



The newborn screening experience of the Marshallese population in Northwest Arkansas

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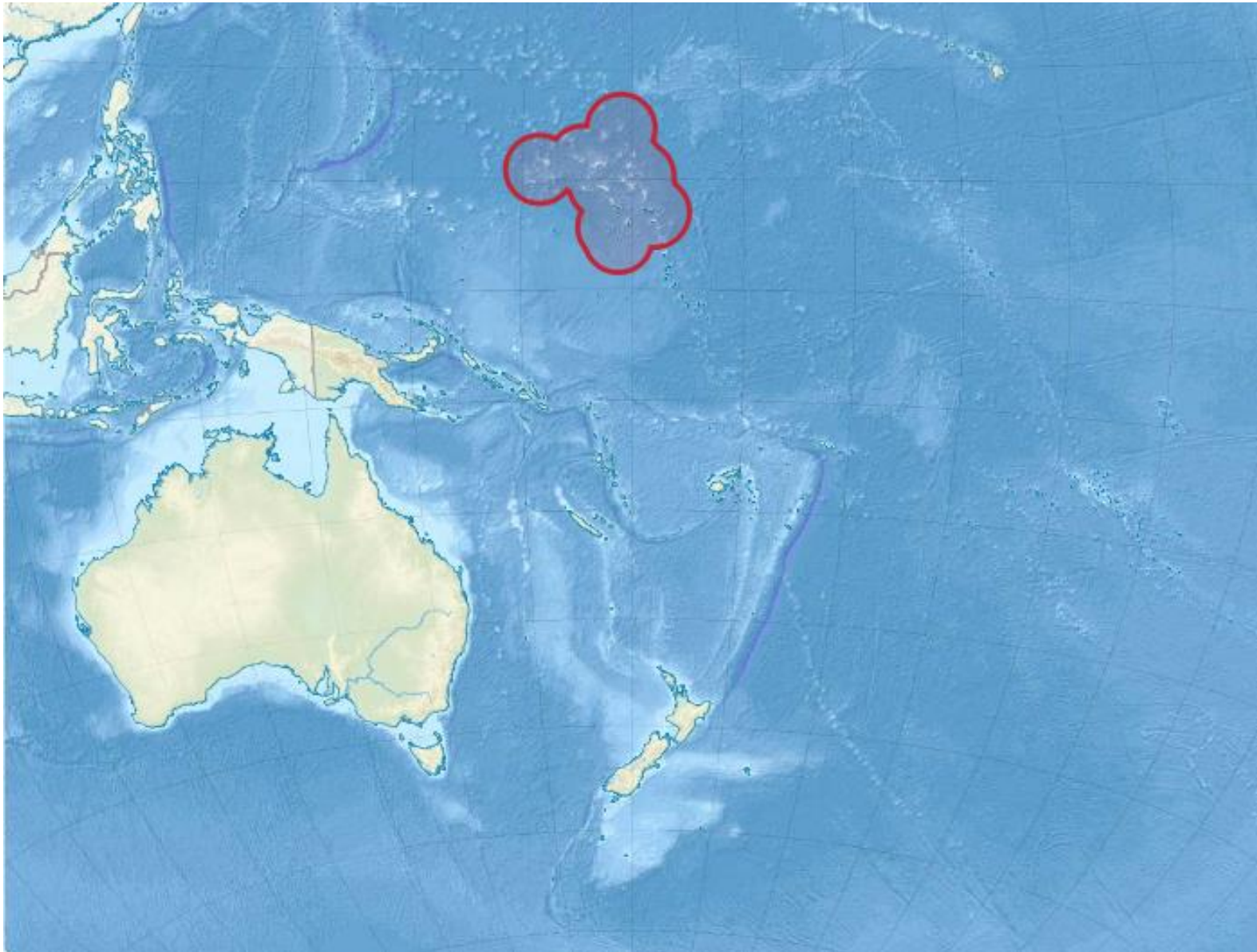
Results and Discussion

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Background





HISTORY OF THE MARSHALL ISLANDS

Figure 1: Marshall Islands in Oceania (TUBS, 2012)

Marshallese in Northwest Arkansas

- Compact of Free Association (COFA) (Brown, 2014)
- Medicaid for COFA migrants (Bill Track 50, 2021)
- As of 2019, 50% of the 12-15,000 Marshallese migrants in Arkansas were uninsured (McElfish et al., 2019; Williams & Hampton, 2005).

Structural Barriers

- Negotiating insurance
- Language Barrier
- Accessing transportation

Socio-economic Barriers

Mothers

Providers

Why Newborn Screening and the Marshallese

- Heartland Regional Genetics Network
- Universality of newborn screening
- Gateway to genetics clinics
- No NBS in the RMI
- Need for more studies assessing perspectives of Marshallese patients and health care providers.



