



# Informed Consent to Medical, Surgical or Anaesthetic Treatment: Reflections from People's Health Voice Focus Communities

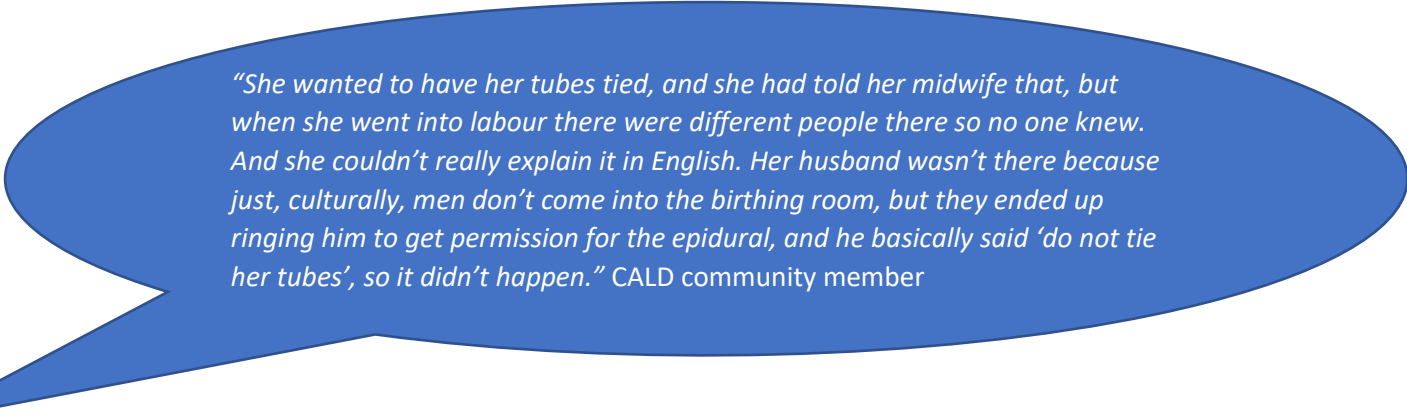
## Language inclusion

While SA Health policy is to avoid the use of family translators where possible, a lack of trained, accessible interpreters means that **informal translation regularly occurs**.

For many CALD patients, involving family in the sense-making conversations needed to support informed consent is welcome, particularly for people from cultural backgrounds oriented to collective decision-making (as opposed to individualized decision-making foregrounding patient autonomy). For them, **being supported in the consenting process by someone they trust, and whose communication style they understand, can scaffold meaningful informed consent** in a manner that could not be otherwise replicated.

For others, however, informal interpreters can open consent conversations up to:

- **influence or persuasion within the translation process**, particularly when proposed medical interventions involve moral/ethical decision-making (e.g. termination of pregnancy, gender-affirming surgery, tubal ligation)



*"She wanted to have her tubes tied, and she had told her midwife that, but when she went into labour there were different people there so no one knew. And she couldn't really explain it in English. Her husband wasn't there because just, culturally, men don't come into the birthing room, but they ended up ringing him to get permission for the epidural, and he basically said 'do not tie her tubes', so it didn't happen." CALD community member*

- **inaccurate or incomplete translation**, particularly in cases where the informal translator themselves has low levels of health literacy.

Formal interpreter provision can also bring complexity into information and consent conversations where patients feel:

- **reticent to ask clarifying questions** of people they don't know

- **pressure to defer to doctors/experts**, which may be exacerbated by the presence of an interpreter

- **concerned about confidentiality**, particularly if the interpreter shares membership of their cultural community, and potentially mutual acquaintances.

