Consumer and Community Involvement Program

SUDDEN INSIGHTS RESEARCH STUDY

Micro Community Conversation SUMMARY REPORT

Prepared By

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November 2025

THE UNIVERSITY OF WESTERN AUSTRALIA

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Answers for Archer SUDC Association Inc

Western Australian Future Health Research & Innovation Fund

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ACKNOWLEDGEMENTS

Acknowledgement of Country

The WAHTN CCIProgram acknowledges the Aboriginal people of the many traditional lands and language groups of Western Australia. We acknowledge the wisdom of Aboriginal Elders both past and present and pay respect to Aboriginal communities of today.

Acknowledgement of Lived Experience

We acknowledge the importance and expertise of the lived experience voice of health consumers and carers. We recognise their involvement in making a difference in supporting health research and impacting the health and wellbeing of our communities.

BACKGROUND

The Sudden Insights research team partnered with the Consumer and Community Involvement Program (CCIProgram) to conduct a Micro Community Conversation (MCC) on obtaining consent for tissue donation for ethically approved research in cases of sudden paediatric death, where the cause remains unascertained. This event gathered a small group (5 people) with the lived experience of being a bereaved parent of a child sadly lost through an unascertainable cause such as Sudden Infant Death Syndrome (SIDS) and Sudden Unexplained Death in Childhood (SUDC). The aim of the conversation was to provide focused, detailed feedback on the acquisition and use of tissue collected at post mortem for research in SIDS and SUDC cases. The insights gained will be used to shape future research by informing ways to improve consent processes, change policy around the use of post mortem tissue and make SIDS and SUDC research more accessible and sustainable into the future.

THE CONSUMER AND COMMUNITY INVOLVEMENT PROGRAM

The Consumer and Community Involvement Program (CCIProgram) is dedicated to embedding the voices of consumers and community members in health research. Established as part of the Western Australian Health Translation Network (WAHTN), the program works to ensure that research is shaped by lived experience and addresses real-world health challenges.

At the heart of the CCIProgram is a team committed to building connections between researchers, consumers, and organisations. This team provides tailored support, guidance, and resources to ensure consumer involvement is an integral part of research design, implementation, and translation.

By championing consumer and community involvement at local, state, and national levels, the CCIProgram continues to evolve, ensuring that health research is informed, shaped and guided by those with lived experience.

WAHTN
Western Australian Health Translation Network

Consumer and Community Involvement Program

THE RESEARCH TEAM

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Ms. Melanie Andrew
University of Western Australia

Presenter

Ms. Rebecca Glorie
Wellmind Psychology

Psychologist

A/Prof Demelza Ireland
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Scribe

WHAT IS A MICRO COMMUNITY CONVERSATION?

A Micro Community Conversation is a small, structured discussion designed to gather insights from a highly targeted group of individuals (4-6 participants) with specific lived experiences. Unlike larger Community Conversations, MCCs focus on in-depth exploration of a particular topic, ensuring each participant has a meaningful opportunity to contribute. The format is designed to be intimate, flexible, and highly focused, making it particularly useful for discussing niche, sensitive, or emerging health research areas.

ABOUT THE MICRO COMMUNITY CONVERSATION

The Micro Community Conversation was held on 26 November 2025, and included 2 research team members, psychologist Rebecca Glorie, 5 consumers from Western Australia (3 in person, 1 online, 1 prepared responses in writing) and 1 member of the Consumer and Community Involvement Program.

Melanie Andrew presented an overview of the project. Demelza Ireland acted as th scribe for the conversation.

I would consent to my child's tissue being donated. We are not going to get anywhere unless something is done - I want answers!

From day one answers were what I wanted and I would consent to anything that helped me achieve getting them.

All babies that die in an at home setting should have to go to the hospital so the family is supported by medically trained staff, then issues like consenting for tissue use in research can be dealt with then.

