# Explaining risk in chronic conditions: the Yolŋu science of signs

## Positionality statement

Minitja Marawili is a senior Yolŋu community member residing on her clan-associated country in Northeast Arnhem Land, where our many research experiences occur. She is a critical thinker and, over many years, has initiated reflective conversations with non-Indigenous researchers Alison Mitchell and Emma Haynes, endeavouring to derive new understandings of issues that affect Yolŋu health and wellbeing. These conversations require non-Indigenous colleagues to be slow thinkers, honing deep listening skills, and to be courageous in imagining new ways of thinking that at times may be uncomfortable. Dawn Bessarab is a Bardi woman and a celebrated social science academic. Dawn Bessarab provides insight into our conversations from a contrasting location, yet with similar expertise in critical and reflective thinking. Emma Haynes and Alison Mitchell have many years' experience in social mixed methods research with Aboriginal colleagues. Their reflective stance is in the role of allyship and learners.

## Introduction

Since 2016, we have collaborated as Aboriginal and non-Aboriginal social science researchers on primarily qualitative mixed methods projects in remote Homelands in Northeast Arnhem, Northern Territory, related to rheumatic heart disease; training Yolŋu community health researchers and, more recently, Yolŋu Wellbeing.[1-11] This perspective article aggregates our learnings regarding use of the term "risk" across many projects, the details of ethics approvals (Menzies Human Research Ethics Committee [HREC] 2016_2678 and West Australian Aboriginal Health Ethics Committee HREC 1112), and research methods are provided in the references.[1-11] The quotes included here are drawn from this previous research. For this article, we completed the CONSIDER reporting criteria checklist for health research involving Indigenous peoples (Supporting Information).[12]

Over time we have observed that well intentioned health communication often causes Aboriginal people who use English as a second language unexpected harm. This arises from the preferencing of biomedical information over local knowledge and inattention to social communicative norms.[6,9,13] For instance, simplified messages during the COVID-19 pandemic pierced the foundations of Yolŋu existence, in particular *gurrutu* (foundational kin relationships). Health directives, such as prohibiting funeral attendance to maintain social distance, led to distress, with some Yolŋu expressing that they would rather die than comply. This clash between biomedical and Yolŋu cultural worldviews demonstrates the impact of power differences and the need to provide conceptually clear information that respects cultural norms and contexts.[14]

Despite these challenges, Yolŋu consistently advocate for collaborative effort to improve everyone's wellbeing.[3] This cultural strength reflects a preference for group work over top-down directives, collaborating around metaphors, and use of local knowledge and concepts.[15] Building on this, we focus on the term "risk" that is so commonly used in reference to chronic conditions and which exemplifies broader power differences and the potential for unintentional harm. We juxtapose this with the Yolŋu suggestions for mitigating the problems this term creates.

## Risk

The term risk references relatively obscure technical knowledge (requiring training and use of mathematics and statistics). Its growing use since the 1950s carries increasingly more negative connotations.[16] Concurrently, applications of risk have expanded from macro-risks, such as war, to more individual-specific risks, such as risk of disease. The term "[is] associated with the scientific examination, quantification, and prevention of threats".[16] Risks are seen as increasingly unknowable and unpredictable,[17] thus positioning risk knowledge holders as having expertise and authority about preventing risk.

Risk permeates biomedical thinking and practice, organising a complex repertoire of disease signs and symptoms into probabilities of occurrence, and is central to evidence-based medicine.[18] Patient non-compliance challenges the aspirations of evidence-based medicine.[19] Discussion of risk can be used as a powerful tool to encourage compliance, "maintaining the authority and control of Western biomedicine, and its practitioners".[20] We introduce the term "biomedics" to refer to all practitioners, health communicators and researchers aligned with evidence-based medicine. Biomedics often assume roles as behaviour managers or communication experts without "exploring and politically engaging with the socio-economic 'causes' of patient non-compliance".[20] Risk data are a form of "data colonialism" in which people are abstracted from "human life" and categorised in ways that inform sociopolitical decisions.[21,22]

## Colliding worlds: the risk of "risk" in the Yolŋu world

Yolŋu report that hearing the term "risk" in medical consultations "hurts" as it is "always a negative story". Observations highlight how serious miscommunication can arise. For instance, an older Yolŋu man on his way to the hospital interpreted his condition as "having the risk" synonymous with a death sentence due to his misunderstanding that risk means that a thing will happen (Wellbeing project

**Emma Haynes**[1]
**Alison Mitchell**[2]
**Minitja Marawili (Yolŋu)**[3]
**Dawn C Bessarab (Bardi)**[4]

**1** University of Western Australia, Perth, WA.
**2** Menzies School of Health Research, Darwin, NT.
**3** Laynhapuy Homelands Aboriginal Corporation, Nhulunbuy, NT.
**4** Centre for Aboriginal Medical and Dental Health, University of Western Australia, Perth, WA.

emma.haynes@uwa.edu.au

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participant). Risk interpreted as a factual prediction leaves Yolngu feeling that "you are powerless" and potentially at fault for having the risk.[14]

Yolŋu author MM's experiences as a patient and caregiver led her to critically examine the use of the term risk and ultimately to speak back — saying to doctors "don't keep telling us about the risk". Framing health information in terms of risk is of little conceptual use to Yolŋu and does not provide usable information. The problem is more than just a language gap, the Yolŋu do not have the biomedics' Western conceptualisations or theories of disease. Discussing risk factors, such as poor housing or inadequate nutrition, exacerbates the feelings of communicative misalignment.

