2021

Paterson Community Insights on Perinatal Health

ACTIONABLE INSIGHTS REPORT

Insights for sustainable solutions that meet expectant moms' needs.

St. Joseph's Health

St. Joseph's Health (SJH) is a healing ministry of the Catholic Church sponsored by the Sisters of Charity of Saint Elizabeth. For more than 150 years, SJH has proudly served as a "safety-net" provider for all who seek our care, regardless of insurance coverage or ability to pay.

St. Joseph's Health
CENTER FOR INNOVATION

The St. Joseph's Health Center for Innovation (CFI) at SJH was established through a grant from the Nicholson Foundation in 2019. The CFI is a multi-disciplinary group focused on improving healthcare through better systems.

HCPC

Launched in 2017 with support of The Nicholson Foundation, the mission of the Health Coalition of Passaic County (HCPC) is to create a thriving and sustainable community coalition dedicated to significantly improving the health and overall quality of life for residents of the greater Passaic County area by specifically addressing social determinants of health.

Introduction

In 2020, as one part of a multi-pronged approach to improving perinatal health for Paterson community, the Center for Innovation at St. Joseph's Health (SJH) received a grant from The Henry and Marilyn Taub Foundation (HMTF) to develop an actionable insights report around perinatal health. We co-developed a North Star goal: to eliminate racial health inequities in the perinatal journey. This report serves as a beginning step to reaching that goal.

The Grant Application

The Center for Innovation at SJH and Health Coalition of Passaic County (HCPC) collaborated to develop community-driven solutions for racial health equity for women and infants in Paterson and Passaic City. This was achieved by implementing short-term improvements to existing program delivery, while gathering data, insights, and feedback from at-risk women through trusted channels in the community.

In order to align on a long-term strategy to bolster CenteringPregnancy, a group prenatal care program, and improve maternal/infant health outcomes, we sought to more fully understand the needs facing women in our community and causes of racial disparities.

We met with moms, dads, community resource groups, and clinicians to understand the care experience for Black and African American women in Paterson, NJ. The care and experiences described by the moms within this report takes place in multiple providers throughout the greater Paterson area.

Concurrently, SJH staff underwent a series of unconscious bias workshops, called Undoing Racism, to internally reflect on and tackle existing biases within our hospital.

We would like to note that we actively sought to align with the initiatives of the State of New Jersey, HMTF, and SJH's broader efforts to ensure that we contributed to building on existing work, and not supplant current initatives.

This report has highly focused on women in our community at highest risk for preterm birth and other adverse health outcomes: primarily resource-constrained women of color living in six high-risk zip codes in Paterson and Passaic City, identified through HCPC's data analysis.

Our original goals were to seek opportunities that:

- support women in accessing prenatal care earlier in their pregnancies. Currently, only 38% of women who receive care in SJH's clinics begin prenatal care in the first trimester, fewer than half of the Healthy People 2020[1] goal of 77.9%.

- engage with moms and expectant moms in the community who are not accessing, or even aware of, resources available to them, including CenteringPregnancy.

- contribute to understanding the needs, social determinants of health, challenges, barriers, and stressors that affect women of color in our community, and are the most significant factors contributing to poor maternal and infant health outcomes.

"Women in New Jersey and their families cannot afford to wait. Women and families in this state deserve better."

- Nurture NJ

(For more information about Nurture NJ, refer to page 6)

Actionable Insights Report

We need to think differently. We need new approaches. Old ways of problem solving have not met expectant moms' needs. Our hope is to put into motion new ways of engaging moms in order to meet their needs. This means that we go to expectant moms experiencing the problems, and together, through rapid-cycle prototyping, develop solutions that work for them.

This report is a living document, which must continue to evolve and grow. It demonstrates how this innovation process contributes to building racial health equity.

SJH's Mission

We are committed to provide exceptional quality care which sustains and improves both individual and community health, with a special concern for those who are poor, vulnerable and underserved.

SJH's Values

We integrate and affirm: dignity, charity, justice, excellence and stewardship in all that we do.

SJH's Vision

We will understand and respond to the needs of our communities, leverage the strengths of our system, provide a transformational healing presence and collaborate with others who share our values.

SJH Innovation

Innovation is an intention of shaping the future, and the future is uncertain. Some thrive in uncertainty, but for others, the fear of making the wrong move can paralyze us. The Center for Innovation at SJH follows a rapid-cycle process to develop meaningful, innovative solutions.

Our North Star: Racial Health Equity

Many racial and ethnic minority groups are disproportionately affected by adverse health outcomes. Inequities can stem from many factors, including: discrimination; disparities in education/income/wealth; and lack of access to health services, employment opportunities, and safe/affordable housing. To compound this, the coronavirus pandemic has fundamentally disrupted our lives and ways of working. This is a new, shifted landscape for providing care.

Inclusive Language & Terms

In this report we use the terms “women”, “mom”, and “mother” to represent those who have the physiological capacity for pregnancy and childbirth. When speaking to community members about gender identity, all female-identifying community members used the above mentioned terms to self-represent themselves.

We recognize that the gender-inclusive term, “birthing people,” is used as well to include transgender men, gender non-conforming, gender queer, and non-binary individuals who are often excluded when discussing perinatal health. We also recognize that not all women and female-identifying individuals have the physical capability to give birth and they are not “less than” those who have the capability.

During our research process we specifically aimed to understand Black and Brown, under-resourced, expectant mothers during their pregnancy experience. We use the word “mom” frequently in this report to represent women in all stages of their pre-pregnancy-to-delivery journey.

Likewise, in this report we use racial terms like “Black” and “African American” to encompass the individuals and communities represented in the African diaspora as well as “Hispanic” to respect the racial and ethnic descriptors that the community members used to describe themselves.

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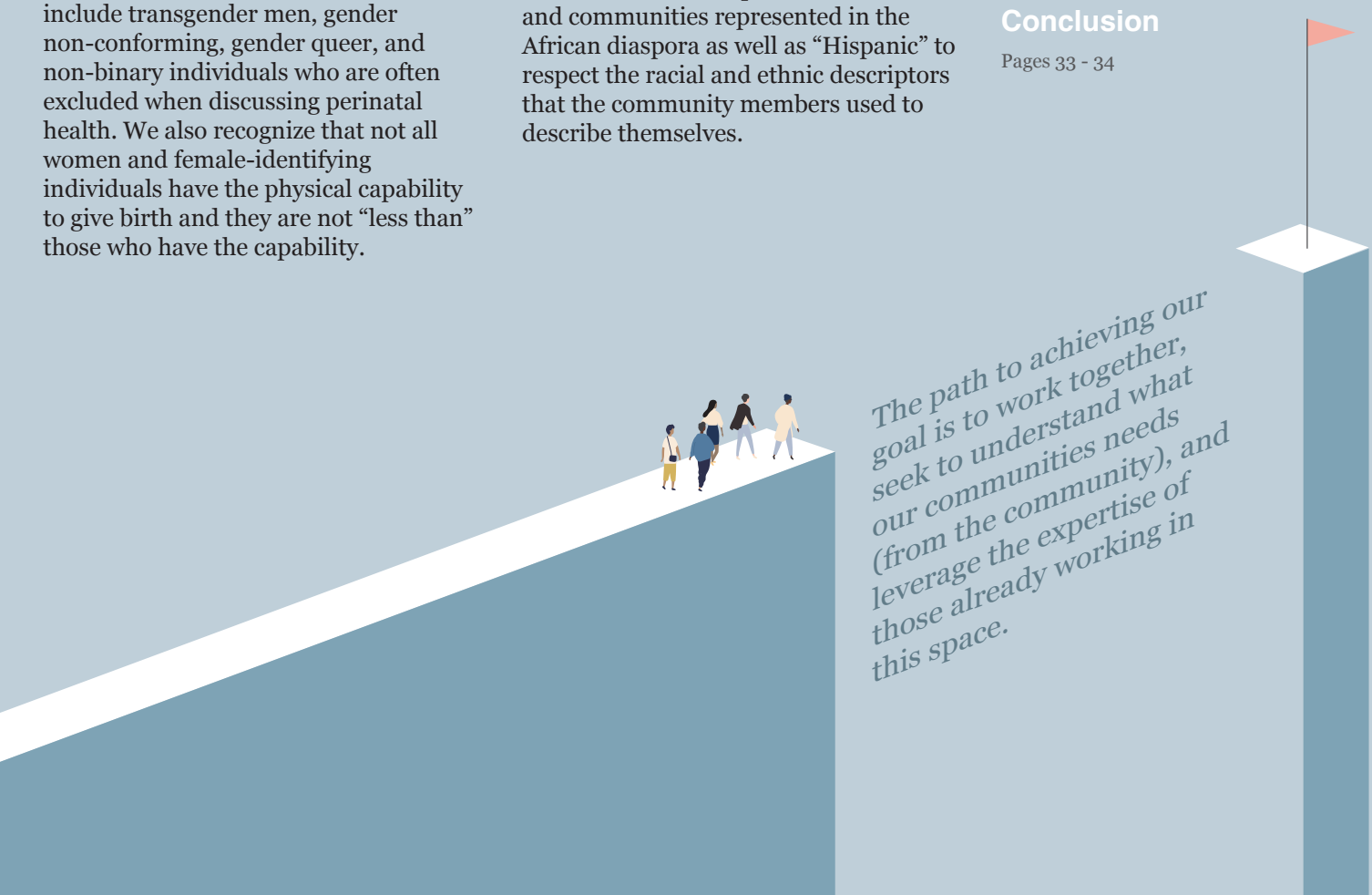


