Indigenous data sovereignty and governance: Considerations for AAC practice with Yolŋu families

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Short Abstract

AAC systems are typically prescribed and developed by speech pathologists in collaboration with a team. Many AAC options remain costly and inaccessible without external funding. Increasingly, free and open-source component technologies are being utilised to support AAC system development at minimal cost, creating opportunities for AAC system development in new languages and low resource contexts. First Nations Australians have different cultural communication needs, participation patterns, and ways of interacting with and using technology. These differences raise unique considerations related to AAC system development, dissemination, and use. Comprehensive low-tech Yolŋu AAC system prototypes were developed in collaboration with Yolŋu families living with Machado-Joseph disease (MJD). How these systems might be stored, maintained, updated and disseminated for maximal use have not yet been determined.

Qualitative research with Yolŋu families living with MJD explored protocols related to data sovereignty, governance and culturally responsive management and dissemination of Yolŋu AAC systems. Participants engaged in *waŋanhamirr ga bala räli*, Yolŋu-led focus groups and semi-structured in-depth interviews. Data were analysed using collaborative oral analysis with Yolŋu researchers and coded to develop key themes.

Key cultural perspectives and decisions related to culturally responsive management and dissemination of Yolŋu AAC system prototypes will be shared. Consideration for how these perspectives might be integrated with mainstream Australian policies and systems related to speech pathology services and funding for AAC will also be discussed. Yolŋu have unique priorities and cultural considerations for AAC system development, governance, access, and distribution to enable self-determination over their own communication data.

Long Abstract

Background

Speech pathologists are key coordinators in the prescription, coordination and development of AAC systems, together with other members of the AAC team, including clients, communication partners and suppliers (Beukelman & Light, 2020). There are many steps to comprehensively assess and determine a person's communication needs and participation

patterns to inform trials before an AAC system/s can be prescribed and or developed, often with an associated funding application. It is during system design, that people who use AAC are most vulnerable to the imposition of other cultural ways of communicating, particularly those of an speech pathologist (Hetzroni & Harris, 1996).

Many AAC systems and associated assistive technologies remain costly and inaccessible to individuals and families without access to external funding. Funding programs also have a specific scope and criteria that determine what and how supports will be funded, impacting the trial process and imposing specific requirements for assessment and funding reports (NDIS, 2023).

Increasingly, free and open-source component technologies are being developed to enable individuals, families and speech pathologists to develop AAC tools and systems at minimal cost (Lundälv et al., 2014). AAC system components also support flexible use across systems and devices and create opportunities for AAC system development in language and cultural contexts where commercial AAC systems do not exist (Lundälv et al., 2014). However, the pervasive Western assumption that knowledge should be free and open ignores important cultural protocols for some Indigenous peoples (Lowitja Institute, 2023).

First Nations Australians with communication support needs have different cultural and communication strengths, needs, protocols and participation patterns (Amery et al., 2020). First Nations Australians also have different ways creating, interacting with, and using technology (Deger, 2006; Rice et al., 2016). Indigenous data sovereignty and indigenous data governance refer to the inherent rights of Indigenous peoples to maintain, control, protect and develop their intellectual property related to the collection, ownership and application of data about Indigenous peoples and their lives (Lowitja Institute, 2023). These differences suggest that First Nations Australians likely hold different priorities, and require that clinicians consider unique concerns related to system development, dissemination, maintenance, and use of AAC systems.

Comprehensive low-tech Yolŋu AAC system prototypes were developed in collaboration with Yolŋu families living with Machado-Joseph disease (MJD) (Amery, Wunungmurra, Bukul̲atjpi, et al., 2022). How these AAC system prototypes might be stored, maintained, updated and disseminated in culturally responsive ways for maximal use has not yet been determined.

Four bilingual, Yolŋu/English aided AAC system prototypes with construction files were developed comprised of an alphabet board; a core word board; a comprehensive communication book with written core words and symbols for fringe vocabulary; and a comprehensive communication book with symbols for core and fringe vocabulary. AAC components include a Yolŋu core vocabulary wordlist of 243 Yolŋu words and morphemes, (Amery, Wunungmurra, Raghavendra, et al., 2022), and a modified Picture Communication Symbols (PCS) Yolŋu symbol set (Amery, Wunungmurra, Bukul̲atjpi, et al., 2022). While PCS were used and modified in the Yolŋu AAC system prototypes, limitations were identified relating to a lack of cultural appropriate symbols and current licensing for legal distribution of PCS, leading to an expressed desire from participants to develop a specific Yolŋu symbol set (Amery, 2023). These desires and considerations limit current options for wider distribution and use.

Method

Qualitative research was conducted with Yolŋu living with MJD, and their extended family members involved in the development of Yolŋu AAC system prototypes (Amery, Wunungmurra, Bukulatjpi, et al., 2022) to explore issues related to Yolŋu cultural and communication protocols, and Indigenous data sovereignty and governance as these concepts and practices relate to AAC system development, storage, maintenance, updates, dissemination, and use.

Yolŋu participants and researchers were invited to participate using purposeful, opportunistic and theoretical sampling (Charmaz, 2014; Minichiello, 2004). Participants engaged in *waŋanhamirr ga bala räli* "talking back and forth" (Armstrong et al., 2023) through Yolŋu-led focus groups and semi-structured in-depth interviews to discuss governance, management and dissemination of the AAC system prototypes. Qualitative data were analysed using collaborative oral analysis with Yolŋu researchers and coded to develop key themes (Charmaz, 2014; Armstrong et al., 2023; Amery, Wunungmurra, Raghavendra, et al., 2022).

Results

Key cultural perspectives, considerations, decisions and processes related to Indigenous data sovereignty, governance, and culturally responsive management and dissemination of Yolngu AAC system prototypes will be shared through stories, videos and photos in this presentation. How these perspectives might be integrated with mainstream Australian policies and systems related to speech pathology service delivery in AAC will also be discussed.

Conclusion

Developing culturally responsive AAC systems and culturally safe supports for First Nations Australians requires unique considerations not only for development, but also governance, access, distribution and use of AAC systems. Careful consideration of these priorities and preferences is needed to support and enable First Nations Australians to exercise self-determination over their cultural and communication data, including in AAC.