Biomedics' reliance on risk terminology clashes with Yolŋu knowledge systems, which prioritise understanding through signs observed in the natural and social environment.

## Yolŋu knowledge based on interpretation of signs

For Yolŋu, correct interpretation of signs is foundational knowledge that determines decisions and actions. This skill is crucial to survival and highly valued. For example, the navigator at the front of the canoe interprets the signs above, below and on the water's surface to make decisions about which direction to steer. Dangerous signs are spoken of in terms of direct appropriate action (climb a tree if a buffalo is threatening). Knowing and masterfully addressing social signs is equally revered, and Yolŋu leaders are adept at keeping the clan group in unison and resolving conflicts, ensuring a sense of group inclusion and wellbeing.

Sign knowledge is embedded in the cultural stance of *nhina, nhäma ga ŋäma* (be still, observe and listen) and learning by experience; "*lundu-nhäma* means identifying the pattern and the style of the past … we must recognize what has gone before and know exactly how it fits in with the whole web of meaning which makes Yolŋu life".[23] Similarly, "in Yolngu science we learn through observation [of] the seasons and we see the changes … [that] tell us different things".[24]

Confusion arises when Yolŋu are not able to see or interpret signs because the signs are unfamiliar or new, such as signs of new diseases. This causes worry and stress, making it difficult to make self-determining decisions, to the point that Yolŋu question the intent of biomedics' explanations and ask "are they trying to kill us this way?".[11]

Yolŋu wish to make meaning (as they would usually easily do) out of new signs and health situations: "We are the intelligent people".[9] However, this is not easy when *nhina, nhäma ga ŋäma* is no longer effective or feasible and new ways of learning are required, such as acquiring knowledge by asking questions and interpreting answers often framed in the technical language of risk and exacerbated by biomedics' unskilled communication. This is uncomfortable and shaming and produces the kind of bad feelings that Yolŋu seek to avoid at all costs.

For the Yolŋu who only "know what sicknesses they had [after doctors] found out through our blood,"[9] it can appear that the unconvincing or unintelligible explanation of diagnostic technology is in some sense the cause of problems. This is especially devastating when traditional leaders and knowledge authorities are bound as such within the mysteries of the encapsulating society.[25]

## Next steps

It is essential for biomedics to connect with Yolŋu frames of reference for health care. One way is to provide Yolŋu with the "deep story" using the language of signs. Our group is working with local Aboriginal community controlled health service biomedics to practise using the language of signs when discussing disease prevention; for example, "we see a sign in your blood that you are heading on the pathway to diabetes". Further, we recommend that biomedics ask patients whether the information has been explained in a way that enables them to feel confident they understand what they need to do to stay well or not get sick (to choose your pathway).

An area for further exploration is the use of risk in the context of procedures and treatments (medicines, surgery) where the term is used to manage and avert blame.

## Conclusion

The difference in worldviews exemplified by the language of risk helps explain why clinicians experience frustration and why patients are not confident that they are receiving good care.

Focusing on the language of signs to promote positive understanding versus the language of, and focus upon, risk has potential to make a difference. Ideally, this would occur through workshops to investigate and provide the "deep story" (full information) in the most appropriate way with reference to language, metaphor, graphics and story. This will require collaboration between biomedics and Aboriginal language speakers, linguists and cultural experts. The approach described here is also transferable to other Aboriginal communities who also struggle with terms such as risk.

More broadly, there are a wide range of other words and phrases where biomedics "seize power",[26] blocking the conversation and potentially causing emotional harm. These words diminish the application of intercultural collaborative approaches and principles, such as relationship building, productive dialogue, cultural safety, and reflexivity, particularly when consulting time is short and the biomedics are attempting to communicate about expertise and experience that patients lack.[8] Such words make it difficult for patients to articulate their often less appreciated knowledge, values and preferences. Practitioners need to develop skills so that they can recognise the extent to which non-problematic, useful or effective explanations have been provided, for example by the degree of patient and family

engagement in the conversation. Thus, we recommend that biomedics examine their communication practices seeking to replace terms that cause harm, such as "risk", to ensure a safe environment for deliberation and disclosure.

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## Supporting Information

Additional Supporting Information is included with the online version of this article.