The path to achieving our goal is to work together, seek to understand what our communities needs (from the community), and leverage the expertise of those already working in this space.

Human Centered Innovation

Overview

When facing a problem, most people jump to a solution, and then take that to their users.

The Center for Innovation's approach is the opposite: we first go to those experiencing the problem, define the root cause, learn how to best meet their needs, and make prototypes to test opportunities. We seek to be inclusive while delivering a rapid-cycle process of design and strategy to improve the lives of the communities we serve. Innovation is needed now more than ever, and we believe that caring for our communities is a key to systemic improvement.

An actionable insights report primarily focuses on the Define and Learn phases of our Innovation process.

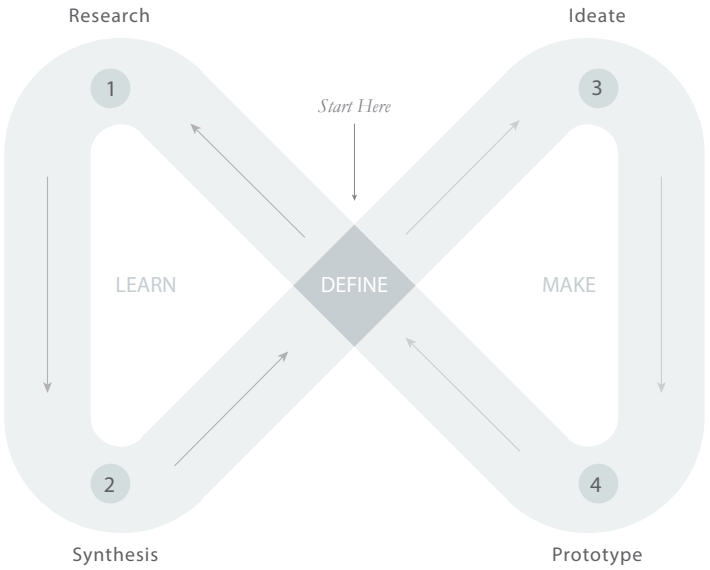


figure 1

Our Process

Above (figure 1) is our rapid-cycle process for innovation to develop meaningful solutions.

First, we **Define** the problem

If you already know the solution, then there's no need for innovation. But, chances are that you don't actually know the right solution. 95% of new products fail. 92% of start ups fail.[2] Keep an open mind. Ask questions of yourself and your users. Search for the underlying problem, because what you see is usually only a symptom of the problem space.

Next, we **Learn** from our users

Users are the reason that you have a job in the first place. They are the people that experience the problem. Understand what drives those users, more than what they say they want. This is done through asking, watching, and analyzing.

Then we **Make** ideas real

Just do it. Repeatedly. Use your user insights to inform how you do it. Don't be precious about your ideas. Start making something. The bare minimum is a good place to start, but it should never be where you end up. Relentlessly keep prototyping, testing, and improving.

What is HCD Research?

Human Centered Design (HCD) research is a rigorous, mixed methods research process developed through traditional qualitative research and community based participatory research. It is centered around recognizing that the users, or in this case, the community, hold the knowledge around solutions. This is leveraged by learning from and with the people that are impacted by the problem space. By going straight to people, we honor and respect their lived experiences as valuable.

At the Center for Innovation at SJH we practice a nuanced form: design justice,[3] that centers the design and research process around folks who have been marginalized by design and co-design with them. Community members are a crucial aspect of our design process and have been invited into our research and ideation processes from the beginning.

Human Centered Innovation

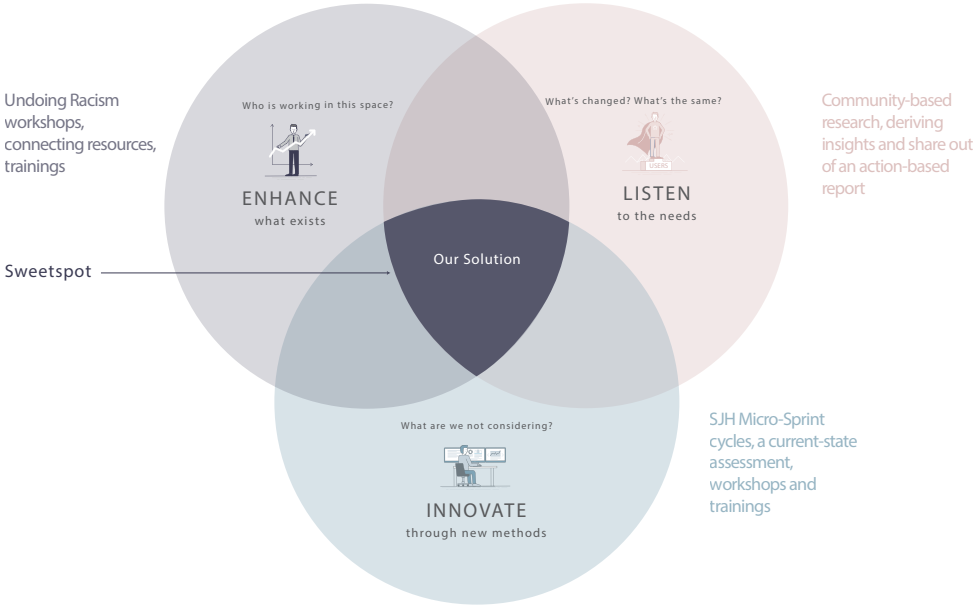


figure 2

Methodology: Ethnography

Ethnographic research is about contextual understanding. In practice, we observe and informally interview people during the course of their daily life. This elicits insights into drivers of decision-making by understanding what some percieve to be mundane.

It can be hard for someone (a user) to explain or talk about what informs their decision-making and experiences, but observing their actions can provide the right insight. Additionally, ethnographic research allows someone to experience the context of the person or people with whom you are designing.

Methodology: Interviews

Interviews are about understanding someone's story. Unlike traditional research interviews where you have a set of questions to ask, human centered design interviews follow a conversation guided by a semi-structured interview format.

If the interviewee wants to bring in another concept or subject, we provide the space to explore it. We embrace listening and are not afraid to ask "why".