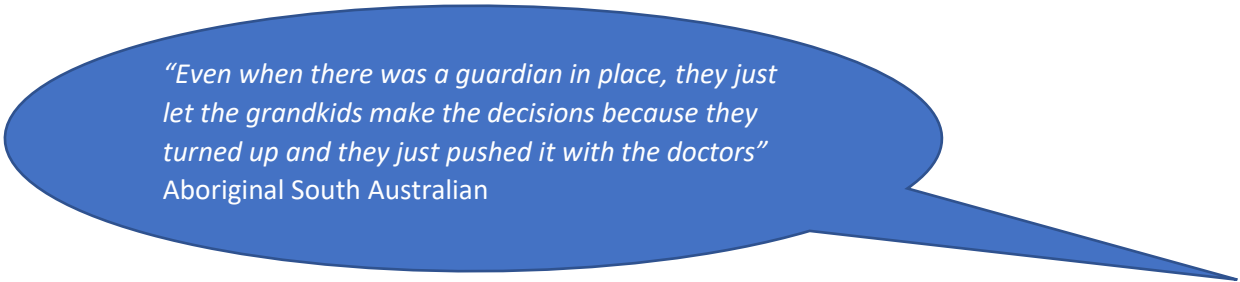
Where providers offer translated information and consent material, or when patients themselves make use of AI translation tools, additional layers of miscommunication can enter the consent

process, e.g. where direct **translation fails to capture precise technical and domain-specific language, and the contextual, ambiguous or figurative language** that is a common feature of consent conversations involving calculations of benefits and risks.

### Cultural inclusion

Aboriginal patients have highlighted several concerns around informed consent that point to the need for deeper cultural responsiveness. These include:

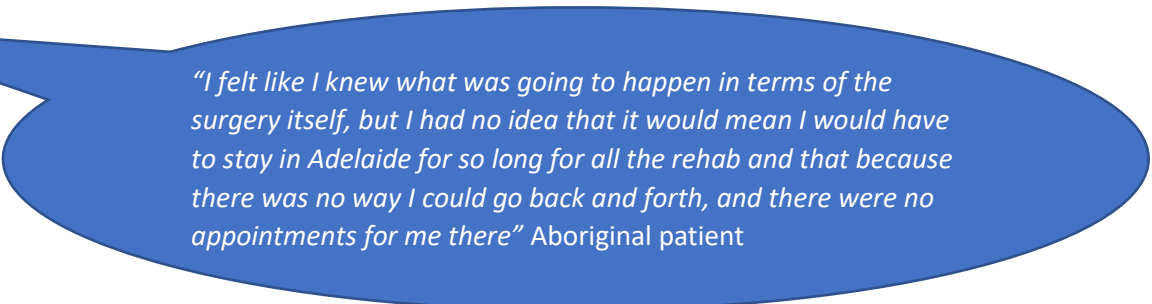
- Situations where the **authority of Elders' appointed guardians is undermined** in relation to consent to treatment and procedures by younger family members, such as grandchildren, who override established decisions.



*"Even when there was a guardian in place, they just let the grandkids make the decisions because they turned up and they just pushed it with the doctors"*  
Aboriginal South Australian

- **A lack of culturally appropriate support during information and consent processes**, leaving patients uncertain about how to ask for the information they need to build a meaningful understanding of procedures and their implications. In particular, concerns have been raised with the PHV about situations in which high-stakes information and consent conversations are held with Aboriginal patients without *any* support person present.

- **Information about potential risks and complications being presented without sufficient context.** For example, without clear guidance as to whether possible complications could be managed by the patient's local health provider it is difficult for patients to make informed choices grounded in realistic expectations, particularly in rural and remote locations.



*"I felt like I knew what was going to happen in terms of the surgery itself, but I had no idea that it would mean I would have to stay in Adelaide for so long for all the rehab and that because there was no way I could go back and forth, and there were no appointments for me there"* Aboriginal patient

### Culturally and Linguistically Diverse communities

Cultural understandings, values, and expectations can add complexity to consent processes, particularly when clinical systems are structured around assumptions that reflect dominant cultural

norms. CALD patients have consistently raised barriers to meaningful participation in consent conversations, including:

