessible to consumers.

Contribute where you feel confident and comfortable but be careful of committing to anything you either don’t have time for or aren’t sure you can/want to do. Ask all the questions you need to, ask for more information about any and all aspects of the committee that you need to. Questions are a powerful tool.

Your opinions and input matter and it’s important that they are recorded in meetings, if you raise something or have questions you can ask to ensure they are recorded in the minutes.

After Meetings

After the meeting, you can organise a conversation with the chairperson and consumer engagement officer and any other consumer advocates on the committee to clarify any questions you may have and to highlight anything in the meeting that could be improved to make future meetings better for consumers.

Fill in any sitting fee and reimbursement forms and return them to the executive officer of the committee. The minutes from the meeting will be sent out to the committee a week or so after the meeting. Read through them and if there are any issues (eg if you notice something is missing or your comments haven’t been included) you can raise them at the next meeting.

Minutes

Minutes are an important document in the running of a committee as they record discussions and decisions that are made in meetings. For many organisations, minutes are a legal requirement for record-keeping and to meet the accreditation standards. They also keep a committee on track to meet its objectives and the work they have to deliver. At the beginning of a meeting, the chairperson will ask for the members to “move” the previous meeting’s minutes – this is your opportunity to raise any issues you have with the minutes.

The minutes will have a set structure based on the agenda of the meeting and will contain;

- Title of meeting
- Date, time and venue
- Members present and apologies
- An action plan of things that have been agreed and/or completed
- Previous minutes and any corrections
- Conflicts of interest
- Items on the agenda and any discussions or decisions made
- Actions and who is responsible and when they are due
- Date, time and venue for the next meeting

Raising Issues and Concerns

There may be times throughout your time on the committee where something goes wrong, for example, you may have a conflict with another committee member, or you may disagree with a decision made by the committee. When these conflicts or concerns arise, you should speak to the chairperson. Health or community services and government departments should have Human Resource processes that will support you manage any conflict. It is important to address any and all conflict – personal or not, in a professional manner. If an issue arises with a fellow committee member, seek advice and support from the chairperson or consumer engagement manager.

Conflict of Interest

Members are asked at the beginning of every meeting whether they have any conflicts of interest. A conflict of interest happens when a member may benefit from a decision or recommendation of the committee or is already involved in the issue in another way. Consumer Advocates often sit on a number of committees on different organisations. Agenda items can come up that the consumer feels overlaps with their other roles. If you are unsure, it is better to raise a potential conflict of interest and explain your reasons- rather than say nothing.

Consumer Sitting Fees and Cost Reimbursement

Sitting fees provide a measure of the value people bring to committee work. They are a measure of the time, effort and significant contributions made and, in the case of consumers, the knowledge, skills and lived experience that is not generally within the shared knowledge or perspective of health service staff.

Why Consumers Receive Sitting Fees and Cost Reimbursements

Sitting fees comprise a payment for service ie the work is valued . Sitting fees should include time taken for preparing for a meeting and other work you may asked to do outside of the committee meeting (including but not limited to reading of minutes/papers, responding to emails, phone calls, and requests for feedback on draft policies etc) and travel time. Sitting and reimbursement fees supported by State and Commonwealth Tribunals determinations on sitting fees and in South Australia, is a SA Health policy.

