

St Vincent's Health Australia Group Policy

All SVHA policies must comply with the Code of Ethical Standards for Catholic Health and Aged Care Services in Australia, the Ethical Framework for Mary Aikenhead Ministries and the SVHA Ethics Policy.

SVHA Research Exceptional Participant Experience Policy

1. Purpose

Policy Statement

The St Vincent's Health Australia (SVHA) Research Exceptional Participant Experience Policy is a framework that brings St Vincent's values of compassion, integrity, justice, and excellence to life in our research. St Vincent's recognises that active involvement of participants in health and medical research benefits the quality of research, as research informs health care.

This policy will assist researchers involved in participant-centred research to:

- Understand the value and importance of the participant's recognition, involvement and collaboration in the planning, design, delivery, evaluation, and improvement of health and medical research.
- Understand the benefits for fostering effective partnerships between researchers and participants.

St Vincent's aims to build a St Vincent's-wide research community that drives excellence in care and champions our mission and values. Our vision is to ensure that our community experiences better care and value through research-driven improvement and access to new therapies and medical devices.

Who does this policy apply to?

The SVHA Exceptional Participant Experience policy applies to all staff, students and collaborators that involve research participants in their research at SVHA campuses and facilities.

2. Risk Statement

St Vincent's Health Australia is committed to maintaining the highest standards of research conduct and integrity, ethical behaviour, clinical governance, and corporate governance.

St Vincent's acknowledges that there is no single approach to partnering with participants in their research journeys. This policy outlines our commitment to creating the exceptional participant experience, where improving patient care is the purpose of all research and participants are critical partners in their research journeys.

3. Definitions

Carers

Families and friends providing unpaid care to consumers where the person being cared for is an older person, or a person with a disability, a mental illness, or an ongoing medical condition.

Communities

Groups of people who have interests in the development of an accessible, effective, and efficient health service that best meets their needs.

Consumers

People who are past, current, or potential users of health care services across the SVHA organisation. This includes women and men, people living with a disability, people from cultural and religious backgrounds, socioeconomic status and social circumstances, sexual orientations, health, and illness conditions.

Health and medical research

Research with a human health focus.

Health consumer representative

A person who has taken up a formal role to advocate on behalf of health consumers and/or to bring a consumer perspective from personal experience in partnership activities within a health organisation, with the overall aim of improving healthcare. A consumer representative may be appropriately trained or undergo training and be supported to advocate for consumer-centred health care.

Participant-centred care

A participant-centred care approach to research involves treating participants and their carers with dignity and respect; communicating and sharing information between participants and their carers; and researchers encouraging and supporting participation in decision-making fostering collaboration with participant and carers and healthcare organisations in the planning, design, delivery, and evaluation of health care.

4. Policy

4.1. National Clinical Trials Governance Framework: National Standard 2 – Partnering with Consumers

Partnering with consumers is essential for ensuring safe and effective delivery of health services and clinical trials. Fostering effective partnerships in clinical trials can lead to a positive experience for participants and carers, improve quality and safety of healthcare, and improve the quality and impact of the research^{1,2}.

The *National Clinical Trials Governance Framework – Partnering with Consumers (Standard 2)*² outlines the roles and functions of partnering with consumers at a clinical trial service, whereby:

- Consumers are partners in planning, design, delivery, measurement, and evaluation of systems to deliver clinical trial services.
- Trial participants and patients are partners in their own care, to the extent that they choose.

The **SVHA Research Exceptional Participant Experience Policy** complies with the core principles from the National Clinical Trials Governance Framework and the National Standard 2 – Partnering with Consumers.

4.2. The Research Cycle and Levels of Participation

Health and medical research usually follow a cycle with three primary phases³:

- **Research preparation** – deciding what to research, how to do it and where to obtain funding.
- **Research execution** – doing the research including recruitment, data collection and analysis.
- **Research translation** – communicating research findings and ensuring these findings translate to improved clinical practice, policy, and education.

The *International Association for Public Participation (IAP2) Spectrum of Public Participation*⁴ has identified five levels of participation to assist organisations in considering the consumer's voice in community engagement programs.

There are multiple ways in which the research participant can contribute to the preparation, execution, and translation phases of health research. Below are the **five levels of participation** in relation to the participant's research journey:

- **Inform:** Participants are informed on their research journey, from research priorities to its execution and dissemination or implementation of results.
- **Consult:** Participants are asked to give feedback on their research journey and are informed of how their input contributes to the research.
- **Involve:** The aspirations and concerns from participants are directly reflected in the alternatives developed for their research journey.
- **Collaborate:** Participants are considered as partners at each stage of their research journey.
- **Empower:** Participants decide on how their research journey is conducted.

4.3. SVHA Research Exceptional Participant Experience

The SVHA Research Exceptional Participant Experience is a framework that will set SVHA Research apart from competitors through:

- Exceptional researchers
- Exceptional research projects
- Exceptional, safe, and welcoming facilities
- Exceptional research journeys co-designed with participants and their carers

Improving patient care is the purpose of all research, and **participants are critical partners** in their research journeys. St Vincent's is committed to creating an exceptional experience for every participant, every time. Researchers involved in participant-centred research are expected to listen to the participant voice, by inviting the community to partner at all levels:

- **In their engagement** through co-design of research projects and processes.
- **In their research journey** through seeking proactive and honest feedback and acting on feedback.
- **In governance** through consumer participation on key committees and Human Research Ethics Committees.