PROMOTION

The Research Team worked closely with the CCIProgram to recruit members of the Western Australian community with a lived experience of losing a child to an unascertained cause such as SIDS and SUDC, to hear their thoughts on consenting to the donation of post mortem tissue for ethically approved research.

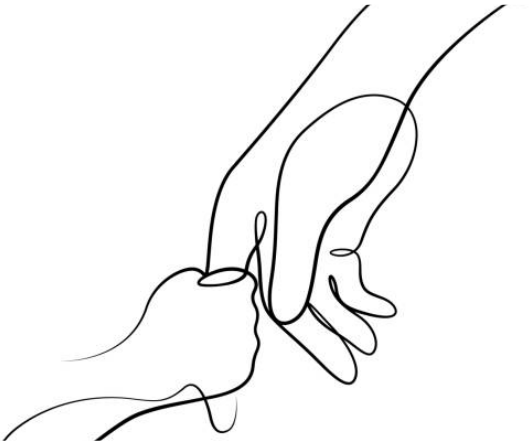
We shared promotional communications across multiple channels. Flyers and social media posts (Twitter, Facebook, Instagram and LinkedIn) were posted and circulated around relevant networks, including consumer and/or related health service provider networks and community groups.

STRUCTURE AND PROCESS

Our research team is deeply mindful of the sensitive nature of this topic and is committed to ensuring the safety and wellbeing of all consumers. The loss of a child is an insurmountable grief, and throughout the process it was important to us to remain considerate of the needs of those with lived experience.

For this reason, we invited a registered psychologist, Ms Rebecca Glorie, to join the research team and this Micro Community Conversation. This was a first for WATHN and the CCIP program, and we hope it becomes a standard component of future community conversations.

Ms Glorie was available to support participants should they became distressed and to ensure discussions were conducted in a mindful and respectful manner to minimise the risk of retraumatisation. The inclusion of Ms Glorie was a positive and valuable addition to the conversation, providing supportive oversight and enhancing the safety and quality of discussions.



The session was facilitated by a CCIProgram representative, who guided participants through structured discussion questions. A researcher acted as a scribe to record key insights shared by attendees.

Consumers were presented with 3 questions to discuss;

- How do you feel about consenting to tissue taken from your child and used in ethically approved research? Why?
- If you were to consent to research, how would you like to give this consent?
- What Information needs to be provided to parents? What information do you want and when? How do you want this information provided?

Each question was allocated 20 minutes for discussion, however we allowed the topic to progress organically and did not constrict conversation to strict time limits. The comments, feedback and suggestions were all captured by the event scribe and are presented in the following pages of this report.

AGENDA

Insights into Sudden Infant Death Syndrome & Sudden Unexplained Death in Childhood - Community Conversation

26 November 2025

eZone North, Room 113, UWA

Agenda

5.45pm	**Registrations**	**All**
6.00pm	**Welcome** • Acknowledgement of Country & Acknowledgement of Lived Experience • Welcome to the workshop • Introductions	**Kerry Mace**
6.10pm	**Presentation**	**Melanie Andrew**
6.30pm	**Process of the evening**	**Kerry Mace**
6.35pm	**Question 1:** How do you feel about consenting to tissue taken from your child and used in ethically approved research? Why?	**All**
6.55pm	**Question 2:** If you were to consent to research, how would you like to give this consent?	**All**
7.15pm	**Question 3:** What Information needs to be provided to parents? What information do you want and when? How do you want this information provided?	**All**
7.35pm	**Next Steps**	**All**
7.55pm	**Evaluation & Honorarium information**	**All**
8.00pm	**Close**	

KEY INSIGHTS OF THE MICRO COMMUNITY CONVERSATION

100% of the next of kin shared that they would consent to the donation of post mortem tissue for ethically approved research.

- Timeframe is irrelevant; all consumers knew within the first day that they wanted answers. Consumers further along in their grief felt they would not be retraumatised by being asked to consent to tissue donation.
- All consumers would welcome the opportunity to have further investigations on their child if it meant answers that could prevent SIDS/SUDC for other families.
- Consumers with partners said they would have asked their partner to co-consent.