Our process is not always about getting to an answer. It is to learn about the experience, the mindsets, and the principles that inform who this person is, and what drives them.

Interviews vs Focus Groups

During our research, we went to community organizations and shared our research process: meeting directly with community members, and having conversations around their pregnancy care.

What we learned was that in Paterson, user research already existed, however, it most often takes the form of a focus group. Most often, focus groups are comprised of structured questions designed for feedback when the solution and product have already been created. We believe that this can remove power from the users to discuss what is important to them and their needs. So, it's fundamentally different from our approach.

Our goal is to have users drive the conversation, share their mindsets, and co-create opportunities.

Perinatal Health

Why It's Important: Racism as a Health Inequity

Racism is a fundamental root cause of health inequities in the United States: it has become entrenched in our culture, systems, and institutions.[4] The effects are evident as Black and African American individuals have poorer health outcomes compared to non-Hispanic white people; even when controlling for the same income, Black and African Americans are still disproportionally affected.[5]

The pervasive impacts of racism are seen at different levels within society. Using Dr. Camara Phyllis Jones' levels of racism framework, racism exists at three levels: institutionalized, personally mediated, and internalized.[6]

For example: at the institutional level, historical unequal mortgage and loan policies in the 1930s for Black individuals led to vital resources (i.e. grocery stores, hospitals, schools) to be unavailable to Black Americans, [7,8] which still has impact to this day around health outcomes,[9] such as preterm birth rates.[10]

At the personal level, Black folks experience racial microaggressions [11] and stereotypes [12] that each cause a molecular pathway for increased risk of chronic diseases.[13]

At the internalized level, racism has a detrimental impact on individuals' values of self-worth and abilities. Perpetual racism at the institutional and personal level cause Black folks to accept erroneous stereotypes around their identity and community which leads to poorer psychological well-being.[14]

Racism is a public health crisis. Through this report we are acknowledging that racism at all levels exists within Paterson and New Jersey and has negatively impacted not only Black and African American women, but all people of color.

The National Landscape

Community Models of Perinatal Health

Currently within the nation, perinatal health for Black women is worsening, with structural racism being identified as the root cause. As a system, healthcare is not immune to structural racist policies and mindsets that cause these inequities. Equity-centered researchers have challenged traditional Western, physician-based medicine and turned their eye to community-based models. The biggest criticisms of the physician centric model are that it continually prioritizes individual, biomedical risk identification without addressing social and structural determinants of health. This is seen when mothers, especially women of color, are blamed for being unable to adequately take care of their health.

Developed by Black women scholars and activists, a new model of patient centered perinatal and reproductive health arose titled Reproductive Justice.[15] The four principles of Reproductive Justice were created to rechallenge power structures existing within healthcare and to recognize the knowledge and wisdom that community members and mothers hold. These include:

1. Every person has the right to decide if and when they become pregnant and to determine the optimal conditions under which they will birth with equitable access to and utilization of culturally relevant options and opportunities for pregnancy, labor, birth, and postpartum.

2. Every person has the right to prevent or end a pregnancy and can do so via options that are accessible, approachable, acceptable, available, accommodating, affordable, and appropriate.

3. Individuals have the right to parent children they already have with dignity and with the necessary social supports in safe, affordable, and sustainable environments and healthy, thriving communities without fear or threat of violence, intimidation, coercion, or control from individuals or the government.

4. Individuals have the right to disassociate sex from reproduction and that healthy sexuality and pleasure are essential components to whole and full human life.

Community informed perinatal and reproductive health models challenge the power differentials and redefine health to be more than just mitigating risk but pursuing justice and liberation in all care experiences. It focuses on institutions and systems that propagate inequities, rather than individual behaviors of moms. While the end goal of having a healthy pregnancy is the same, this new model takes a different systemic approach in tackling how it can improve the pregnancy and birthing experience for women of color.

An important note: St. Joseph's Health is a healing ministry of the Catholic Church sponsored by the Sisters of Charity of Saint Elizabeth. As a Catholic healthcare institution, which upholds its Core Values of Dignity, Charity, Justice, Excellence, and Stewardship, St. Joseph's Health has a strong commitment to the community, which includes working towards justice and serving the poor, vulnerable and underserved. As ministry of the Church, St. Joseph's abides by the Ethical and Religious Directives for Catholic Health Care Services (ERDs), 6th Edition.[16] Based on the Catholic Church's theological and moral teachings, the ERDs provides a context for Catholic healthcare in addition to offering moral guidance on various aspects of health care delivery. Some of the Directives found within the ERDs are specific to perinatal health and include (for example) the prohibition of abortions/tubal ligations and the prescribing of contraception within the institution. In accordance to these Directives, St. Joseph's Health demonstrates a commitment to providing care that upholds human dignity, attends to the whole person and promotes the common good through the services that it provides every day.

The New Jersey Landscape

New Jersey Tackling Maternal Health

At the federal and state level, Black and African American women are disproportionately leading in all major negative prenatal and maternal health outcomes such as maternal mortality, infant mortality, and preterm births. New Jersey, specifically, has the fourth highest maternal mortality rate of all 50 states. To combat this health disparity, the First Lady of New Jersey, Tammy Murphy, officially launched Nurture NJ in early 2019.[17] Nurture NJ is a statewide initiative committed to ensuring equity in maternal and infant health outcomes for Black and Brown women and to reduce overall maternal and infant mortality and morbidity in the state. In 2021 with the support from The Nicholson Foundation and Community Health Acceleration Partnership, a strategic plan for Nurture NJ was shared to agencies and stakeholders to make "New Jersey the safest and most equitable place in the country to give birth and raise a baby".

In the report, a key stakeholder and ecosystem map was developed to carry out an extensive list of strategic recommendations to tackle maternal health inequities at every level. There are three key temporal components established in the ecosystem: preconception, during pregnancy, and subsequent to pregnancy. Each phase has a respective objective. Preconception is focused on ensuring that all women are healthy and have access to care before pregnancy. During Pregnancy is focused on building a safe, high-quality, equitable system of care and services for all women during prenatal, labor and delivery, and postpartum care. Lastly, Subsequent to Pregnancy is focused on ensuring supportive community environments and contexts during every other period of a woman's life so that the conditions and opportunities for health are always available.

The First Lady's strategic plan created a comprehensive list of tangible recommendations, providing every stakeholder in the perinatal health space with next steps. Our report focuses on a smaller set of key stakeholders we identified to create impactful change within Paterson.

For the past three years, Ms. Tammy Murphy has also held both annual Black Maternal and Infant Health Leadership Summits and Family Festivals where they respectively attract key stakeholders in maternal and infant health to discuss and identify solutions and partner with local organizations to connect families with state, county, and local resources.

> "The disparities in maternal and infant outcomes are not the result of differences in genes or behaviors but are mostly explained by the differential historical, social, economic, and health environments experienced by Black and brown women.
>
> These economic and social differences matter for health; they are determinants of health, and as long as they exist, so will the disparities in maternal and infant health."
>
> - Nurture NJ

The Local Landscape

Paterson and Passaic County

Within New Jersey, Passaic County is leading in preterm births and lagging in mothers who receive early prenatal care. In 2018, 9.5% of New Jersey mothers had preterm births, whereas 11.2% of Passaic County mothers had preterm births and, of these Passaic mothers, 17.5% were Black and African American (the total population of Black and African American individuals are 15.1%). In 2018, 73.2% of New Jersey mothers received early prenatal care, compared to 67.2% of Passaic County mothers. For Black and African American Passaic County mothers, only 55.9% received early prenatal care.[18] To understand how to improve maternal and infant health outcomes, David Asiamah PhD of The Health Coalition of Passaic County (HCPC) developed a communication action plan [19] to decrease the preterm birth rates for women of color. Through this plan, HCPC devised strategies to increase provider use of the Perinatal Risk Assessment and patient enrollment into Central Intake as well as to increase community partner utilization of a community health screen. The three key audiences for HCPC's communication plan were women of childbearing age, social service organizations and faith-based institutions, and providers. HCPC created a tool called a Project Information Sheet to answer the following questions:

1. What themes and key words will resonate with best?
2. What does the audience think now about Central Intake?
3. What do we want the audience to think?
4. What are their greatest needs and challenges?