- **Clinician assumptions that patients are familiar with culturally-specific health concepts** (e.g. individual patient autonomy), **structures** (e.g. the distinction between in-patient and out-patient services; how public and private systems intersect in terms of access, referrals, payment and follow-up), **and clinical norms** (e.g. expectations around asking questions, disclosing personal information, and consenting without the involvement of family or community members). These assumptions can create significant barriers to understanding, particularly when they are not made explicit or adapted to align with patients' cultural frames of reference.
- **Gendered dynamics within consent conversations that may be invisible to clinicians.** For example, we have received accounts from CALD women who feel unable to ask questions in clinical settings attended by male doctors or partners, and others who have been reluctant to consent to procedures in which head coverings must be removed by male practitioners. In situations where women are not aware that head coverings will be removed, learning afterwards that this has happened can be particularly traumatic.

*"Of course she [speaker's mother] wasn't going to ask those questions with my Dad in the room, and he just always went with her. She was literally asking me after the hysterectomy what it was they had taken out."* CALD community member

### Accessibility of written information and consent material

Accounts have been shared with us of patients being given written information and consent material that they:

- **are unable to hold.** For example, community conversations with seniors raised a common complaint that many older patients, when asked to complete consent documentation in-person/during consent discussions with clinicians, lack the manual dexterity to handle multi-page documents attached to clipboards and require physical assistance to read and sign forms.
- **are unable to see.** For example, one patient explained that they were provided with consent information about an eye procedure immediately after they had been administered eye drops that completely blurred their vision.
- **are unable to read.** The complexity of treatment information and documentation can be a barrier to meaningful understanding and consent for people with low literacy levels, dyslexia and other information processing support needs. Stigma and shame associated with each of these circumstances can lead patients to sign forms without having understood their contents – a situation more likely when information is presented only in hard copy, as opposed to in an electronic form that would allow users to apply text-to-speech, to use coloured overlays, or to increase the size, background colour and contrast.

*"They gave me a huge stack of paperwork. And I just said 'that's not going to help me. I'm dyslexic'. They just said 'do your best'"* Young person in out-of-home care

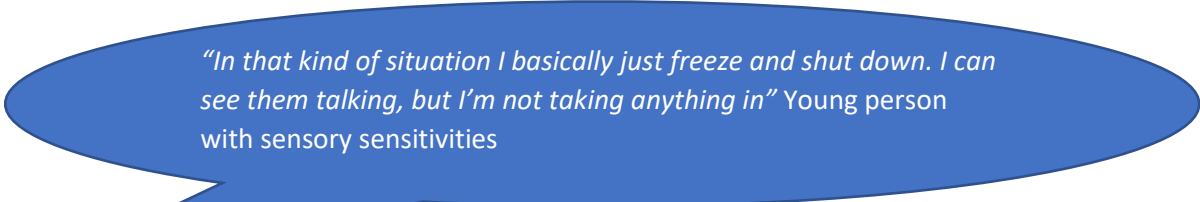
- **are unable to remember.** Short term memory loss, dementia or brain injury can prevent patients' ability to process and retain information necessary to provide informed consent. The option to voice-record relevant conversations with clinicians has been raised with us as a potential means of supporting patients' decision-making.

- **unable to understand.** Written medical information is frequently presented in complex, high-register language that is inaccessible to many patients. Community members have raised a desire for easy-read/Plain English versions of information and consent documents to be made available as a matter of course, along with visual materials co-designed with community to support informed consent to common procedures.

### **Accessibility of consent conversations**

Even when consent processes meet procedural requirements, they may fall short of being truly accessible. Patients have highlighted a number of barriers that limit their ability to engage meaningfully in these conversations, including:

- **Difficulty understanding spoken communication** (e.g. when surgical masks are worn, or when practitioners speak with an unfamiliar accent) and keeping up when the **pace or complexity of spoken information is not adjusted** to support comprehension.
- **Sensory overwhelm**—particularly for neurodivergent people, who may find the clinical environment (bright lights, noise, time pressure) overstimulating, making it difficult to process and retain verbal information.



