Patient-Centered and Prioritized Agenda

MULTIPART AGENDA INCLUDES:

Finalized: January 2022
About the National Maternal Health Research Network (NMHRN)

With funding from the Patient-Centered Outcomes Research Institute, the National Maternal Health Research Network (NMHRN) was formed in 2019 and led by Health Resources in Action (HRiA) – a Boston-based public health institute. The goal of the project was to build the capacity of patients and other stakeholders to impact maternal health outcomes by contributing to a patient-centered outcomes research (PCOR) agenda to facilitate systemic change. In this work, NMHRN prioritized the voices of participants who were Black, Native/Indigenous, and/or residing in rural areas to understand the factors and impacts of discrimination that contribute to the disparities in maternal outcomes.

Over a 2-year process, more than 100 stakeholders from grassroots, community-based organizations, healthcare organizations, academia, and other sectors, provided input in the agenda-building process by sharing multi-level solutions to improve birth-related outcomes. The activities resulted in the Network’s final products: the governance document—The Charge; the 2020 Symposium: Moving Towards Justice in Maternal Health: A Roadmap for Action; the patient engagement framework, and the multi-part patient-prioritized and-centered agenda, which also includes research principles, consensus statements and associated strategies, and recommendations.

The specific aims of this program included:

1. Forming a national stakeholder group comprised of diverse stakeholders;
2. Developing a shared understanding of patient-prioritized issues contributing to adverse maternal outcomes;
3. Providing PCOR, Comparative Effectiveness Research (CER), and other trainings to increase the capacity and readiness of stakeholders involved in this network to address these issues; and
4. Developing a patient-prioritized agenda that includes patient-centered research questions and related actions to reduce adverse maternal health outcomes.

The Network’s activities concluded in 2022.

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Agenda Building Process

**WHAT IS IT?**

The following patient-prioritized and centered agenda is intended to provide a framework and recommendations to guide funding and patient-centered research efforts and related actions, including addressing research gaps, examining opportunities for systems and policy change, and advancing the field towards equity in maternal health and birth-related outcomes. The goal of NMHRN was to put forward a research agenda that strives to be patient prioritized and aligned with patient-centered outcomes research (PCOR).

The agenda development process prioritized patient and stakeholder engagement and input at each point. Steps involved in this process included patient listening sessions to gather qualitative data, identification, and prioritization of key themes by the Patient Advisory Committee, and continuous review and engagement of a working group made up of field leaders and stakeholders.

**LISTENING SESSIONS**

Between August and September 2020, eight (8), one-hour patient listening sessions were conducted. The sessions were all held virtually and were facilitated by patient champions and NMHRN members using a semi-structured discussion guide. Notes were taken to capture the conversations. Topics asked about in the guide included participants’ perspectives on and experiences with pregnancy, birth, and the post-partum period, as well as their vision for the future for birthing people, children, and families.

In total, thirty-six (36) people participated in listening sessions, representing nearly every region of the United States. Following the completion of the sessions, participants were asked to respond to an anonymous survey providing their racial and/or ethnic identity. A majority of respondents identified themselves as Black or African American (69.4%, n=25). Slightly more than a quarter (27.8%, n=10) identified as White or Caucasian, while one participant (2.8%) identified as Hispanic/Latino.
Following the completion of the listening sessions, notes were analyzed for key themes using a grounded theory approach in NVivo 12 software. Analyzed data were reviewed and synthesized by members of the Agenda Working group, from which the following key themes emerged:

- **Pregnancy**: Misinformation adds difficulty to seeking prenatal and postpartum care

- **Birth**: Women of color experience disproportionate trauma in the health care system. Birth support resources such as doulas are essential to reducing traumatic birth experiences.

- **Postpartum Care**: There is a major absence of postpartum care, which needs to be filled by education and services.

- **Issues Outside the Health System**: COVID-19 has exacerbated financial constraints.

- **Visions for the Future**: Increase clinician diversity, educational resources, and insurance coverage.