One differentiation between HCPC's action plan and this report is the goal of whose work to effectively communicate with key stakeholders in the perinatal health space to get moms into addtional existing services. From HCPC's research, key communication strategy channels and facilitators were established to improve use of perinatal care services.

All Resources

What resources and services are available to women in the community that affect perinatal health?

Current State List

From the City of Paterson and Health Coalition of Passaic County, a comprehensive list of organizations, governmental programs, and independent services were curated by NowPow, [20] a community referral platform. While this list comprises all the resources available to a Paterson resident, each one of these resources has differing levels of accessibility reflected by what they offer.

We found that there are over 120 resources available in Paterson, NJ.

With all the organizations, governmental programs, and independent services, we performed an exhaustive audit of the offerings provided and cross referenced each to what type of premature birth risk factor they impacted [21] (order does not reflect significance):

1. Medical Care and Complications
2. Late or No Prenatal Care
3. Domestic Violence
4. Social Support
5. Stress
6. Work and Physical Ability
7. Environmental Toxins
8. Drug and Alcohol Abuse
9. Food and Nutrition
10. Mental Health and Wellness
11. Housing Assistance
12. Childcare and Schools

The highlighted organizations note resources for expectant mom that are intentionally designed to support

- 1. pregnancy care
- 2. postpartum care

A List of All Available Resources

4Cs of Passaic County
Alzheimers Association Greater NJ
American Red Cross of Northern NJ
Bangladeshi American Women's Development Initiative - BAWDI
Boys and Girls Club of Paterson/Passaic
Calvary Baptist Community Center
Camp YDP
CAPCO
Catholic Charities Diocese Child Protection & Permanency
Chosen Generation Corp
Christ Church United Methodist
Circle of Care
City Green
CSP-NJ Respite House
CUMAC
Enrichment Center
Eva's Village
Faces of Fallen Fathers
Fair Hearings Hotline
Family Care NJ
Family Intervention Services
Family Support Org of Passaic County
Father English Community Center
George & Enid Brooks Foundation
Gilmore Memorial Preschool
Girl Scouts of Northern NJ
Golden Years Adult Day Care Center
Good Grief
Good Shepherd Mission
Greater Bergen Community Action
Habitat Homeowners Association
Hackensack Meridian School of Medicine
Hamilton Partnership for Paterson
Health Coalition Passaic County
Helpful Hands
Hispanic Multi Purpose Services Center
Home Care Options
Inner City Ensemble
InnerFaith Performing Arts Center
Islamic Center of Passaic County
John P Holland Charter School
Lighthouse Pregnancy
Medicare
M&S Psychotherapy and Counseling
Madison Avenue Crossroad Ministries
Make the Road NJ
Manavi
Memorial Day Nursery
Mental Health Association in Passaic
New City Kids
New Destiny FSC
New Jersey Community Dev Corp
North Porch
Northeast NJ Legal Services
NJ Dental Clinical Directory
NJ Medicaid
NJ SNAP
NJ WorkAbility
Northwest Cap
Oasis
Options Counseling Center
P-Casa
Palestinian American Comm Center
Partnership MCH
Passaic County CASA
Passaic County Community College
Teacher's Excellence Project
Passaic County Department of Senior Services Disability Veteran's Affairs
Passaic County Safe Kids
Passaic County Women's Center
Paterson Alliance
Paterson Cares
Passiac County Social Services
Paterson Division of Health
Paterson Counseling Center
Paterson Education Fund
Paterson Habitat for Humanity
Paterson Housing Authority
Paterson Music Project
Paterson Public Schools
Paterson Relief/ New York City Relief
Paterson Board of Education
Paterson Task Force
Planned Parenthood
Rebuilding Together North Jersey
RENEW Life Center
Senior Health and Social Services
Social Security Administration
St. Joseph's WIC
St. Joseph's Health
St. Luke's Baptist Church
St. Paul's Community Dev Corp
Star Of Hope Ministries
Straight and Narrow
SAIF
The Amazing Help
The Center for Alcohol/Drug Resource
The Kintock Group
The Stork Club
True Care
Turning Point
United Way of Passaic County
Wafa House
WorkFirst NJ/Temporary Assistance
YMCA of Paterson

Existing Perinatal Resources

A Deeper Dive

A bit more about the resources highlighted on the last page:

Greater Bergen Community Action

Provides virtual prenatal support, family development, preparation for baby and childcare.

Lighthouse Pregnancy Resource Center

Provides pregnancy tests, medical confirmation of pregnancy via ultrasound, options education, limited STD screening, and material resources and referrals, and post-abortion counseling.

New Destiny Family Success Center

Provides access to maternal and family health services for community members

NJ Medicaid/SNAP

Provides health insurance and nutritional assistance and nutrition education.

Oasis

Provide pregnant women social work, community events, community baby showers, and workshops.

Partnership Maternal & Child Health of Northern NJ

Provide direct resources and referrals for pregnant women to resources in the county.

Planned Parenthood

Provides women healthcare and referrals for pregnancy care.

St. Joseph's WIC Program

Provides nutritional food to pregnant women, infants, and and children up to the age of 5 as well as breastfeeding and lactation support.

St. Joseph's Health & CenteringPregnancy

Provides world class obstetrical care and group prenatal care.

Catholic Charities Diocese

Provides pregnant specifc services and special early intervention help for infants between age 0-3.

New Jersey Division of Child Protection & Permanency

Provides child protection and welfare to families to have safe, healthy, and connected families.

North Porch

Provides emergency aid, in the form of baby supplies, to mothers and infants.

4Cs of Passaic County

Provide families high quality childcare that is available, accessible, and affordable.

Understanding

To better understand the current state of perinatal health resources in Paterson, we interviewed a number of key resources. Many of these organizations were involved in the original kickoff planning session and others were selected based on moms highlighting them in their stories.

New Destiny Family Success Center

https://newdestinyfsc.org/what-we-do/

New Destiny Family Success Center (NDFSC) was established as a grassroots initiative in 2005, partnering more than 75 community leaders, concerned citizens, and local government agencies interested in strengthening families and building an accessible network of support. Family Success Centers are "one-stop" shops that provide wrap-around resources and supports for families before they find themselves in crisis.

KEY STAKEHOLDERS

Carolyn McCombs
Kashieka Phillips
Anny Alonzo

KEY GOALS

Foster healthy families from diverse backgrounds, reducing isolation, and building community.

DATES OF ENGAGEMENT

2021.06.22: Mother Interview Planning

SJH CenteringPregnancy

https://www.centeringhealthcare.org

The Centering Pregnancy program at St. Joseph's Health Medical Center. Improving health, transforming care and disrupting inequitable systems through the Centering group model. Centering Healthcare Institute imagines a U.S. healthcare system that offers not why medical interventions, but combats isolation and builds communities, empowers and educates patients, and serves as a partner to connect the most vulnerable with resources that contribute to overall health.

KEY STAKEHOLDERS

Debra Katz

KEY GOALS

Improve health, transform care and disrupt inequitable systems through the Centering group model.

DATES OF ENGAGEMENT

2021.06.09: Observation
2021.08.16 Mother Interview

Partnership for Maternal & Child Health of Northern NJ

https://partnershipmch.org/about-us/

The Partnership for Maternal & Child Health of Northern NJ (PMCH) was a merger of three state child and maternal health consortia in 2012. Licensed by the New Jersey Department of Health and Senior Services, the Partnership serves as the lead planning agency for maternal and child health services in Northern New Jersey. The consortium conducts extensive community outreach and educational programs for the consumers and health care providers in the state of New Jersey.