Consumers felt the organ donation approach would be a good model for tissue donation.

- If children who died at home were taken to hospital before going to the morgue, families could be better supported in the medical rather than coronial system. Consent for tissue donation at this time would be ideal.
- Given it is already a difficult time, and parents are desperate to know what happened to their child, consent within the 24-48 hr could be sought if required to ensure research quality.

The existance of archival tissue was not something the consumers were aware of, however none were angry, instead they were hopeful that this tissue could be used for research that may help find answers, 100% would consent to its use.

- Next of kin were upset to know archival tissue was available, that could be used for research, but was not being put to good use.
- None of the consumers felt they would be re-traumatised by being contacted to use archival tissue. Whilst they appreciate the concern of the Coroner, they would like the opportunity to make this decision for themselves.
- An opt-in consent process was received well by the group and should be considered for archival tissue.

KEY DISCUSSION POINTS OF THE MICRO COMMUNITY CONVERSATION

Theme	Consumer Comments
Support for tissue donation for ethically approved research	• All participants strongly supportive; desire for answers; would have consented at time of autopsy; motivation to help future families; continued search for information years later.
Timing of consent	• Could consent at hospital (if taken there, not everyone is); 24–48 hours post-death acceptable if needed; timing confronting but acceptable due to need for answers; consent at autopsy viewed as reasonable.
Who should obtain consent	• Never police; preferred medical staff, social workers, chaplains, or researchers; organ donation model seen as appropriate; want compassionate, medicalised approach.
How consent should occur	• Not by email or letter; initial phone call only to book a meeting; in-person or scheduled conversation preferred; not at funeral home; avoid cold calls; want opportunity to ask questions.
Involvement of researchers	• Prefer contact with researcher directly or a known staff member; want relationship-based communication; researcher involvement increases trust.
Awareness and views on archival tissue	• Many unaware; not upset they hadn't been told; pleased tissues exist; want them used; believe consenting years later is no more traumatic than at autopsy; anger that overprotection may limit research.
Biobanking	• Seen as "future proofing"; leftover tissue should be stored, not destroyed; want shared access across researchers; prefer active consent model over waiver, but understand waiver's purpose. Supportive of an opt-in approach, promoted through trusted organisations like Red Nose Australia.
Notification of tissue use	• Want to know when samples are used; prefer updates from researcher or original consenter; group-level results acceptable; value any new knowledge; want significant findings of individual child to be shared with Coroner for further investigation.

KEY DISCUSSION POINTS OF THE MICRO COMMUNITY CONVERSATION

Theme	Consumer Comments
Information needs	• Want plain language, sensitive information; don't want lists of specific sample types; want ongoing updates about research; desire community connection around research involvement.
Desire for answers	• Persistent across all timeframes (12 months–40 years post death); parents would "still say yes" years later; high levels of guilt and ongoing need for explanation.
Concerns about current processes	• Confusion about requirement to send child to hospital, all feel this should be the standard; unclear autopsy consent processes; frustration at lack of SIDS/SUDC research; belief that ethical caution may hinder research progress.
Expectations for research impact	• Want research to inform improvements in clinical and forensic practice; desire for better systems and guidelines; want tissue use to meaningfully contribute to care improvements.
Research collaboration	• Want research to be collaborative, desire for a holistic approach to research rather than a tunnel vision approach. Receptive to the Sudden Insights Research Study and thankful for the opportunity to be given a voice to inform future research.

"To me, now, its important to know that the death of my child, and me agreeing to providing samples, could potentially help other parents in the future."

"I had absolutely no idea there was tissue stored until I pushed and pushed the coroner. The fact that they conduct autopsies, find nothing, then just close it absolutely baffles me. Why are you storing tissue if you do absolutely nothing with it and don't give parents the opportunity to do something with it?"

