Guidelines for collecting patient stories from speakers of Aboriginal languages in Central Australia through culturally congruent processes

"Sitting down like this, having an ALO interpreter, patient, and the white fella, and these little things (recorders) - it's good sitting like this and getting the story. We get the recording, and then we will listen to it and write it out. Before, a white fella would give you a piece of paper to fill out – you would either have to tick boxes or answer questions by writing your answers in, and people found that a bit hard. … But this way, it's good." (ALO)

These guidelines are based on the findings from a trial of processes for collecting stories from patients at Alice Springs Hospital (ASH). This activity was part of the EQuALS research project: *'Exploring and improving processes for speakers of Aboriginal languages to influence the safety and quality of their health care, Phase 2'*. The project was funded by an MRFF Rapid Research Translation Grant through CAAHSN (the Central Australian Academic Health Science Network).

The team who worked on these guidelines included participating patients, Aboriginal Liaison Officers (ALOs)/ Aboriginal language interpreters from ASH, researchers from the Northern Institute, Charles Darwin University (CDU) and staff from NT Health Safety and Quality team.

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NT Health have produced a comprehensive guideline for Patient Reported Experience Measures (PREM). This document provides additional detail about using a conversational approach to gathering patient experience information in one context.

Between August and November 2023, patient stories were collected with a sample of speakers of Western Arrarnta, Luritja, Pitjatjantjara, Alyawarre, and Aboriginal English. All patients had experienced a recent admission at Alice Springs Hospital. After sharing their stories, patients were also asked to give feedback on the process of sharing it. We listened back on the patient stories and interpreted their feedback into English. The staff who collected the stories also recorded their reflections on the process. These guidelines come from an analysis of the combined findings. They might be relevant for other language groups but need to be checked with speakers of those languages first.

TO DO BEFORE THE PATIENT STORY CONVERSATION

- Plan together and consider all the headings below.
- Ask healthcare staff which patients are close to discharge. These might be suitable patients to invite to share their story (see 'when').
- Ask ALOs who might be suitable to talk with. They know many of the patients.
- Think about whose story has been collected recently. Be mindful of collecting stories from a variety of people who speak a variety of languages.
- You need an ALO and/or Aboriginal language interpreter with you to record a patient story with a person who primarily speaks an Aboriginal language. But remember that the ALO team are very busy and have many demands on their time. Discuss time and workload allocations with the ALO team leader before you start.
- Plan time for interpreting the patient story afterwards and responding to the issues raised. This may take a lot more time than collecting the story. Negotiate with workload managers to make sure you can respond to the patient's story in useful and timely ways.
- A trusted person should explain the patient story process and check if the person feels comfortable to participate before you approach them to start.

> *"She is confident. Maybe because she knew who I was. And before we had this sit down though, I did approach her and ask her if she was interested and if she was happy to – I told her about it first, … Yeah, so we went back to the ward looking for her a few days later to ask her if she was still interested. … She was comfortable because she knew me. I'm her Aunty."* (ALO)

- Be honest with the likely timelines so you don't give patients or team members unrealistic expectations. Remember the conversation itself is the shortest part of the patient story process. There is also a lot of work to do lining up the conversation time, interpreting the recording, analysing the patient's feedback, communicating feed-back through quality improvement systems, and then for them to respond with actions.

  " Half an hour to do the conversation, but we did spend an hour looking for her before. And then it's gonna be lots more time to interpret it." (Researcher)

- Plan for time to spend on interpreting and analysis with the Aboriginal language interpreter before you start.

WHY – Understanding and explaining why we are collecting patient stories

"We should explain to them at the start where the information is going to go and how we will try to use it to change or respond. This needs to be clear so people might be open and let us know what goes on." (ALO)

- Clearly explain why we're doing the patient story.

  "It'll be good if ALOs lead the way with the questions. They'll feel more relaxed. Say 'Why are you asking me this? Why have I got to do this test?' … and I'll say 'to make things better for you, especially you patients that come here'." (ALO)

- Some patients have repeated admissions to hospital when their stories aren't heard.

  "Some of these mob don't complain – they don't know how to put in complaints. Especially if they are feeling sick. The ones that know how to put in a complaint might think it's going to get nowhere anyway." (ALO)

WHO should collect the patient story

"You've got to have an Aboriginal person with you" (ALO)

- Discuss with the ALO/ Interpreter team who is the right person to do the interview. This will vary and does not only depend on language group, although in practice there are also very few staff per language group. For example, the conversation is better if the patient knows who the ALO/ Interpreter is. It can take time to build trust and it can be better if the ALO/ Interpreter already has a connection with the patient.

  "Having a familiar ALO who has been part of their care is good for patient trust and communication process of course." (Researcher)

- Sometimes the ALO/ Interpreter who has been part of the patient's health journey is not the right person.

  "The patient may not share all concerns with this person if they see them as part of the hospital team, because criticism may feel directed at the ALO. … It's something to be aware of." (Researcher)

- We need to collect stories with people from a range of different language groups.