KEY STAKEHOLDERS

Mariekarl Vilceus-Talty
Liliana Pinete
Marie Kinsella

KEY GOALS

Meet the healthcare needs of women, infants and children in NJ while coordinating education, outreach and advocacy through regional planning and collaboration.

DATES OF ENGAGEMENT

2021.08.25: PMCH Learnings

Health Coalition of Passaic County

https://healthcoalitionpc.org

The Health Coalition of Passaic County (HCPC) seeks to create a thriving and sustainable community coalition dedicated to significantly improving the health and overall quality of life for residents of the Greater Passaic County area by specifically addressing social determinants of health. With a focus on Perinatal & Pre-term birth-rates, in 2018, HCPC conducted an in-depth analysis of pre-term birth rates.

KEY STAKEHOLDERS

Kim Birdsall
David Asiamah
Maddy Pena Reynoso

KEY GOALS

Power up their partners so together they can build and promote a culture of overall health and well-being for all residents of the greater Passaic County. HCPC programs are designed around the individual to meet their needs and build community capacity.

DATES OF ENGAGEMENT

2021.05.25: HCPC Learnings
2021.06.04: HCPC Team Sharings
2021.09.15: Report Feedback

Healthy Women Task Force Team

n/a

The HCPC Healthy Women Task Force Team (HWTFT) is a sub-group of HCPC member organizations who work to address the needs of women in the community. Formed in 2019, the mission of the HCPC HWTFT is to improve women's overall health, eliminate barriers to quality healthcare for women of childbearing age, and take collective actions in an effort to reduce preterm birth rates in Passaic County. The task force team develops strategies to improve access to prenatal care, identify financial resources, and improve nutrition and physical activity opportunities for women.

KEY STAKEHOLDERS

HCPC : Maddy Pena Reynoso
PMCH: Lorelly Frias
NDFSC: Kashieka Phillips
SJH WIC Program: Anny Uddin
PCCC: Renee Griggs
Lighthouse: Debbie Provencher
4Cs: Joanne Cummings

KEY GOALS

Implement health promotion and health education activities to advance the health literacy of women in Paterson and Passaic County. In addition, the HCPC HWTFT works to advance the role of the HCPC by powering up partners to seek and better understand the journey and experiences of high risk, marginalized women in the community.

SJH WIC Program

https://www.wicprograms.org/ci/nj-paterson

WIC (The New Jersey Supplemental Nutrition Program for Women Infant and Children) is a successful public health nutrition program that provides wholesome food, nutrition education and community support for income eligible women who are pregnant and post-partum, infants, and children up to five years old.

KEY STAKEHOLDERS

Dorothy Monica
Anny Uddin

KEY GOALS

Safeguard the health of low-income women, infants, and children up to age 5 who are at nutrition risk by providing nutritious foods to supplement diets, information on healthy eating, and referrals to health care.

DATES OF ENGAGEMENT

2021.06.21: WIC Learnings
2021.06.28: Further Learnings
2021.07.26: Mother Interview Planning
2021.09.16: Report Feedback

Understanding

CUMAC

https://www.cumac.org/

CUMAC is a 501(c)(3) non-profit organization with programs that include a food pantry that serves over 40,000 people every year; a food depot that handles nearly 2 million pounds of food for a network of over 50 agencies; a disaster relief program, a thrift shop that provides high quality, low cost items to the community, the Pathways to Work program that offers job training to those seeking gainful employment; Place of Promise, which provides a permanent supportive housing program for the chronically homeless; and the Community Food Coalition, a collection of pantries working together to stop hunger in New Jersey.

KEY STAKEHOLDERS

Mark Dinglasan
Kayann Foster
Akeera Weathers
Shanee Alston

KEY GOALS

Fight hunger and its root causes through a holistic, trauma-informed approach that provides groceries and basic necessities to families and individuals in need.

DATES OF ENGAGEMENT

2021.07.06: Mother Interview Planning
2021.07.11: Mother Interviews
2021.08.11: Father Interviews
2021.09.14: Report Feedback

Lighthouse Pregnancy Resource Center

https://lighthouseprc.org/

Lighthouse Pregnancy Resource Center serves women, men, and teens at-risk for, or facing, an unplanned pregnancy or related concern. They do not provide or refer for abortion; they do provide valuable services to support informed choices that will enhance moms' lives and the lives of others. Their free and confidential services include pregnancy tests, medical confirmation of pregnancy via ultrasound, options education, limited STD screening, material resources and referrals, and post-abortion counseling.

KEY STAKEHOLDERS

Debbie Provencher
Jan Rowland

KEY GOALS

Provide hope and help to those in pregnancy-related turmoil.

DATES OF ENGAGEMENT

2021.08.12: Mother Interview Planning

RENEW Life Center

https://renewlifecenternj.org/

RENEW Life Center provides a safe, agenda-free learning environment where adults can examine their lives and investigate new information relevant to their experience in poverty. RENEW offers the knowledge and tools mom's need to assess their resources, make plans for the future, and chose a team to help them fulfill their goals.

KEY STAKEHOLDERS

Marisol Rodriguez
Sheri Drost

KEY GOALS

Help families overcome generational poverty by providing life-changing programs that lead to economic self-sufficiency, healthy relationships, and restored dignity.

DATES OF ENGAGEMENT

2021.08.02: Mother Interview Planning

Planned Parenthood of Metropolitan New Jersey

https://www.plannedparenthood.org/health-center/new-jersey/paterson/07514/paterson-center-2557-90920

Planned Parenthood is a trusted health care provider, an informed educator, a passionate advocate, and a global partner helping similar organizations around the world. Planned Parenthood delivers vital reproductive health care, sex education, and information to millions of people worldwide.

KEY STAKEHOLDERS

Erin Chung
Sandra Mercorelli

KEY GOALS

Help people live full, healthy lives — no matter a patient's income, insurance, gender identity, sexual orientation, race, or immigration status.

Provide the high-quality inclusive and comprehensive sexual and reproductive health care services all people need and deserve — with respect and compassion.

DATES OF ENGAGEMENT

2021.08.05: Planned Parenthood Learnings

Bangladeshi American Women's Development Initiative (BAWDI)

bawdi.wordpress.com

The Paterson Bangladeshi community has been in this city for over 30 years, and number over 10,000 residents, yet there is no space for women to connect with one another or to get important resources for self-empowerment. BAWDI hopes to change this and grow opportunities and connections for the Bangladeshi women in Paterson and their families.

KEY STAKEHOLDERS

Tania Chowdhury
Nadia Hussain

KEY GOALS

Promote, support, and address the unmet needs of Bangladeshi women and children in our Paterson community and throughout New Jersey through grassroots organizing, connection to services, advocacy, disseminating information and educating community members on social issues, and cultivating a safe space for sisterhood.

DATES OF ENGAGEMENT

2021.07.30: BAWDI Learnings

Additional Resources

Central Intake (Partnership)
Paterson Community Health Center FQHC
Eva's Village
Straight and Narrow
NJ State Department of Health

SJH Perinatal Care

To better understand the current-state of perinatal healthcare in Paterson, we had to understand what the process is like for women to recieve prenatal care at SJH's OB Clinic as well as the clinicians and providers who deliver care. SJH is the only hospital in the city of Paterson and provides care to all who seek it. "Clinics" refer to the care provided through the Department of Community Medicine which primarily serve patients covered by Medicaid or charity care, and those who are uninsured.

SJH OB Team

https://www.stjosephshealth.org/womenshealth

The nationally-recognized Department of Obstetrics and Gynecology (OB/GYN) at SJH is a designated Level III Perinatal Center. Board-certified obstetricians, perinatologists, urogynecological surgeons, gynecological oncologists, reproductive endocrinologists, advanced practice nurses, and midwives are part of our comprehensive medical team. Patients can receive genetic counseling and maternal fetal medicine services at the SJH's Centers for High Risk Pregnancy.