MICRO COMMUNITY CONVERSATION QUESTIONS AND RESPONSES

ATTENDEE INSIGHTS

The following pages contain the responses and thoughts shared by attendees at the Micro Community Conversation.

QUESTION 1

HOW DO YOU FEEL ABOUT CONSENTING TO TISSUE TAKEN FROM YOUR CHILD AND USED IN ETHICALLY APPROVED RESEARCH? WHY?

PROMPTS:

- Can you recall consenting to the autopsy of your child?
- To collect tissue at postmortem parents would need to consent before the autopsy takes place, this is usually between 24-48 hrs after the death of their child. Do you think this timeframe is reasonable? If not, what would a reasonable timeframe be to be contacted?
- How would you feel about being contacted possibly years later about the archival tissue?
- What does it mean to you to know that your child's tissue is or isn't being used in research?

Participants engaged in a detailed discussion on consenting to additional investigations and research following the death of their baby.

Key insights included:

- **Strong motivation to find answers –** Participants described an urgent desire to understand why their baby died, with some engaging with researchers soon after the death, conducting their own research, and even expressing a wish to retrain as a researcher to help uncover answers.
- **Willingness to consent to further investigation –** Participants consistently indicated they would have readily approved additional investigations at autopsy, describing an immediate and desperate need for information and clarity. Several reflected that, in hindsight, they would have *"100% said yes"* to research use of tissue at the time of autopsy.
- **Shared decision-making and ongoing uncertainty –** Participants emphasised the importance of joint decision-making with their partner and noted that not knowing the cause of death contributes significantly to long-term distress and complexity in bereavement.

One participant expressed, *"I instantly approved anything that could help find answers — not knowing what happened makes everything harder"*, highlighting the role of unanswered questions in compounding grief and the perceived value of research engagement for bereaved families.

QUESTION 2

IF YOU WERE TO CONSENT TO RESEARCH, HOW WOULD YOU LIKE TO GIVE THIS CONSENT?

PROMPTS:

- Would you prefer to be contacted directly or through another trusted pathway to consent, i.e. researcher, medical professional, coronial counsellor, peer support councillor, organisation like Red Nose Australia, or other parent with lived experience?
- What would be the best medium to use to contact you, phone, email, SMS or in person?
- Would you be happy to consent online or would you like to meet the research team first?
- How would you like the tissue that remains after the study to be stored or disposed?
- Would you be comfortable with a broader consent model, such as waiver of consent?
- Do you have any ideas on how best to convey to families that are not currently aware that there is archival tissue stored for their child.

Next of kin engaged in a detailed discussion on how consent for research should be sought following the death of a baby. Key insights included:

- **Timing and context of consent –** Participants felt consent could reasonably be sought at or around the time of autopsy, particularly if this aligns with optimal sample collection and the possibility of obtaining answers. While acknowledging profound shock and dissociation at that time, many indicated they would still be inclined to consent because of a strong desire for information. A single, comprehensive consent discussion covering all current and future research use (including fresh and archival tissue) was viewed as preferable to repeated requests over time.
- **Who should request consent –** There was unanimous agreement that police should never seek research consent. Participants strongly favoured a medicalised approach, comparable to organ donation, with consent requested by trusted professionals such as doctors, social workers, or chaplains. Direct contact with researchers, or at least the opportunity to speak with the research team, was also highly valued.
- **Approach and communication –** Participants emphasised the need for sensitive, personal communication, ideally initiated by phone to arrange a meeting rather than a “cold call,” and explicitly rejected consent being sought via email, letter, or at a funeral home. Families wanted time to ask questions, clear explanations of potential benefits, and reassurance that research might contribute to answers for their family or others in the future.
- **Views on archival tissue and future use –** Many participants were unaware at the time that tissues were being stored long-term, but were not distressed by this in retrospect. Instead, they expressed relief that tissue exists and strongly support its use in research. Any anger was directed at the idea that stored tissue might remain unused or be destroyed. Participants felt that being asked to consent years later would not be more traumatising than being asked at autopsy, noting that grief does not diminish with time.

