



Key learnings from Rare Disease Project ECHO®

Series 3: Session 4 (5 December 2024) – Clinical yarning

Opening presentation

This session was presented by Dr Yarlalu Thomas, a Nyangumarta Pitjikirli man, medical doctor and co-founder of [Lyfe Languages](#). The presentation was about providing culturally appropriate care for Aboriginal people with rare and genetic conditions.

Yarlalu began by describing two programs he is involved with: Pilbara Faces and Lyfe Languages.

The [Pilbara Faces](#) program aims to find diagnoses for children with rare and genetic diseases. Around 25% of children in the Western Australian Undiagnosed Disease Program are Indigenous; this is not due to a higher prevalence of rare and genetic conditions in Indigenous populations, but because Indigenous people are often unable to access services to diagnose their conditions and because genomic databases underrepresent Indigenous people.

Pilbara Faces has partnered with [Cliniface](#), which uses 3D facial visualisation, measurement, and analysis software to diagnose children with rare diseases. The tool had been of limited use in Aboriginal people due to the lack of reference data. The Pilbara Faces team gathered reference data that will help facilitate diagnoses for Aboriginal people using the Cliniface tool.

[Lyfe Languages](#) is a project that translates complex medical terminology into Indigenous languages. The [Lyfe Languages web application](#) is a valuable tool to help health professionals communicate with people who speak Indigenous languages, and where English is not their first language.

Tips for working with Indigenous families

Before the consultation

- Recognise that Aboriginal and Torres Strait Islander peoples are many different communities. Engaging with a local Aboriginal or Torres Strait Islander health worker is important to support culturally safe and appropriate care
- Some Indigenous people have a traditional skin system relating to the group they were born into. This system guides formation of relationships within the community
- Be aware that many Aboriginal and Torres Strait Islander peoples have negative perceptions of, and experiences with, the health system due to colonisation and ongoing individual and systemic racism
- Set up the consultation room so the patient and their family can sit beside rather than directly opposite the clinician - many Indigenous people find it disrespectful to look people directly in the eyes

During the consultation

- If you are offering a handshake, offer this as a soft handshake
- It can be helpful for introductions to be done by someone who knows the family already, or an Aboriginal or Torres Strait Islander Health Worker
- Offering a cup of tea can be a sign of respect and helpful in creating a safe space
- Consider Indigenous family structures and how they may impact decision making. For example, it is important to ask which people need to be in the room. It may be preferred that diagnostic information is given to a respected extended family member, who will then go home and inform those closer to the patient (such as their parents)
- Be aware of the impacts of a genetic diagnosis and be open to gently exploring potential cultural interpretations of the inheritance of genetic conditions
- When taking a family history, be aware that when loved ones pass away, Indigenous people may not speak the name of the person who has passed for a while. This is so their spirit goes back to country. You might say something like 'We usually ask about your family to help understand this genetic condition. I might need you to bring up names of people that have passed away. Is that okay? Would you like to bring in another family member to explain this to me? Or is there someone else who would be to talk about this with?'
- Using open-ended questions, such as asking a patient or their family to explain what they understand from the consultation, can help you assess understanding. Indigenous people may be anxious in a clinical setting due to historical and current poor treatment, and may reply 'yes' when asked if they understand, when in fact they do not.
- Check what a person's preferred language is and if a translation service is required to assist with communication. An Aboriginal or Torres Strait Islander health worker can not only help with translation but also cultural safety and therefore should be always offered to join the consultation if available
- Resources to help explain medical concepts in Indigenous languages and translate complex medical terms are available on the [Lyfe Languages webapp](#).

After the consultation

- Consider the barriers to follow up and what you can do to reduce these, for example
 - Geographical location – is your patient travelling home, or somewhere else? What services are available there and to facilitate remote care? Webapps like [Mappa](#) are useful for this
 - Sorry business – your patient may be busy and unable to attend follow ups for a period of time

Key recommendations for caring for Indigenous patients were:

- Be open to learning about the cultural preferences for your patients- engaging with a Aboriginal or Torres Strait Islander Health worker and asking open respectful questions about people's preferences are good strategies
- Plan the appointment to ensure it is a culturally safe space, being mindful that direct eye contact may be disrespectful
- Consider the different Indigenous family structure and cultural practices that can influence which family member attends appointments and who important health information should be given to.

Useful resources for clinicians and patients discussed this session were:

- [Lyfe Languages web application](#) – free online indigenous translator
- [Mappa](#) – free online mapping platform that helps all people better access health care that is as close as possible to family, home, and work
- [Cliniface](#) - free 3D facial visualisation, measurement, and analysis software helping clinicians and researchers to understand how facial variation relates to rare diseases and other conditions.
- An article by Ghamrawi et al: [Communicating medical information with Aboriginal patients: lessons learned from GPs and GP registrars in Aboriginal primary care.](#)