- Allow flexibility so the ALO/ Interpreter can use their own conversation style and adapt the conversation style to suit the patient they are talking to.

  "It's good because patients need someone to help them out … some are confused, some are shy, some – you get a lot of shy people and you've got to slowly get them out of their shell." (patient)

- The person who doesn't speak the language shouldn't interrupt.

- Bring family along on the health journey too – ask the patient if they'd like anyone else present.

- ALOs/ Interpreters are busy but some like the chance to sit down with people and listen to patient stories as it can be enjoyable work.

HOW to listen to a patient story

"ALOs will put it a nice way in their language" (ALO)

- Give a patient choices about which languages they want to speak to share their story. Some patients will choose to mix languages.

- Remember that many health conditions can affect how a patient is thinking and communicating so we need to allow extra time and flexibility for patient stories. They may also want someone who knows them well to support them while they share their story.

  "I think sometimes once you've had a stroke, sometimes your thought processes are a little bit changed and I definitely noticed that in talking to her today. She kind of would jump around a little bit but - and it took a little while of speaking with her to perhaps get some of the insights of the frustrations. Like, she kept using the word frustration but wasn't able to articulate what the frustrations were." (Healthcare provider)

- How you would ask in English is different to how it would be asked in another language.

- Allow flexibility so ALOs/ Interpreters can use their own conversation styles and adapt the conversation style to suit the patient they are talking to. This will look different for each language group, ALO/ Interpreter and patient, for example:

  - Some will just ask the patient to tell their story

  - Some wait to ask questions after the patient has shared their story

  - Some people will keep it general to make sure they aren't telling the patient what they can and can't say

  - Some will be straightforward and prefer straight up questions

  - Some like to write down questions so they know the sorts of things to cover in the discussion

  - Most will share something about their own experiences to encourage the patient to share also

- The ALO/ Interpreter might prompt the patient with little bits of the story that they already know from working with the patient. They might remind them of the next part of a story then straight away hand it back to the patient to tell it their way.

- Speak with a tone to help the patient feel comfortable – have a nice and gentle, calm presence.

  "The way we speak too, the tone, nice and gentle, calm presence. It made her feel comfortable to share." (ALO)

- Talk calmly, not rushing.

- Reassure the patient so they know you are listening to them during the story. For example say: 'Mm' and show interest with your body language.

- Notice how the patient is responding and take cues from them about whether you continue or stop.

  "his voice sounds like he didn't want to talk much" (ALO)

- Listen until the patient has said everything they want to say. After that you can ask clarifying questions if needed.

- A little audio recorder doesn't bother most patients, but some don't want their voice recorded.

- If you are asking something in English, remember you and the patient and the ALO/ Interpreter may all have different sets of assumed knowledge. Try to be specific and particularly don't assume everyone understands health related terminology or other culturally specific concepts in the same way.

  "But we don't think to explain that, because we think it's assumed knowledge. … I think we've definitely got some work to do with taking a step back when we speak to a patient." (Healthcare provider)

WHEN to collect the patient's story

"You've got to wait until the patient is ready to tell their story" (ALO)

- Don't ask them when they are feeling too sick, too tired, or no good. e.g. don't try to talk when they just got off dialysis.

  "Sometimes they say things are good just to get rid of you, because they don't want to talk and they think nothing is going to be fixed anyway." (ALO)

- Notice the patient's voice tone to see if they are in the mood to talk.

- If they're not in the mood, offer to come back at another time.

  "Before I came in I said to my niece – do you feel OK to do this today, right now? Marra wulhuma?" [in Western Arrarnta] (ALO)

- These could be good times:

  - After they have left the hospital ward and are back in the hostel

  - The day before discharge – on the day of discharge they probably just want to leave and go home

  - When they are not busy – e.g. sitting outside getting fresh air or waiting for their bus to go home.

WHERE to meet the patient

"Because they think 'if we do tell them the truth in the room, we might get into trouble'. … Get them on their own and somewhere out of the ward, and they'll tell you." (ALO)

- Patient bedside isn't a suitable place because other patients or staff could listen in, and there are disruptions:

  "It could make the person uncomfortable, or they might not want to open up or share explicit detail, knowing that there is someone listening in. It's best to have a private space." (ALO)

- Arrange seating so everyone is comfortable for the conversation

- Offer to talk in a private and confidential space – e.g. in a room at a hostel

  "You might feel shame to talk knowing that there was another patient in the room. I was thinking that you might have felt embarrassed and that's when I told this lady that we should wait until she's over here [at the hostel]. So that no one else can listen." (ALO)

- Different people may feel comfortable in different spaces. Ask the patient and ALO/ Interpreter where they'd like to sit to talk. Maybe invite them into the ALO office for feedback or sit outside with them and do the interview. Some people may feel comfortable in the transit lounge or waiting for the bus but others may not – it depends on privacy and who else is around at the time.