These key themes were shared with the overall agenda working group, participants at the virtual symposium, and with the Patient Advisory Council.

### PATIENT ADVISORY COMMITTEE

Members of the Patient Advisory Committee (PAC) reviewed and discussed data from the listening sessions. Informed by these data and their own experiences as patients, the PAC prioritized seven topics for further research and advocacy, which informed the creation of the research agenda. The prioritized topics are:

- Increase the number of clinicians of color in the health care workforce
- Grow the community healthcare worker workforce
- Increase the diversity and availability of post-partum care for birthing people
- Increase maternity supports (e.g., doula services)
- Engagement of fathers and partners
- Supporting patient choice of where to birth

### PCOR AGENDA WORKING GROUP

The PCOR Agenda Working group was created to help develop the research agenda. The working group was comprised of stakeholders and community leaders working in fields related to maternal health and birth equity. Working group members informed the creation of the research agenda, including the development of patient engagement strategies and the patient listening sessions.

Following the listening sessions and the prioritization of topic areas done by the PAC, working group members were asked to provide input on each of the prioritized topic areas. Their feedback was framed using the following three questions:

- What are the research questions needed to explore this topic further?
- How can work in this area support movement towards birth equity?
- Where are the levers of change? What can we, as a network, lift up to move those levers?

Agenda members’ responses to these questions were used to inform the creation of the research questions presented in the agenda.

To support any work that arises from the research agenda in being patient centered, working group members collaborated on the creation of guiding research principals. The research principal consensus statements and recommendations are intended to guide researchers and advocates as they explore the prioritized topic areas.
Patient Engagement Framework

• Power to outvote
• Patient Advisory Committee has same power as steering committee
• Power to remove folks from virtual meetings by utilizing ground rules
  + if members do not feel comfortable
  + if a stakeholder’s attendance is not mission-aligned, e.g., stakeholder is narrowly focused or being insensitive to lived experience of members
• Smaller group of representatives from PAC involved in decision making for Network, reviewing info
• Include community in all processes: development and finalization of work
• Members’ voices are just as important as any researcher and have power to influence outcomes of decisions
• BI-DIRECTIONAL learning relationships

NMHRN’s Steering Committee and Patient Advisory Committee developed the Patient Engagement Framework to ensure safe participation in the initiative.
Part 1: Research Principles

1. We agree that research should be led by and centered on those with lived experiences.

Recommendation: Individuals with lived experiences should be engaged from the beginning of the work, including development of methodology and budget for a project.

Recommendation: Researchers should establish a collaboration agreement with communities at the beginning to specify what collaboration will look like throughout the course of the project.

2. We agree that collected data should be owned by the communities it comes from.

Recommendation: Data should be shared in a way that communities can use. Research staff should collaborate with communities to identify what this means at the beginning of the project.

Recommendation: Data agreements should be utilized to ensure transparency in the data sharing process and should include data ownership, data reporting, collection and reporting schedules, expectations and consequences of not adhering to expectations.

Recommendation: Researchers should clearly communicate to communities how they intend to use and share the data.

3. We agree that the outcomes of research should be meaningful for focus communities.

Recommendation: Researchers should engage with communities at the beginning of a project to identify community needs and adjust research plans accordingly.

Recommendation: Any outcomes of research (e.g., proposed interventions) should be relevant to the focus community and feasible to implement and sustain after research concludes.
We agree that the work and knowledge of those with lived experiences should be compensated appropriately.

**Recommendation:** Researchers should work with communities to identify the most appropriate incentive/compensation method, as it may not always be monetary. Virtual data collection (e.g., a focus group over Zoom) should be compensated the same as in-person data collection.

**Recommendation:** Individuals with lived experience that are a part of the research team (e.g., designing methodology, collecting data) should be compensated commensurately with other research staff.

We agree that opportunities for bi-directional capacity building should be intentionally built into projects.

**Recommendation:** Research staff should identify and prioritize opportunities for researchers and communities to learn from one another and build capacity on both sides.

