# "We've wanted to vaccinate against it and now we can": views of respiratory syncytial virus disease and immunisation held by caregivers of Aboriginal children in Perth, Western Australia

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### Abstract

**Objective:** Respiratory syncytial virus (RSV) is a major cause of respiratory infection with a higher burden in Aboriginal and Torres Strait Islander infants and children. We conducted a pilot qualitative study identifying disease knowledge and willingness to immunise following the changing immunisation landscape for infant RSV in 2024.

**Methods:** Yarning groups were held with a convenience sample of parents/carers of Aboriginal children attending playgroup at a metropolitan Aboriginal Health Service in Western Australia. Data collected in the form of notes were thematically analysed.

**Results:** We heard from nine parents/carers over two yarns in March/April 2024. Level of RSV awareness largely depended on lived experience of an RSV infection with some participants only first hearing of RSV following announcement of the immunisation program. Most participants were willing to accept immunisation. There was a strong preference for information on disease and immunisation safety coming from a 'trusted Aboriginal voice', but the level of information varied.

**Conclusions:** This pilot study provides initial insights into community views of RSV disease and immunisation. More RSV disease awareness is needed in the Indigenous community.

**Implications for Public Health:** These findings will help inform current and future RSV immunisation programs for Aboriginal and Torres Strait Islander populations.

Key words: Respiratory syncytial virus (RSV), aboriginal, immunisation, community attitudes

## Background

R espiratory syncytial virus (RSV) is the leading cause of acute lower respiratory infection worldwide.<sup>1</sup> Infants and young children with medical co-morbidities are most at risk for severe RSV infections requiring hospitalisation.<sup>2,3</sup> In Australia, Aboriginal and/ or Torres Strait Islander children experience RSV hospitalisation rates at higher rates than non-Aboriginal children.<sup>4</sup> The RSV immunisation landscape is progressing rapidly with global licensure of a maternal vaccine and infant monoclonal antibodies. The WA government announced the first-in-Australia RSV infant immunisation program with the long-acting monoclonal antibody, Nirsevimab, to be given

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free for infants, as well as Aboriginal and/or Torres Strait Islander and medically-at-risk children <18 months from April 2024.<sup>5</sup>

Aboriginal and/or Torres Strait Islander families consider their children to be their greatest asset and recognise that understanding of Indigenous culture and engagement with Indigenous community members are needed to achieve better outcomes for them. <sup>6</sup> Yarning is a recognised and accepted form of information gathering involving Aboriginal and/or Torres Strait Islander people.<sup>7</sup> The process of yarning involves free-flowing conversation and deep listening in a safe and respected environment and has been used previously to exchange information about immunisation.<sup>8,9</sup>

We undertook a pilot qualitative study using yarning to assess the knowledge and attitudes of caregivers of Aboriginal and/or Torres Strait Islander children towards RSV and new RSV immunisations.

## **Methods**

We conducted yarning groups with a convenience sample of parents and carers of Aboriginal and/or Torres Strait Islander children attending a fortnightly playgroup at an Aboriginal Health Service in Perth, WA. Participants were invited to attend by staff at the service. We ran two small group yarns (approximately 90 minutes each) at the service in March 2024 (before the WA RSV infant immunisation program was implemented) and April 2024 (after the implementation). Both yarns were facilitated by SJC (non-Indigenous), with the first also co-facilitated by VS (Aboriginal). Using best practice methods, we consulted with elders of the Aboriginal and/or Torres Strait Islander community in Perth at our Institute research projects forum before commencing the project. Based on these discussions, we did not audio-record the yarns. Rather, handwritten notes were taken by HM (non-Indigenous) and electronic detailed notes, including quotes, by CH (non-Indigenous).

The yarn guide was developed with guidance from Aboriginal and/or Torres Strait Islander community members, and broadly covered RSV knowledge, willingness to immunise with Nirsevimab (or a future maternal vaccine) and information sources. Prior to the yarning questions, demographic data were captured in a short survey, and participants were given a brief overview of RSV and lung disease using a flipchart developed internally.<sup>10</sup> Information was also provided on the WA RSV immunisation program. This overview allowed participants to ask direct questions, which were captured as topics that participants were eager to learn more about. Collected data were thematically analysed in an inductive manner, following the Braun and Clarke method.<sup>11</sup> Participants provided informed, written consent. At the conclusion of the yarn, participants were provided with a supermarket gift voucher.

## Results

We heard from a total of nine parents/carers of Aboriginal and/or Torres Strait Islander children. Participants were aged between 20–38 years, eight identified as female, and six identified as Aboriginal (but all cared for a child identifying as Aboriginal and/or Torres Strait Islander). A third of participants had TAFE (Technical and Further Education)-equivalent or higher education level, a third had Year 12 or equivalent, and the remaining third had Year 10 or equivalent. Eight participants cared for children aged <5 years (range of children per participant was 1-3). Four participants (including a couple caring for a 4-month-old child) had children eligible for Nirsevimab immunisation under the 2024 WA program.