- **Consent models and alternatives –** While waiver of consent was acknowledged as having practical advantages (rapid access to large sample numbers) and they were not adverse to it, it was not the preferred option. Participants expressed a desire to be informed if their child's tissue was used and supported opt-in biobank models and long-term tissue storage as a form of "future-proofing" research, provided governance and transparency were strong.

One participant expressed, *"If it was okay to ask about organ donation, why wouldn't it be okay to ask about research samples that might give answers?"* highlighting the view that research consent, when handled sensitively by medical professionals, is both appropriate and meaningful to bereaved families.

QUESTION 3

WHAT INFORMATION NEEDS TO BE PROVIDED TO PARENTS? WHAT INFORMATION DO YOU WANT AND WHEN? HOW DO YOU WANT THIS INFORMATION PROVIDED?

PROMPTS:

- How much information would you want about the research project before giving consent
- Would you want to specify the research study your child takes part in or would you be ok to consent to research generally?
- Do you have any ideas on how best to convey to families that are not currently aware that there is archival tissue stored for their child.

Participants engaged in a detailed discussion on consent for the use of biobanked tissue samples for research. Key insights included:

- **Scope of consent –** Some participants were open to their samples being used for research in general, while others preferred that biobanked samples be used specifically for SIDS/SUDC research. There was no expectation for consent to be sought for each individual study, but participants strongly desired transparency about the use of their child's samples.
- **Communication and follow-up –** Participants emphasized the importance of being informed when their samples are used. Ideally, a researcher—or someone they know, such as the initial consent officer or a consumer researcher—would contact them with plain-language, sensitive explanations of study results. They did not want to be left wondering whether their child's tissue contributed to a study.
- **Feedback and engagement –** While returning individual results was not necessary, participants valued receiving group-level findings, contributing to broader knowledge that could help other families or future pregnancies. Active consent was seen as including awareness that their samples could be used in future projects and the possibility of being contacted again for updates or results. They also noted that personal findings of significance, if discovered, should be communicated to the coroner to support accurate determination of cause of death and address enduring parent guilt.
- **Community and support –** Participants expressed a desire to feel part of a research community, with regular updates about ongoing SIDS/SUDC research that could involve their child.
- **Preferences around information detail –** Participants preferred not to receive specific information about the types of samples taken, focusing instead on research outcomes and contributions to knowledge. They also emphasized the need for research to inform improvements in clinical practice and the handling of the post-mortem and consent process.

One participant expressed, *"Any result is a good result — it doesn't have to be about my baby personally, it's about learning more to help others",* highlighting the altruistic motivation to support research while remaining engaged and informed.

EVENT SUMMARY

The Micro Community Conversation provided a rich and focused discussion, allowing researchers to explore specific lived experiences in depth. Participants found the session valuable, with many expressing appreciation for the opportunity to contribute directly to research.

Next Steps:

- The research team will use these insights to inform research design and to facilitate discussions about coronial practices.
- Future Community Conversations may be conducted to explore national views and opinions on the topic.
- Findings from this MCC will be integrated into the Sudden Insights Research Study, funding proposals and guide coronial policy recommendations.

WHAT'S NEXT FOR THE SUDDEN INSIGHTS RESEARCH STUDY?

Information gathered from the Micro Community Conversation will be used to inform the development of a national survey exploring consent processes and other barriers and enablers for the use of tissue taken at post-mortem from children who died from SIDS or SUDC. Findings from this survey will then be used to guide future SIDS and SUDC research practices, with the aim of establishing more sustainable, ethical, and accessible research in this field.

Research in this field is ethically complex and is often hindered by a lack of clear pathways to proceed. The Sudden Insights Research Study is committed to navigating this lengthy and challenging process in pursuit of answers for families, while also paving the way for research facilitation in the future.

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