*"In that kind of situation I basically just freeze and shut down. I can see them talking, but I'm not taking anything in"* Young person with sensory sensitivities

- **Cognitive overload during periods of stress**—patients experiencing acute stress, pain, or emotional overwhelm are often not in a position to absorb complex information or weigh up options effectively, even if they appear outwardly engaged in consent conversations.

### **Information and consent conversations involving carers**

Informed consent processes often overlook the nuanced roles of carers whose involvement can be pivotal in supporting patient understanding and decision-making. Concerns raised include:

- **Exclusion of young carers:** Young carers are frequently sidelined in discussions where their support could scaffold patient comprehension and informed choice, especially when they are the most trusted and consistent presence in the patient's life.

- **Assumed decision-making authority:** Clinicians may default to engaging with carers even when the patient has the capacity to make decisions independently—effectively bypassing the patient and undermining their autonomy.

*“They just looked straight past me to my mum without even talking to me. They just assumed because of my physical disability that I couldn’t understand what they were saying.”* Disability advocate

- **Reliance on support workers:** In child protection contexts, it is often assumed that support workers will facilitate processes of informed consent. This expectation rests heavily on the worker’s own health literacy and the nature of their relationship with the young person—relationships that are frequently short-term and lacking a foundation of trust.
- **Both too much—and too little—is expected of young people in care:** On one hand, young people may be asked to make difficult decisions without sufficient support or explanation. On the other, their views can be dismissed, especially when professionals assume they lack the maturity or understanding to make, express, and advocate for their medical and personal choices. This creates consent processes that do not prioritise young people’s voices and fail to address their informational and emotional needs.

### **Consent to medical treatment in the criminal justice system**

Engagement with individuals who have experienced incarceration has highlighted serious concerns around the issue of consent to medical treatment within prison populations. For instance, we’ve heard accounts of **prisoners being denied the right to postpone non-urgent surgeries/medical procedures** until after their release—even when that release is imminent. As a result, they have been shackled and escorted through public hospital entrances for procedures to which they felt pressured to consent. This experience can be deeply **re-traumatising, especially for women with histories of domestic violence and coercive control**.

Similar reports describe female prisoners facing punitive consequences for refusing other health interventions such as invasive examinations or mandatory vaccinations. These examples point to significant limitations on bodily autonomy, often masked by **consent processes shaped more by institutional convenience and control than by individual choice**.

### **Mental health contexts**

People experiencing mental health issues often face significant barriers to giving genuinely informed consent. **In periods of acute distress or cognitive impairment, it may not be possible for individuals to understand or retain complex information about treatment options**, especially when explanations are rushed, overly clinical, or not adapted to their communication needs. We have received accounts of patients feeling pressured to agree to interventions—particularly in institutional settings—where **power dynamics and previous traumatic experiences with the mental health system constrain their capacity to speak up**, to ask questions or to withhold consent.

Language barriers, a lack of culturally appropriate support, and the absence of independent advocacy further compounds patients' experience of pressure and lack of control.

### **Residential aged care**

In residential aged care settings, consent processes are often complicated by:

- **assumptions around lack of capacity.** We have heard on a number of occasions that, when Substitute Decision-Makers are appointed and Advance Care Directives prepared, both aged care staff and clinicians defer to these people and documents even when patients themselves are still capable of informed decision-making.
- **family dynamics.** Disagreements between family members around consent to medical interventions for older loved ones can result, at best, in delays to medical/surgical interventions and, at worst, to provision of life-prolonging treatment that is at odds with patients' stated preferences
- **Inaccessibility of additional information/second opinion.** Community members have shared with us that constraints on aged care residents' capacity to seek second opinions or additional information – particularly when doing so would require the support of overstretched staff – means that many consent to interventions with which they are uncomfortable, or that they do not fully understand. Reluctance to disagree with or challenge care staff on whom they are reliant also constrains residents' capacity to provide free and informed consent.
- **poor storage, accessibility and communication of Advance Care Directive documentation/binding refusals of care.** Accounts have been shared with us of aged care residents being taken to hospital in ambulances because documentation of their wish not to be moved or receive intervention was not accessible to/checked for/found and communicated by responsible staff.