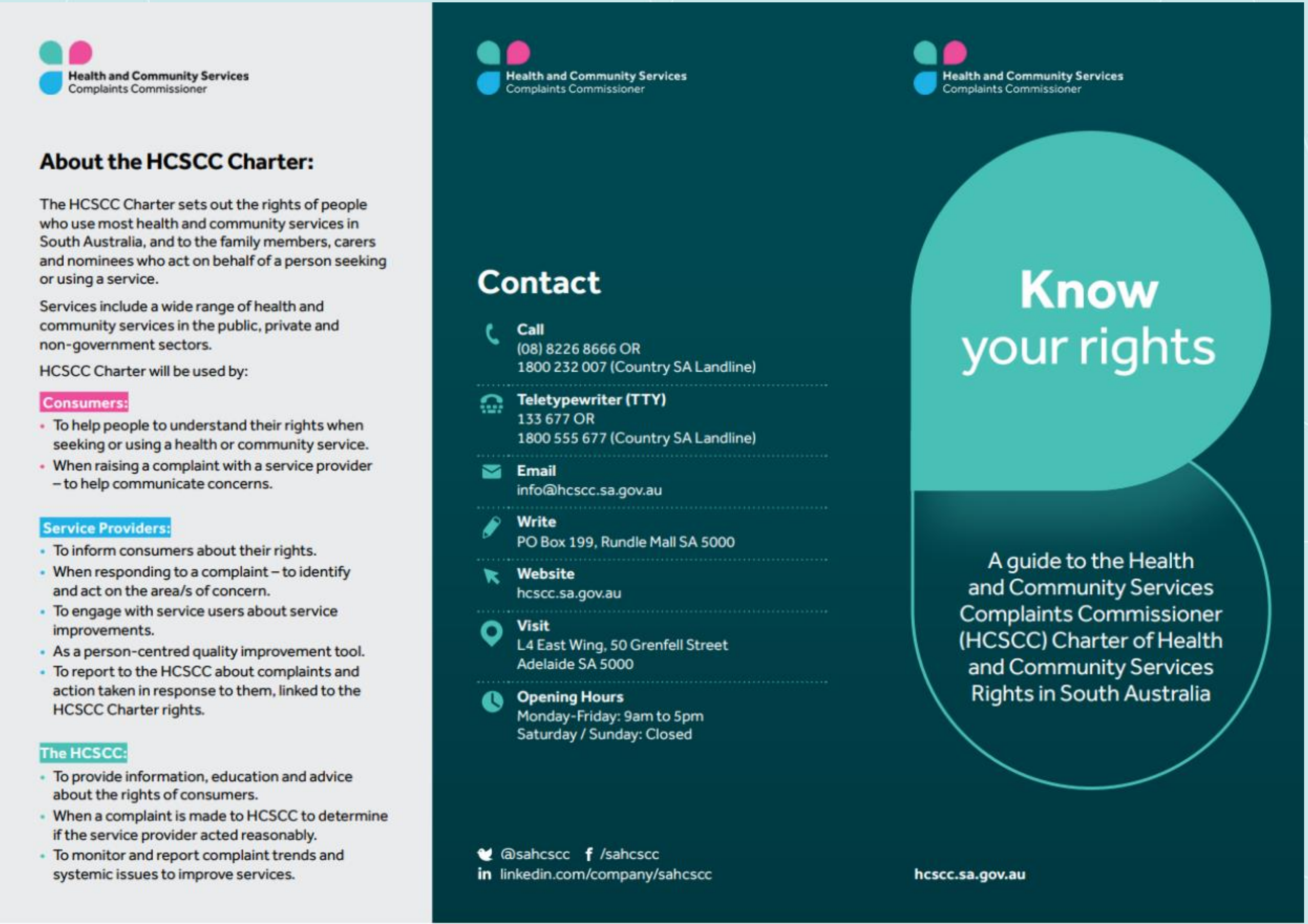
Many consumers often lose paid employment or negotiate unpaid leave, and/or pay childcare fees, to prepare for and attend commitments as a consumer advocate. Some of these costs can be claimed. Reimbursement of some costs is outlined in the policy. You should be given clear information about sitting fees and any reimbursement of costs the organisation will pay as part of your recruitment process. If not – you should ask to see their sitting fee and reimbursement policy.

Reimbursement is payment to cover costs incurred to participate (eg parking, transport, carer fees). It is based on receipts submitted in line with the organisational policy. It ensures that costs to consumers do not create artificial barriers to participation.
Although payment of sitting fees is within the capacity of properly funded organisations/ projects and research grants (eg large non-government bodies, research advisory groups) it may not always be possible for small not-for-profit organisations. Some smaller organisations may offer an alternative to payment (a principle of mutual benefit). For example, an under-funded or self-funded organisation or group might negotiate for consumers to receive a lower or no payment and also offer them to attend a training program for free. They may also offer a gift card for an easily accessible organisation eg Coles Myer).

For some consumers the costs associated with attending meetings makes it difficult for them to be involved. No one should be financially disadvantaged in their consumer advocate role. Health services are responsible for considering such costs that can create barriers to participation particularly for rural and remote communities, people with access support needs, disadvantaged communities. A small token of appreciation of the individuals’ commitment and contribution may be considered.
You can read the sitting fee and reimbursement policy on the SA Health website.

Resources for Consumer Advocates

Charter of Health and Community Services Rights in South Australia



Health and Community Services
Complaints Commissioner

About the HCSCC Charter:

The HCSCC Charter sets out the rights of people who use most health and community services in South Australia, and to the family members, carers and nominees who act on behalf of a person seeking or using a service.

Services include a wide range of health and community services in the public, private and non-government sectors.

HCSCC Charter will be used by:

Consumers:

- To help people to understand their rights when seeking or using a health or community service.
- When raising a complaint with a service provider – to help communicate concerns.

Service Providers:

- To inform consumers about their rights.
- When responding to a complaint – to identify and act on the area/s of concern.
- To engage with service users about service improvements.
- As a person-centred quality improvement tool.
- To report to the HCSCC about complaints and action taken in response to them, linked to the HCSCC Charter rights.