WHAT to talk about as part of the patient story (and what not to talk about)

"What you're doing is a good thing, you know. People need to be heard. As long as you've got that person's recording of how they feel inside, they're expressing themselves. (Patient and interpreter)

- A patient story is a rare chance for the patient to share their holistic journey.

  "I think, coming out of speaking with her, like my mind was reeling as far as all of the quality improvements that we could put in place. And it was a really holistic view because I think, when you're speaking with patients, sometimes you're thinking about just their journey and not the holistic journey." (Healthcare provider)

- Sometimes the patient may also tell you about the impacts of their hospital stay on their family members and their life outside hospital and this is important and relevant to listen to.

  "But maybe we can make an impact on the little things that can actually impact her wellness from a kind of spiritual point of view, rather than her wellness from getting better." (Healthcare provider)

- Avoid patients having to tell their story over and over again

- Check if the patient needs more support NOW – if there are urgent and stressful issues that the patient wants to share, it is appropriate to listen and seek support quickly within the health system and through prompt referrals.

- Many patients are afraid to ask questions but may respond when someone else (e.g. ALO) shares some of their own experience

- Patients open up more when they're speaking their own language

- Sometimes patient stories "go around" rather than being direct, and that's OK

- Some patients won't want to share details about their treatment

  "Not a lot of people would feel easily comfortable to sit down and share their medical journey. Sometimes people get shame too, they don't want people to know

about what's going on with them. … I do reassure the patient and tell them don't get embarrassed about me being in here- I'm here to help, it's part of my job." (ALO)

- If the patient raises something that's on their mind, spend time exploring the details of their points before you move on

- If you don't speak the language, don't interrupt to ask another question or change the topic. You might be interrupting during an important point.

"I didn't know what detail the patient had shared about this so should have stayed quiet in case she wanted to share more." (Researcher)

WHAT TO DO AFTER THE CONVERSATION

"We need make sure that we do something valuable with this - seeing as she shared her story, it'd be good to interpret it properly so that we can respect it." (Researcher)

- Straight after the conversation, the healthcare provider and ALO/ Interpreter should talk through the key points and write a brief summary of the topics discussed. Then plan and book in time for interpretation of full details from the auditory recording in the near future.

- Listening to patient stories can be *"really powerful to hear her journey"* (Healthcare Provider). The healthcare provider and ALO/ Interpreter should debrief together - have a chat about how you feel about the conversation, what went well and what you'd each change for next time. Remember that patient stories can be confronting and worrying.

- Make sure the ALO/ Interpreter has someone to talk to if they are distressed by the patient story.

- The people who collected the story should talk straight afterwards to get an idea of the topics covered but be aware that this is only a basic outline and the story will include a lot more valuable information.

- Identify any issues that need immediate action. Discuss possible actions with the patient. Then start the action. (e.g. address safety issues, or support the patient with referrals to access services on discharge).

  "some people keep having to come back to hospital because their stories aren't heard"(ALO)

- The healthcare provider and ALO/ Interpreter should discuss possible approaches to addressing issues identified. People with different cultural lenses will provide different insights into solutions.

  "What I thought needed to change from the story and what they (the ALO) thought needed to change did not align often. Asking them what they wanted to change was powerful and insightful." (Healthcare provider)

- Involve the ALO/ Interpreter team in addressing the issues. It's valuable to have an ALO who knows their patient journey and the health system so they can help with any issues going forward.

- Be aware that when you debrief or discuss key issues before full interpreting, you are filtering the patient story through your own healthcare provider lenses. Full understanding of the story requires analysis with someone from the same community and language group as the patient.

- Reflect on your own experience of listening to the patient story – it can be a valuable learning experience for you too.

  "So yeah, on reflection, it was a huge learning experience for me. And, you know, I've been a nurse for 23 years but certainly took a lot out of her words. … I feel really honoured to have had that time with her. And definitely walked away with new insights. Putting ourselves in her shoes for a little bit. Yeah, I'm just reflecting on it now. It was definitely powerful, really powerful to hear her journey." (Healthcare provider)

- Plan how to do the interpreting of recordings – this can be a big job and needs negotiating with other workloads.

- Allocate time for interpreting, analysis and entering feedback into quality improvement systems.

- Be aware that you may need to discontinue if the patient has since passed away. This may depend on the interpreter and patient's wishes.

  "We can talk about what they said but it's not comfortable to listen to the voice of someone who has passed away." (ALO)

- Raise issues within the system and document them in the quality improvement system. Follow your organisation's current policy and processes for documenting risks and feedback.

- Be specific and use the patient's words when you document the issue.

  "I just started spiralling with some of the quality improvements that we could put in place to make her ongoing journeys easier. But it was very - she was very respectful, but it was very raw. Like, you could see through her facial expressions, the frustration that she felt. … I feel like her words will then be able to be used to create an impact and be able to make some of the changes that need to happen." (Healthcare provider)