Methods



Methods

- Qualitative
- Semi-structured telephone interviews with novel questionnaires
- UAMS IRB #206716

Study Populations

Marshallese Mothers

- 18 - 40 years old
- Pregnancy within the last 2 years
- Live in NWA

Health Care Professionals (HCPs)

- 18+ years old
- Provide care to Marshallese newborns or pregnant mothers in NWA

Arkansas Newborn Screening (AR NBS) Staff

- 18+ years old
- Work for the AR NBS program



Results and Discussion



Content Analysis

- None of the mothers had experienced positive NBS results.
- None of the mothers remember receiving educational material about NBS.
- All but one of the mothers remember using a professional Marshallese interpreter during their prenatal visits.
- All agreed that NBS was important to the health of their children.

Would NBS
work in the
RMI?

Mother 1 - “There’s not enough resources, I feel like they wouldn’t have the stuff to work with.”

Mother 6 - “...some parents would say ‘No’ because they don’t believe in vaccination.”

Mother 2 - “...some parents may feel sorry [for the baby] and not allow them [the health team] to prick their heels.”

Discussion

- Educational programming has the potential to shift parental opinions about NBS in the RMI.

Themes from Marshallese Mothers

1. Marshallese mothers' understanding of NBS.
2. Marshallese mothers' preferences regarding NBS education.

Theme 1
Marshallese
mothers'
understanding of
NBS

- **Mother 1** – “Isn’t when the baby is being screened to see if the baby has jaundice and stuff like that? Uh, I forgot what they tested him for but... they took him right after birth and run labs on him, I think.”
- **Mother 5** – “...they should have told me what they did if I had fallen asleep after delivery.”

Theme 2
Marshallese
mothers'
preferences
regarding NBS
education

- **Mother 4** – “I wish that they would explain more on what they’re doing or explain like more on what they’re providing me and baby with so I can understand. That’s why I didn’t understand the NBS part [of the interview]... because they just said they would put this on her but they didn’t really explain what was going on.”
- **Mother 2** – “...we usually don’t understand what the materials are about and for what because they’re all in English.”

Themes from AR NBS staff and HCPs

3. Positive outcomes following a connection with a Marshallese family.
4. Perceptions about the NBS education process for Marshallese mothers.

Theme 3

Positive outcomes following a connection with the family

- NBS4 and NBS5 reported they never had a Marshallese newborn lost to follow-up.
- Effectiveness of Marshallese community health workers.
- **PII** – “They are the best! We love them so much, I'm like they don't pay you people enough... Y'all can find anybody, anywhere, no matter what.”

Theme 3

Positive outcomes following a connection with the family

- **P11** – “I really love the Marshallese population. They're so compliant. Once you get them in there, they're compliant. It's just getting them in there so that you can identify problems early on...”
- **P4** – “...I feel like if they have shown up for their initial appointment with us...they are more likely to follow up because, you know, we've kind of established that relationship with them and...[the interpreter] is really good about working with families... maybe because we haven't been able to kind of make that connection and establish that rapport with them.”

Discussion

- No Marshallese newborns lost to follow up were reported, but that is not the only metric of success.
- Marshallese community health workers are major players in increasing health care access for Marshallese patients.
- Relationship building and up-front education are crucial for positive health outcomes for Marshallese patients.

Theme 4

Perceptions about the NBS education process for Marshallese mothers

- Of the pre-NBS HCPs, only one reported providing NBS education.
- All HCPs expressed interest in NBS educational material in Marshallese.
- None of the HCPs knew about the Marshallese NBS brochure on the ADH's website.
- No HCPs mentioned having educational material in Marshallese.

Theme 4

Perceptions about the NBS education process for Marshallese mothers

- **P4** – “I do not know if we have anything in Marshallese.”
- **P9** – “We don’t have anything [educational material] in Marshallese with us, we have them in English and Hispanic...they never read the documents provided to them but we give them anyways.”

Theme 4

Perceptions about the NBS education process for Marshallese mothers

- **P5** – “I don't know that those mothers understand that that test has even been done.”
- **P7** – “...ultimately, I don't think a lot of them understand what the NBS and the process of it.”
- **P8** – “...if it's a Marshallese patient, the nurses always tell me if they needed interpreting and some of them say no and some of them say yes but I've never come across any PKUs or NBS with the Marshallese there.”

Theme 4

Perceptions about the NBS education process for Marshallese mothers

- **P5** – “It would be helpful, it would be very, very helpful.”
- **P10** – “If they had explained to them, you know, that they were doing this test, and you may hear from the doctor, if you don't hear anything, everything's fine, [that would be beneficial].”

Theme 4

Perceptions about the NBS education process for Marshallese mothers

- **NBS4** – “...I think the system needs to be changed state wide, not just for the Marshallese...if they were better educated, and told ‘If you get a phone call from the Department of Health, or some newborn screening, please call them back it's very important’ I think that would help.”

Discussion

- Marshallese mothers are not provided the level of education on NBS that they or their HCPs would like them to have.
- Prenatal education on any topic is not adjusted for Marshallese mothers.

Practice Implications

- Improved NBS education for everybody.
 - Before NBS occurs
 - Appropriate language
 - Simple
- Improve knowledge of existing resources.
- Increase access to trained Marshallese medical interpreters.