Approximately half of the participants were aware of RSV as their child had previously experienced an RSV infection, or they themselves had experienced an RSV infection. Participants reflected on some of the symptoms, including 'bad wheezing', 'really bad bronchiolitis cough', 'breathing into her ribs', and 'pale' skin. One mother said her baby was hospitalised 'with the breathing tubes' for a week at age 2-3 months; her baby had a confirmed RSV infection and was told the baby had bronchiolitis. Other participants said that despite their baby having RSV-like symptoms, their children weren't tested. Instead, participants reflected that medical professionals would state 'same thing as always....viral infection'. Other participants said they were not aware of RSV, had only heard of the abbreviation but were not aware of symptoms or severity, or had only recently become aware due to the immunisation program and hearing about it from their general practitioner (GP) or on the news. They had heard that 'imms are going to be free for all babies to keep them out of the hospitals and from getting sick'.

Most participants said they would hypothetically immunise their infant if it was offered and available to them regardless of whether they were eligible for the 2024 program. One willing participant said, "I want to prevent her from getting sick and prevent her from going to the hospital", and another said, "I want the best for him". The infant of one participant already received Nirsevimab, on the advice of their GP during a routine vaccine appointment. Of those who would be willing to immunise, participants also viewed routine vaccines in a favourable way and were following the recommended schedule. Participants were seemingly aware of how devastating it can be when a newborn acquires a respiratory infection, as they described themselves as 'germaphobes' and implemented boundaries with family members and their baby, such as no kissing, no smoking, and sanitising hands.

There was only one participant who was hesitant about Nirsevimab, as well as routine childhood vaccines. Her views had changed since the COVID-19 vaccine mandates were temporarily implemented in WA during 2021/2022, saying, "*don't tell me what to do*". Some participants reflected on how even though COVID-19 vaccines and Nirsevimab are both new products, they 'feel different about this one [*Nirsevimab*]' because most parents have either seen their children, or the children of friends/family, suffer from an RSV infection and are eager for prevention. Those who were willing to immunise their baby said they would prefer immunising at a GP clinic or at an Aboriginal medical or health service and would not consider any pop-up immunisation stands.

All participants were eager to learn more about the WA RSV immunisation program eligibility. Additionally, participants wanted more information on RSV hospitalisation rates among Aboriginal and/ or Torres Strait Islander children, why Indigenous children are at higher risk of severe disease and if there is a genetic or environmental factor associated with this risk, how the risk of RSV compares to other respiratory infections, prevention measures for respiratory infections in children, and the safety of Nirsevimab. Common information sources for diseases and vaccines that were used by participants included family members, Aboriginal medical or health services, GPs who identify as Aboriginal and/or Torres Strait Islander (with a preference for female), Tiny Hearts Education,<sup>12</sup> and other trusted parents within their social networks. Participants suggested these same sources should be used to distribute information about RSV and Nirsevimab to carers of Aboriginal and/or Torres Strait Islander children and suggested the use of posters and brochures. Importance was placed on information coming from a trusted Indigenous voice. Participants were wary of information shared in the news or on social media, however, would trust information shared on social media pages of Aboriginal medical or health services. Views from participants were divided regarding how much information should be shared with parents, with one participant pointing out that '*not all blackfellas want the same info*'. Some participants wanted dot-point summaries, some wanted illustrated information with real stories from Aboriginal and/or Torres Strait Islander families, and others, wanted a substantial amount of information on Nirsevimab safety and efficacy, saying, "don't sugarcoat nothing".

## Discussion

Through this culturally accepted form of gathering data from families and carers of Aboriginal and/or Torres Strait Islander infants and children, participants indicated a high willingness to immunise and eagerness to learn more about RSV disease and prevention. Insights gained from our yarns highlight the importance that information regarding disease severity, immunisation and safety come from trusted voices within the Indigenous community. Of note, awareness of RSV disease severity appears highly linked to personal and lived experience of RSV infections in infants, a similar finding to our earlier national cross-sectional online survey.<sup>13</sup> To maintain high levels of vaccine uptake and confidence, it is of critical importance to ensure adequate access for Indigenous families to preferred health care providers for RSV immunisation.

This is the first study that has explored the awareness of RSV among Aboriginal and/or Torres Strait Islander families. These results will inform future efforts to co-design culturally appropriate education resources for RSV disease awareness and immunisation strategies. However, while these results provide some insights into community opinions and experiences, they are not (and were not) designed to be representative of the entire Indigenous population in WA. Through best practice methods, working alongside Aboriginal staff, we are planning further qualitative work to understand community attitudes in Indigenous families across other metropolitan and regional areas of WA.

We hope that these initial results will inform the current and future immunisation programs in WA and be relevant to policymakers considering implementing the immunisation to First Nations populations in other areas across Australia.

# **Conflicts of interest**

The authors declare the following financial interests/personal relationships which may be considered as potential competing interests: Hannah Moore reports financial support was provided by Telethon Kids Institute. Associate Professor Richmond and Associate Professor Moore is in receipt of research funds from Merck Sharp & Dohme (Australia) Pty Ltd and Sanofi-Aventis Australia Pty Ltd (unrelated to the work presented in this paper). Associate Professor Richmond and Associate Professor Moore also received institutional honoraria for participating in advisory committees (Pfizer, Merck Sharp & Dohme, EvoHealth) also unrelated to the work presented in this paper. If there are other authors, they declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

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## Ethics

Ethical approval was granted by the Western Australian Aboriginal Health Ethics Committee (HREC1214) and Child and Adolescent Health Services Human Research Ethics Committee (RGS5741).

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