SERVICES

1. The Low Risk Pregnancy Clinic is a clinic for mothers with no pregnancy complications.

2. The High Risk Pregnancy Clinic is a clinic that oversees the most medically complicated cases.

3. The pregnant teen/adolescents clinic, up to the age of 21, is a special clinic assisted by Nurse Midwives to support young mothers.

4. CenteringPregnancy is group prenatal care bringing women due at the same time out of exam rooms and into a comfortable group setting.

KEY STAKEHOLDERS

Dr. Roger Kierce
Pamela Schaefer
Carla Rizzo
Debra Katz

KEY GOALS

To provide culturally competent, compassionate, timely, consistent, and comprehensive care to ensure optimal outcomes for our mothers and their babies.

OB Clinic Patient Process

We have mapped the most common process + journey

FIRST TIME VISITS

	1. Schedule	2. Arrival	3. Check In	4. Registration
	Calls SJH call center to set up appointment. Bring proof of address and ID.	Arrives to the lobby of the DePaul outpatient center and goes to the 2nd floor.	Check in at a mobile kiosk desk with receptionist who "arrives" them in the EMR and hands them a color-coded number.	Check in with front desk before being called to see the provider.

OB Clinic Staff Stories

Getting to know the team

The Receptionist

She prepares for the day by printing out the patient schedule and carefully selecting color coded numbers that she will hand out to each patient. She wants to make sure no patient is standing and that everyone patient feels welcomed into the clinic.

SJH Perinatal Care

5. Vitals

They are put into an exam room by the Medical Assistants who takes their vitals and perform an interview about the reason for visit.

The Medical Assistants
They are ready for any job that needs to be done and are busily rushing between the rooms. They often develop the closest bonds with the patients.

6. Check up

Provider reviews intake/case and completes an in-depth medical exam.

The Advanced Practiced Nurses

They take great care and time to develop trust between them and the patient because there's a lot of sensitive information around their personal lives and health.

The Midwives

They prepare to host the CenteringPregnancy session by ensuring the room is set up in a circle with a fuzzy carpet and refreshments. They are excited about the outcomes of this program so far.

7. Tests

Providers perform specific exams and imaging as neeeded.

The Residents

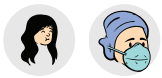
They are involved in the full spectrum of OB/GYN services. Their care is directly supervised by an on site attending physician.

The Maternal Fetal Medicine Physicians

Having dedicated their careers to Paterson patients, our MFM physicians have improved perinatal outcomes for high risk patients for over 30 years.

8. Waiting

Patient gets dressed and goes back to waiting room to wait for the nurse.



The Nurses

They have an enormous passion for serving patients. Seeing patients have babies makes them feel like they are part of their family as well.

The Attending Physicians

The attending physicians are there to support the residents, students, and practitioners. Beyond providing care, they need to make sure that the residents on the floor are adequately trained and knowledgeable to provide the highest level of care to the moms.

9. Services

Nurse brings patient to social worker to complete initial psychosocial assessment, as well as to a financial counselor, and a dietician.

The Social Workers

They manage a huge caseload of patients and become attached to them.

The Financial Counselor

They work closely with patients to ensure charity care. It's hard to see patients not qualify for charity care.

The Dieticians

They work to ensure that patients feel empowered around their nutritional health and ensure there is no stigma around health topics such as diabetes.

10. Labs

Patient goes to lab to complete blood work as necessary.

11. Checkout

Patient stops back at front desk for check out. Nurses provide patient with discharge plan and follow up appointment plans.

The Optimal Clinical Pathway

This diagram represents the optimal clinical pathway for pregnancy based on the Guidelines for Perinatal Care (8th Edition) by the American College of Obstetrics and Gynecology [22] and is followed at SJH.

From a SJH clinical perspective, there are generally 3 critical moments/points at which an expectant mom needs to see a doctor. Missing these exponentially creates negative downstream issues.

- 1st critical point
- 2nd critical point
- 3rd critical point

Each month shows the key elements of care to optimize the health of a pregnancy and the advantages of seeking care early. Along the top are highlighted areas that call out critical tests and/or services that are missed opportunities if someone is not receiving timely prenatal care.

The first critical moments are the genetic risk assessment (12 weeks), and fetal anatomic ultrasound (18 weeks). At this point, the baby is the perfect size for the clinician to be able to see all parts of the anatomy in order to identify any abnormalities. Past this point, the baby's size prevents the physician from seeing a full picture. At the second critical point, patients start seeing medical complications that arise or worsen because of pregnancy. At this point, clinicians are able to reassess where patients are and how the pregnancy is affecting both your maternal and fetal health. At the third critical point, patients need to be aware of how to assess their own condition and symptoms and report anything unusual.

"The beauty of prenatal care is that it helps to alleviate the fear of the unknown."

- Dr. Roger Kierce, Chairman, SJH OB/GYN

On average, there are about 12 visits during the course of a pregnancy. These visits increase in frequency in the third trimester due to an increase in potential adverse events as the birth nears.

Pre Pregnancy

1st CRITICAL

MONTH 0

Family Planning

Health Screening for Women of Reproductive Age

Engaging in responsible family planning

Influenza, Tdap, Human papillomavirus, general vaccines

Substance Use and Substance Use Disorders

Chronic Medical Conditions: Diabetes, Thyroid Disease, and Maternal Phenylketonuria

Medication Use

Prepregnant Genetic Screening

Prepregnancy Nutritional Counseling
Dietary supplments of Folic Acid

MONTH 1

Pregnancy Confirmation

MONTH 2

Visit 1

Viability Ultrasound

Cervical Cancer Screening

History & Physical Exam
Assessment of obstetric risk factors; smoking and substance use assessment; family history; family planning; depression screening; domestic violence screening; weight gain recommendations

Consultation
Scope of care provided; lab studies and indications; expected course of pregnancy; signs and symptoms to be reported; role of health care team; anticipated schedule of visits; physician or midwife schedule + labor and delivery coverage; cost to patient of prenatal care and delivery; insurance discussion; practices to promote health maintenance

First Trimester Patient Education
Nutrition; exercise; weight gain; dental care; nausea and vomitting; vitamin and mineral toxicity; teratogens; air travel

MONTH 3

Visit 2

Genetic risk assessment (10+ weeks).

Fetal Heart Rate

Ongoing Pregnancy Risk Identification for Consultation

Depression and Domestic Violence Screening

Smoking and Substance Abuse Assessment

MONTH 4

Visit 3

Nuchal Translucency

Depression and Domestic Violence Screening

Smoking and Substance Abuse Assessment

Second and Third Trimester Patient Education
Working; childbirth education classes; choosing a newborn care provider; anticipating labor; preterm labor; breech presentation at term; trial of labor after cesarean delivery; elective delivery; cesarean delivery on maternal request; umbilical cord blood banking; breastfeeding; preparation for discharge; and neonatal interventions

- Clinical Consideration
- Immunization
- Lifestyle & Nutrition

The Optimal Clinical Pathway

Post

2ND CRITICAL

3RD CRITICAL

MONTH 5

Visit 4,5

Fetal anatomic ultrasound (18-20 weeks).

At this point, the baby is the perfect size for the clinician to be able to see all parts of the anatomy in order to identify any abnormalities. Past this point, the baby's size prevents the physician from seeing a full picture.

Diabetic Screening

Complete Blood Count

Depression and Domestic Violence Screening

Smoking and Substance Abuse Assessment

MONTH 6

Visit 6,7

Underlying medical conditions

At this point, clinicians are able to reassess where patients are and how your pregnancy is affecting both your maternal and fetal health.