We agree that researchers must demonstrate transparency throughout the entire project.

**Recommendation:** Research staff should share information, such as why data are being collected and how they will be used or how the budget was created and what it looks like, with focus communities. Researchers should also be transparent about project timelines, anticipated start/end dates, and transition planning.

**Recommendation:** Research staff should ensure that information is accessible for communities and that participants are encouraged and empowered to ask questions about the entire process.
Part 2: Patient-Prioritized Topic Areas

Increase the number of clinicians of color in the health care workforce

Questions for Advocacy and Research Activities:
What are the structural barriers that prevent people of color from joining the health care workforce? Where are those barriers? How can they be addressed? Are there specific provider types (e.g., MDs, CNM, APRN, etc.) where there are greater barriers to entry?

What are the structural barriers that prevent people of color from remaining in the health care workforce? Where are those barriers? How can they be addressed? Are there specific provider types where there are greater barriers to retention?

What is the pipeline into the health care workforce? How does it differ between different racial/ethnic groups, different communities, or by geography? What would a more universal pipeline look like? What would be the benefits and drawbacks of having that?

Grow the community health care worker workforce

Questions for Advocacy and Research Activities:
What are the resources that are needed to grow the workforce equitably and sustainably?

What needs to change to support CHWs, both in their work and their own lives (e.g., living wage and beyond)? What is preventing organizations from offering CHWs a living wage? How could this be addressed?

What would it mean for CHWs to be able to bill for their work?

Increase maternity supports (e.g., doula services)

Questions for Advocacy and Research Activities:
How can doula services be supported structurally across the system, particularly through Medicaid?
Increase the diversity and availability of post-partum care for birthing people

Questions for Advocacy and Research Activities:
How can post-partum care be reimagined holistically? What are the structures needed to support that reimagining?

Where are the structural barriers in the current landscape of post-partum care and how can they be addressed?

How can improving and expanding the CHW workforce impact the landscape of post-partum care?

How can telehealth services be utilized to improve access to post-partum care services?

Engagement of fathers and partners

Questions for Advocacy and Research Activities:
What are the systemic/structural barriers to father/partner engagement?

What role does stigma play in how fathers/partners are engaged and how can it be addressed (e.g., how FMLA/parental leave is applied and used)?

How do fathers/partners want to be engaged?

Supporting patient choice of where to birth

Questions for Advocacy and Research Activities:
Where in the Medicaid system could we advocate for change so that birthing people can have choice?

Increasing educational supports for birthing person

Questions for Advocacy and Research Activities:
How can the system be reimagined to facilitate assessing and honoring the preferences of the birthing person with regards to education and supports?

What role does stigma play in assessing and providing supports and education to birthing people? How can it be addressed structurally/systemically?
Part 3: Consensus Statements and Associated Strategies

The consensus statements and associated strategies were developed from the broader membership and build upon the Network’s agenda. They provide a roadmap for patient advisors/grassroots advocates, researchers, and health care systems to facilitate the work that the Network established.

### Consensus Statements

| We agree that birth equity is a basic universal human right which entails birthing with respect, compassion, dignity, informed decisions, access to fair and equitable resources, and assurance that the birthing person’s voice and preferences are heard, received, and prioritized by the healthcare provider and / or system of care in a quality and just environment. |
| STRATEGY(S) |
| Provide birthing people with access to optimal birth experiences by supporting them with resources and freedom to choose a birth plan, maternity care provider(s), and where to birth (e.g., birthing center, home, or hospital). |
| Conduct research in a manner that affirms the dignity of all participants and centers equitable implementation of findings. |
| Create research-based models of care to support birthing persons of different cultures, socio-economic statuses, education levels, sexual orientations, and religious backgrounds. |

| We agree that we must prioritize the voices and stories of ALL birthing people in research to (1) understand the inequitable experiences of navigating the healthcare system (2) identify strategies to support healthy birth-related outcomes and (3) develop and finalize a patient-centered and prioritized agenda that identifies maternal health and birth-related research gaps and inequities. |
| Connect and engage a community of diverse stakeholders including individuals with lived experience, researchers, and funders to develop products that prioritize the birthing person’s voice. |
| Increase capacity of stakeholders involved in research partnerships by providing related trainings about patient-centered outcomes research, collaboration, and maternal health. |
CONSENSUS STATEMENTS