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References

- A. Brown, personal communication, December 2019.
- Ayers, B. L., Hawley, N. L., Purvis, R. S., Moore, S. J., and McElfish, P.A. (2018) Providers' perspectives of barriers experienced in maternal health care among Marshallese women. *Women Birth*, 31, e294-e301. doi:10.1016/j.wombi.2017.10.006
- Ayers, B. L., Purvis, R. S., Bing, W. I., Rubon-chutaro, J., Hawley, N. L., Delafield, R., Adams, I. K., and McElfish, P.A. (2018). Structural and socio-cultural barriers to prenatal care in a US Marshallese community. *Maternal and Child Health Journal*, 22, 1067-1076.
- Baby's First Test. (2020). *Critical congenital heart disease*. <https://www.babysfirsttest.org/newborn-screening/conditions/critical-congenital-heart-disease-cchd>
- Bill Track 50 (2021, January 25). IA HF211. <https://www.billtrack50.com/BillDetail/1286338#:~:text=The%20state%20elected%20to%20provide,are%20otherwise%20eligible%20for%20Medicaid.>
- Blocker, K., Hallford, H.G., McElfish, P., Danylchuk, N., and Williamson, L.D. (2020). Eliciting culturally and medically informative family health histories from Marshallese patients living in the United States. *Journal of Genetic Counseling*, 29, 440-450
- Choi, J.Y. (2008). Seeking health care: Marshallese migrants in Hawai'i. *Ethnicity & Health*, 13(1), 73-92. doi: 10.1080/13557850701803171
- Choi, J.Y. (2013). Reconstruction of health seeking behaviors: A comprehensive study of three Asian Pacific immigrant groups. *Qualitative Health Research*, 23(4), 517-530. doi:10.1177/1049732312469731
- Chudleigh, J., Buckingham, S., Dignan, J., O'Driscoll, S., Johnson, K., Rees, D., Wyatt, H., and Metcalfe, A. (2016). Parents' experiences of receiving initial positive newborn screening (NBS) result for cystic fibrosis and sickle cell disease. *Journal of Genetic Counseling*, 25, 1215-1226. doi: 10.1007/s10897-016-9959-4
- Critical Measures (2016, May 14). *New 2016 ACA Rules Significantly Affect the Law of Language Access*. <https://cmelearning.com/new-2016-aca-rules-significantly-affect-the-law-of-language-access/>
- Evans, A., Lynch, M., Johnson, M., Bonhomme, N. (2019). Assessing the newborn screening education needs of families living in medically underserved areas. *Journal of Genetic Counseling*, 29, 658-667

References

- Faulkner, L.A., Feuchtbaum, L. B., Graham, S., Bolstad, J. P., and Cunningham, G. C. (2006). The newborn screening education gap: What prenatal providers do compared to what is expected. *American Journal of Obstetrics & Gynecology*, 194, 131-137. doi:10.1016/j.ajog.2005.05.075
- L. Hays, personal communication, April 7, 2021.
- McElfish, P.A., Hallgren, E., and Yamada, S. (2015). Effect of US health policy on health care access for Marshallese migrants. *American Journal of Public Health*, 105, 637-643.
- McElfish, P.A., Purvis, R. S., Riklon, S., and Yamada, S. (2019). Compact of the free association migrants and health insurance policies: Barriers and solutions to improve health equity. *The Journal of Health Care Organization, Provision, and Financing*, 56, 1-5. doi:10.1177/0046958019894784
- Nembhard, W. N., Ayers, B. L., Collins, R.T., Shan, X., Rabie, N. Z., Chang, D., Robbins, J. M., and McElfish, P.A. (2019). Adverse Pregnancy and Neonatal Outcomes Among Marshallese Women Living in the United States. *Maternal and Child Health Journal*, 23, 1525-1535.
- Newcomb, P., True, B., Wells, J. N., Walsh, J., and Pehl, S. (2019). Informing new mothers about newborn screening bloodspot repositories during postpartum hospitalization. *The American Journal of Maternal/Child Nursing*, 44, 332-337. doi:10.1097/NMC.0000000000000562
- Purvis, R. S., Bing, W. I., Jacob, C. J., Lang, S., Mamis, S., Ritok, M., Rubon-Chutaro, J., and McElfish, P.A. (2017). Community health warriors: Marshallese community health workers' perception and experiences with CBPR and community engagement. *Progress in Community Health Partnerships*, 11, 315-320. doi: 10.1353/cpr.2017.0037
- Teherani, A., Martimianakis, T., Stenfors-Hayes, T., Wadhwa, A., & Varpio, L. (2015). Choosing a Qualitative Research Approach. *Journal of graduate medical education*, 7(4), 669–670. <https://doi.org/10.4300/JGME-D-15-00414.1>
- Watson, M. S., Mann, M.Y., Lloyd-Puryear, M.A., Rinaldo, P., Howell, R. R., and American College of Medical Genetics Newborn Screening Expert Group (2006). Newborn screening: toward a universal screening panel and system - Executive summary. *Pediatrics*, 117, S296-S307. doi:10.1542/peds.2005-2633I
- Williams, D. P. & Hampton, A. (2005). Barriers to Health Services Perceived by Marshallese Immigrants. *Journal of Immigrant Health*, 7(4), 317-326. doi:10.1007/s10903-005-5129-8