The HCSCC:

- To provide information, education and advice about the rights of consumers.
- When a complaint is made to HCSCC to determine if the service provider acted reasonably.
- To monitor and report complaint trends and systemic issues to improve services.

Health and Community Services
Complaints Commissioner

Contact

Call
(08) 8226 8666 OR
1800 232 007 (Country SA Landline)

Teletypewriter (TTY)
133 677 OR
1800 555 677 (Country SA Landline)

Email
info@hcscc.sa.gov.au

Write
PO Box 199, Rundle Mall SA 5000

Website
hcscc.sa.gov.au

Visit
L4 East Wing, 50 Grenfell Street
Adelaide SA 5000

Opening Hours
Monday-Friday: 9am to 5pm
Saturday / Sunday: Closed

@sahcscc f /sahcscc
in linkedin.com/company/sahcscc

Health and Community Services
Complaints Commissioner

Know your rights

A guide to the Health and Community Services Complaints Commissioner (HCSCC) Charter of Health and Community Services Rights in South Australia

hcscc.sa.gov.au

Five Guiding principles:

Diversity: South Australian society is made up of people with different cultures, needs, values and ways of life and this is to be recognised and respected.

Decision-making capacity: Some people may have impaired capacity to make decisions due to illness, injury, disability or development. Impaired capacity may be temporary or permanent, partial or complete.

If a person has impaired decision-making capacity the service provider should enable supported decision making.

If a person has impaired decision-making capacity the service provider must involve or seek the consent of a substitute decision maker, including a carer.

Individuals with impaired decision-making capacity must not be disadvantaged in the provision of health or community services.

Partnership: A genuine partnership between service users, carers and providers promotes safe, high quality services and the best possible outcomes. This requires sharing relevant information and treating each other with respect.

Provider contribution: Providers of health and community services are recognised for their contribution to the healthcare, well-being and welfare of individuals.

Authority: Some rights can be affected when legal orders or processes are in place.

Eight Charter rights:

Access: Right to access health and community services

I have a right to access health and community services that meet my identified needs.

Safety: Right to be safe from abuse

I have a right to be safe from abuse, or the risk of abuse, and to have my legal and human rights respected and upheld. *I have a right* to receive services free from discrimination and harassment.

Quality: Right to high quality services

I have a right to receive safe, reliable, coordinated services that are appropriate to my needs and provided with care, skill and competence.

Services I receive should comply with legal, professional, ethical and other relevant standards.

Any incidents involving me are managed openly to ensure improvements.

Respect: Right to be treated with respect

I have a right to be treated with courtesy, dignity and respect. *I have a right* to receive services that respect my culture, beliefs, values and personal characteristics.

Information: Right to be informed

I have a right to open, clear and timely communication about services, treatment, options and costs in a way that I can understand. When needed, I have the right to a competent professional interpreter.

Participation: Right to actively participate

I have a right to be fully involved in decisions and choices about services planned and received. *I have a right* to support and advocacy so I can participate. *I have a right* to seek advice or information from other sources. *I have a right* to give, withhold or withdraw my consent at anytime.

Privacy: Right to privacy and confidentiality

I have a right to have my privacy respected and my personal information kept confidential and secure. Personal information about me may not be disclosed without my consent, unless the disclosure is required to lessen or prevent a serious threat to life, wellbeing, or safety or is required by law.

I have a right to request and gain access to my records, unless there is legal restriction in place. I can nominate person/s with whom information can be shared.

Comment: Right to comment and/or complain

I have a right to be listened to and to comment on, or make a complaint about services sought or provided to me. *I have a right* to have my complaint dealt with properly and promptly, and without retribution as a result of having made a complaint.

I have a right to a representative of my choice to support and advocate for me when making a complaint. My feedback and complaints are managed openly to ensure improvements.

The Charter describes what consumers, or somebody they care for, can expect when receiving health care; https://www.safetyandquality.gov.au/australian-charter-healthcare-rights

National Safety & Quality Health Service Standards

NSQHS
STANDARDS

The primary aims of the National Safety and Quality Health Service (NSQHS) Standards are to protect the public from harm and improve the quality of health service provision;
https://www.safetyandquality.gov.au/standards/nsqhs-standards

National Standards for Mental Health Services

The NSMHS outlines service standards for all mental health services including government, non-government and private sectors across Australia;
https://www1.health.gov.au/internet/publications/publishing.nsf/Content/mental-pubs-n-servst10-toc

DAVID PLACE
Chief Executive Officer

Government
of South Australia

SA Health

SA
Ambulance
Service

Any questions, please contact the Senior Community Engagement Advisor -

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THANK YOU.

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