4.4. Creating the SVHA Research Exceptional Participant: Our People

At SVHA, our researchers are fundamental to the participant experience, and this means:

- Recruitment of the right people aligned with the SVHA mission and values and an exceptional experience culture (feeling welcome, valued, safe).
- Behaviours and mindsets that create an exceptional experience begin at recruitment, induction, orientation and through ongoing reflection – **'We are all role models.'**
- Our researchers experience enriched careers through connections with and involvement in research and research translation.
- Research leaders at all levels lead for an exceptional participant experience.
- Staff wellbeing is prioritised to enable our people to deliver exceptional participant care and research.

The *SVHA Research Exceptional Participant Experience* exemplifies the Levels of Participation throughout the Research Cycle via four key pillars:

4.4.1. Participant-Centred Culture

Investigators and researchers working in participant-centred research at St Vincent's are expected to foster a participant-centred culture by:

- Focusing on the participant's experience and not on the task.
- Ensuring that participants are empowered to make decisions on their research journey.
- Encouraging participants to co-design research projects.
- Leading as role models for supporting the exceptional participant experience.
- Supporting multidisciplinary teams that are open to change, learning and continuous improvement.

4.4.2. Exceptional Care

St Vincent's is committed to providing exceptional care through our research:

- Clinical research should lead to high-value care.
- Research is embedded in safe and high-quality care.
- All participants should have equity of access to opportunities in research, and diversity should be encouraged.
- Researchers should prioritise participant safety first.
- Digital solutions should be optimised for participant engagement.
- Research should inform evidence-based healthcare decisions and new models of care.

4.4.3. Exceptional Research

St Vincent's promotes exceptional research by:

- Championing research projects that are high quality and high impact.
- Ensuring research projects are translational and clinically relevant.

- Encouraging researchers to consult with participants at all phases of research – they should be encouraged to co-design the research journey.
- Employing the right staff with the right skills to work in participant-centred research.
- Recruiting and/or educating all researchers involved in participant-centred research in the right actions and behaviours.
- Promoting a supportive and inclusive environment.

4.4.4. Effective Communication

Investigators and researchers at St Vincent's are expected to promote effective communication through the following means:

- Shared decision-making between the research team and the participants.
- Supporting health literacy around research purpose and processes.
- Facilitating innovative communication tools for informed consent.
- Fostering effective communication to participants throughout the trial journey.
- Ensuring that effective interdisciplinary communication is centred on participant care.

4.5. Creating the SVHA Research Exceptional Participant: Our Facilities

The hospitals and facilities at St Vincent's provide a safe environment for every participant, irrespective of their faith, culture, or individual needs. St Vincent's is committed to providing co-designed remote research opportunities beyond the physical walls.

4.5.1. Clinical research destination of choice

St Vincent's is committed to be the clinical research destination of choice for:

- **Participants** by fostering a safe and inclusive environment.
- **Researchers** by providing exceptional training and opportunities.
- **Clinicians** by supporting excellence in research translating into excellence in clinical care.
- **Collaborators** and **industry stakeholders** by facilitating ease of access for research translation.
- The **Community** by promoting health research and awareness.

4.5.2. Safe and welcoming environment

St Vincent's advocates for a safe and welcoming research environment by:

- Ensuring that participants feel comfortable to express their concerns and aspirations in the research journey.
- Facilitating culturally sensitive engagement with diverse populations.
- Embracing Culturally and Linguistically Diverse (CaLD) populations.
- Providing researcher training and support for engaging diverse and CaLD participants.

4.5.3. Models of research design and activity

St Vincent's models of clinical research design and activity centres on the participant

through:

- Innovation in study design to include the participant voice.
- Innovation in study activity to reduce participant burden.
- Innovation in study engagement, including remote trials, telehealth trials and hybrid models.
- Participant experience informing design and function.
- Collaborative clinical trial delivery co-designed around the participant's involvement.

4.5.4. Digital and innovative solutions

St Vincent's strives to be at the forefront of digital and innovative solutions for participant-centred research through:

- Enhanced connectivity for study participants.
- Increased access to remote and telehealth trials.
- Digitised participant journey (i.e., participant engagement systems and portals).
- Researcher support, training, and resource portal to enhance participant engagement.
- Evidence-based research and innovative practices.

4.6. Participant Feedback and Engagement on Research

SVHA Research endeavours to hear from the participants and the community about their attitudes and expectations of the research activities, research delivery and staff via:

- Consumer forums
- Proactive participant feedback opportunities
- Real-time consumer feedback
- Research training in consumer engagement

5. Relevant References

1. Australian Commission on Safety and Quality in Health Care. [National Safety and Quality Health Service Standards](#). 2nd ed. – version 2. Sydney: ACSQHC; 2021
2. Australian Commission on Safety and Quality in Health Care. National Clinical Trials Governance Framework – Guide for Implementation. Sydney: ACSQHC; 2020
3. National Health and Medical Research Council, Australian Research Council and Universities Australia. *Australian Code for the Responsible Conduct of Research*, Canberra: Australian Government; 2018
4. International Association for Public Participation. *IAP2 Public Participation Spectrum*. Accessed from: [IAP2 Published Resources - IAP2 Australasia](#)
5. South Australian Health and Medical Research Institute and Health Translation SA. A Consumer and Community Engagement Framework for the South Australian Health and Medical Research Institute – Final Report, Adelaide: SAHMRI; 2020

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