RhoGAM

Depression and Domestic Violence Screening

Smoking and Substance Abuse Assessment

MONTH 7

Visit 8,9

Hct/Hgb

Depression and Domestic Violence Screening

Smoking and Substance Abuse Assessment

MONTH 8

Visit 10-13

Self Assessment

Patients need to be aware of how to assess their own condition and symptoms and report anything unusual.

GBS Culture

Depression and Domestic Violence Screening

Smoking and Substance Abuse Assessment

MONTH 9

Labor and Delivery

Maternal Fetal Triage Index

Three-Tiered Fetal Heart Rate Interpretation System

Blood pressure and pulse monitoring

MONTH 10

Post Delivery Consultation

Postpartum Form

Establish Breastfeeding Care

Postpartum Immunizations

Postpartum Care plan

Care team, postpartum visits, blood pressure monitoring, contraceptive plan, infant feeding, pregnancy complications, mental health

Anticipatory guidance

Postpartum considerations

Changes in lochia pattern, activities, care of breasts, perineum, and bladder, dietary needs, exercise, depression, signs of complications, contact information for community based lactation support, contact information for postpartum care team and follow up, signs and symptoms of preeclampsia

MONTH 11

Followup Visit

Full assessment of physical, social, and emotional wellbeing

Interval history and physical examination of woman's current status and role of being a mother

Breastfeeding, infant feeding

Evaluation of weight, blood pressure levels, breasts, and abdomen, pelvic examination.

Pap test

Family planning discussion

Pregnancy Care Experience

Meeting with Moms & Dads

Following our human centered design process, we worked together with community partners and shared our unique methodology. Together, we invited community members to share their stories and experiences with us. While our partners are all driven by the goal to provide the right resources to expectant moms, they all operated differently because of their different clientele and services. To ensure appropriate and sensitive engagement with moms, we carefully co-designed with community partners through a series of in-person and virtual meetings.

Barriers to Our Process

Like many others experienced, COVID-19 disrupted our work plans. First, finding community members to speak to took longer than we expected. We learned that many of our partner groups transitioned to providing support and resources online, so there were less direct physical engagements with community members. Second, we had to shift our approach to the research. Traditionally, we prefer to conduct interviews in person, in spaces that make interviewees feel comfortable. In order to respect what community members felt comfortable doing, we provided the option to community members to speak with us via phone and video call, whichever they preferred.

We were told that community members would not be comfortable speaking with us around their experience. However, we found that to be quite the contrary.

Moms and dads spoke with us and some have even shared that they appreciated us giving them the safe space to reflect and tell their story.

Research Overview

When speaking to mothers and fathers around their pregnancy experience we had a few general questions that we used as conversation starters. As referred in the earlier section, these questions served as guiding points but were not prescriptive.

1. What was your experience like receiving care when you were pregnant inside and outside the hospital?

2.What or whom was most helpful during your pregnancy?

3.What did support during pregnancy look like?

4.Now that you have been through a pregnancy, what advice would you give other women?

5. What would you wish to be different for your kid(s) if they have kids?

A flyer distributed by partner organizations to their cliente

We spoke to 20+ community members who were referred to us via:

CUMAC
WIC
New Destiny FSC
Lighthouse Pregnancy
RENEW Life Center
SJH OB Clinic

Optimal Path vs. Lived Experience

When we spoke to mothers we learned that their experience did not align with what was designated as clinically ideal.

Pregnancy care often has an emphasis on the episodic moments that occur in healthcare. Often what happens at home, in the community is not acknowledged.

We Met With

16 Moms AGED 19-34

Identify as Black/African American

Identify as Latinx

Identify as White/Caucasian

4 Dads AGED 19-34

Identify as Black/African American

Zipcodes (for Women only): 07501, 07503, 07504, and 07522
These zipcodes represent those with the highest preterm birth rates with those in 07522 and 07514 leading.

Our Process

Of the 20 women interviewed, we visually depicted three of their stories around their perinatal experience.

While the findings of this insights report were compiled by St. Joseph's Health and strategic partners, the moms interviewed and described in the report were provided care from multiple health systems both inside and outside the greater Paterson area, including, but not limited to, St. Joseph's Health.

Stories

We spoke with 20 moms and dads, and their stories spanned a spectrum. They include both good and bad experiences, moments of truimph, and moments of despair. Great care was taken to choose these three stories, as they are representative of what we heard was the broader experience felt by women in the community.

What you will read are real women's stories, taken verbatim from what they shared in the interviews

1. Alexis, 33 (pages 19 - 20)

A mother of two who is going through a unique pregnancy care experience for her third child, which resulted in an emergency delivery.

2. Stacey, 25 (pages 21 - 22)

A working professional who is well accustomed to the Paterson services and resources space and still had difficulty navigating the space when she was pregnant.

3. Cindy, 19 (pages 23 - 24)

A first year college student who had to leave school when she learned she was pregnant.

All individuals have been de-identified to protect their anonymity.

In respect and appreciation for the stories you are about to read, please keep an open mind and absorb what the women are saying.

These women honored us by sharing the most intimate and true moments of their motherhood.

A Mom's Story

Alexis 

Alexis is a 33 year old mother of two who is going through a unique pregnancy care experience for her third child. She is passionate about her story and identity as a mother.

Alexis identifies as Black and African American, and resides in Paterson (07504).

KEY MOMENTS

- Couldn't move up her appointment
- Emergency C-section at 27 Weeks
- Baby stayed 4 months in NICU

"I found out about my pregnancy late and was feeling really bad."

1. Feeling that she might be pregnant, Alexis went to the Lighthouse Pregnancy Resource Center, a resource support she has used before with her first two children, to confirm her pregnancy. The test confirmed she was pregnant and further along than she realized.

2. Based on her past pregnancy experience, she knew to call a local clinic to set up her first appointment. She chose the same doctor she'd used before, mostly out of convenience because they had her medical records.

6. Further into her pregnancy, the pain from preeclampsia became worse, her ribs started hurting and she called her clinic asking to move up the appointment, but her next appointment wasn't for another 5 weeks and unmovable. "Those doctors don't listen."

7. Eventually, the pain became so unimaginable she went to the Emergency Department and was later sent to Maternal Fetal Medicine for monitoring. Here, she met a MFM doctor she labeled as a hero because he decided she needed to deliver that night. "That doctor saved my life and my baby's life."

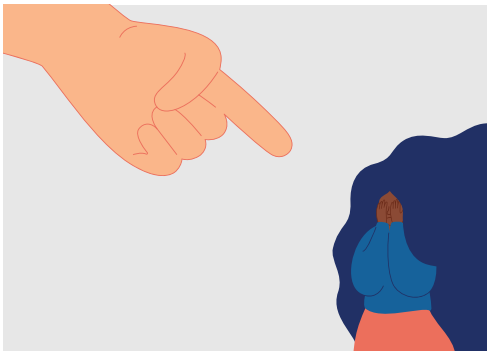
How does this story relates to the optimal clinical journey?

A. Alexis discovered that she was pregnant late.

B. She didn't know how/when to report health symptoms

C. Alexis deliverd at 27 weeks (13 weeks before the ideal delivery time).

Alexis



3. As she prepared for her first appointment, she remembered the caregiver at the labor and delivery unit who told her to not come back again... and now she's here for her third child.

4. Alexis was hoping to get her doctor that was nice before with her other pregnancies, but she was disappointed that the doctor had left and now her experience was "awful". She felt that her new doctors were there just for money.