We agree that having intentional and safe space for representative voices to discuss their pregnancy and healthcare experiences in planning, developing, finalizing, and interpreting and implementing dissemination of collective work within networks and partnerships creating solutions to improve maternal health outcomes, affirms that these voices matter and are integral to the collaboration process.

Partner with individuals who are or have been pregnant to prioritize birthing people’s voices, identify inequities (ways in which systems fail birthing people), and challenge power.

We agree that centering birthing people in patient-centered outcomes research (PCOR) is key to creating equitable changes that support preconception, pregnancy, birth, delivery, and postpartum outcomes.

Foster communication and mutual respect among stakeholders within the research partnership including birthing people, researchers, and birth workers that will translate into greater patient advocacy and improved communication with the care team e.g., maternal and child health professionals such as clinicians, social workers, lactation specialists, and other stakeholders.

We agree that birthing people deserve provision of quality healthcare, e.g., preconception, throughout pregnancy, and post-partum care. Quality healthcare is defined as equitable, supportive, easily navigable, and valuable bi-directional provider-patient communication.

Establish safe, affordable, and informed care throughout pregnancy, delivery, and postpartum based upon collaborative maternity care e.g., OB-GYN, midwifery, family medicine, lactation support, pelvic floor therapy support, chiropractic, doula care, community health worker, urology – circumcision, pediatrics.

We agree that white supremacy culture and racism is embedded in the current U.S. healthcare system and requires intentional dismantling to enable justice for all birthing people.

Hold healthcare systems and providers accountable to provide just and dignity-affirming care; and, communicate and enact associated consequences related to not providing equitable and unbiased care to all birthing people.
Part 4: COVID-19 Working Group’s Recommendations

COVID-19’S IMPACT ON MATERNAL CARE

A diverse coalition of multisectoral stakeholders assembled to share their learnings about the pandemic impacting communities of color and further exacerbating inequities in maternal and infant health.

Disruptions to Maternity Care

Recommendation:

- Leveraging the knowledge and models of care of midwives and community birth centers to educate birthing people on how to monitor health (e.g., blood pressure) and look for concerning signs
- Teaching birthing people to take their own blood pressure and test urine in addition to providing supplies to do so
- Cost-analysis study about providing blood pressure cuffs and urine analysis test strips to patients—this could save lives and potentially lower health care costs
- “Virtual Village”— a postpartum and breastfeeding support group that incorporates a mental health professional and discusses various topics

Telehealth Challenges

Recommendation:

- Develop text messaging check ins
- Robust and culturally-centered home visiting programs
- Hybrid models for prenatal and postpartum care
- Ensure patients have internet and are equipped for telehealth visits and subsidize the cost if they are not
Addressing Mistrust in COVID-19 vaccinations

**Recommendation:**

- When discussing COVID-19 vaccines with a birthing person who expresses concerns, it is critical to:
  - Be aware of historical and current injustices perpetrated against communities of color.
  - Actively listen to and validate expressed fears and concerns.
  - Continue to care for patients who decide not to be vaccinated, to share resources, and to encourage the continued use of prevention measures.
- Create customized public health communication messages for birthing people about the safety of vaccinations and the importance for keeping their newborns safe.

Management of Postpartum Care

**Recommendation:**

- Provide toolkits to birth workers for monitoring postpartum health (mental and physical)
- Pair remote monitoring with more education
- Incorporate clinical staff to provide at home visits
- Increase frequency of mental health/wellbeing checks to support birthing people who have anxiety (related to COVID-19) and incorporate mindfulness resources
- Expansion of Medicaid coverage to one year postpartum
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