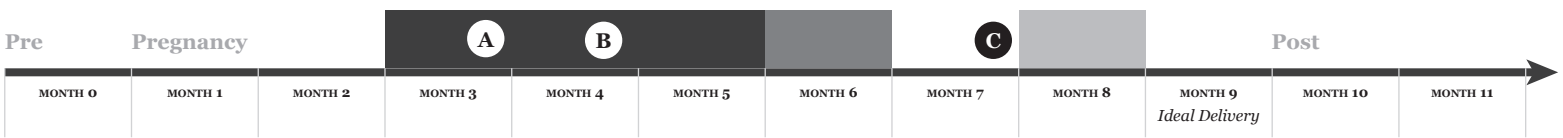
5. During her prenatal care she was diagnosed with preeclampsia. She would feel bad from time to time, but she didn't really know how to tell when something wasn't normal. In hindsight, her biggest wish was that she just knew what preeclampsia was and what to do when she wasn't feeling well.

"The NICU staff was great, especially the social worker."

8. After being rushed into delivery and not knowing about any of the details, she gave birth to her third child at the 27 week mark. The baby had to stay in the SJH NICU for 4 months, where she said the staff were kind, especially a social worker.

9. It was hard not being with her baby and the whole experience led her to form severe post-partum depression. She also wished she had a doula because she felt like she needed someone who was trained and could help defend her rights as always not even your family and close ones know what is going on.

10. She visited her baby as much as possible, but she also had to take care of her two older children at home. She was connected to New Destiny and Lighthouse for support to help with them. They would come to the house and help with food. She felt these women were "beautiful" because they listened and provided her with resources she needed .



A Mom's Story

Stacey 

Stacey is a new mother who is well accustomed to the existing social services and resources within Paterson and Passaic. During her pregnancy she found that she was lost and didn't know what existed despite working in the space.

Stacey identifies as Black and African American, and resides in Paterson.

KEY MOMENTS

- Heard stories of other Black and African American women being treated unfairly

- Attending online prenatal classes in Canada because they were unaccessible and unavailable locally

- Felt lost after delivery and suffered with post-partum depression/anxiety

1. Before Stacey even was pregnant, she had heard stories of what it means to be black and pregnant in Paterson, from moms being denied care to moms being told to "hold it in" when it comes to childbirth.

"I know that (this other person) will get better care than me and my neighbor..."

2. During work while on a call, she heard a white colleague express happiness about giving birth. All she could think was "Damn, why is she so happy to deliver at that hospital?" "Oh, because her experience will be different than my neighbor".

6. After all of that, she didn't even know she was considered high risk which led to her getting a C-Section and her child having to spend 3 days in the NICU. When her child came home, she realized there were so many things she didn't know.

7. She saw a lot of things online on social media about being a mother and glorifying motherhood and when she tried to replicate what she saw online herself, she felt frustrated.

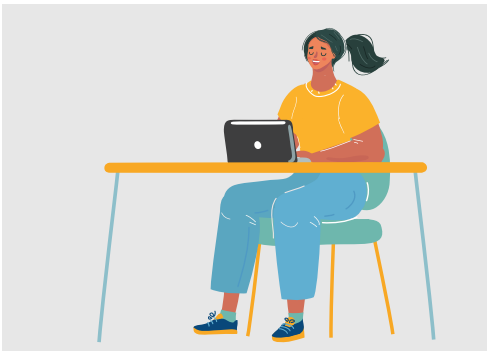
How does this story relates to the optimal clinical journey?

A. Stacey sought out more prenatal education.

B. She didn't know she had pregnancy complications that led her to be labeled high risk.

C. Stacey tried to breastfeed, but had complications which led to a sense of shame.

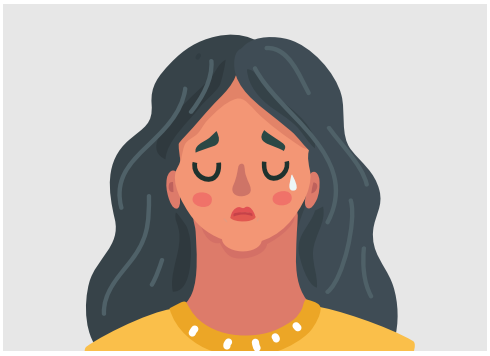
"We shouldn't have to learn as we go."

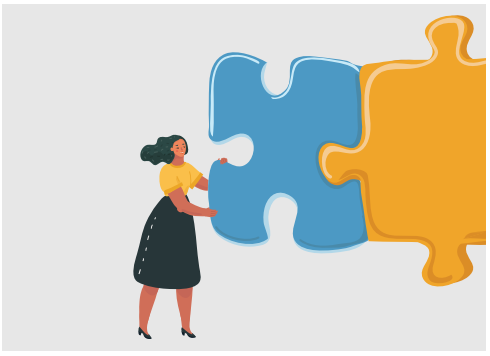


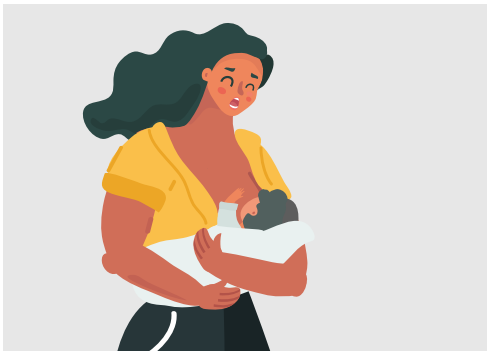
3. Once she was pregnant, she attended prenatal classes but felt like the classes were lacking. She learned the basics, but the classes missed out on a whole spectrum of needed information for childbirth and having newborns.

4. As she progressed in her pregnancy care, she saw more and more experiences that led to her actually realize "this is why our numbers are so high... [Providers] don't listen to women about their problems. Even if [we are saying] we are experiencing pain we are sent home and then something bad happens".

5. Stacey knew things were not right and she deserved better but there was no opportunity to even receive those resources. She ended up researching and finding free online classes in Canada because of what was missing here. She wanted a doula to advocate and help her through her pregnancy, but she learned she would have to pay out of pocket because she didn't have Medicaid.



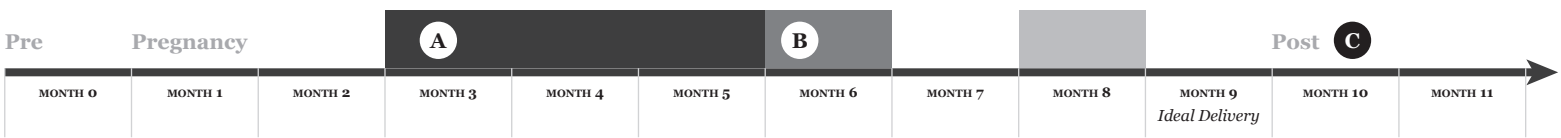




8. Feeling so lost, she was desperate for any help. She had post-partum depression and anxiety and was crying in the bathroom because there were no solutions available to her, even though she knew they had to be out there somewhere.

9. While there were moments of happiness like when the baby smiled or passed gas after having some issues, there were also hard moments. Getting her child to breastfeed was challenging as the baby was demanding. Breastfeeding is the idea of "gold" and something you had to do as a mom from what she was told.

10. Her husband was extremely supportive and confused during this process as well. They both wanted to make it to Black Breastfeeding Week .



A Mom's Story

Cindy

Cindy is a first year college student who learned that she was pregnant, resulting in her having to drop out of school and quickly learn what motherhood is. She had the support of her partner as well as both large families.

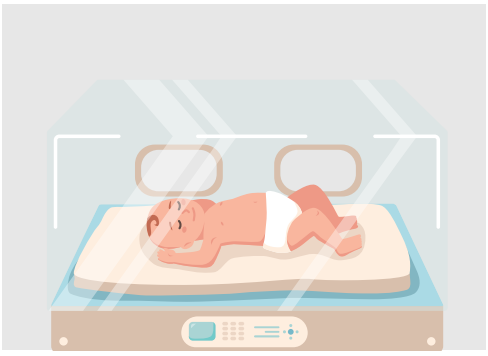
Cindy identifies as Hispanic and resides in Paterson (07504).

KEY MOMENTS

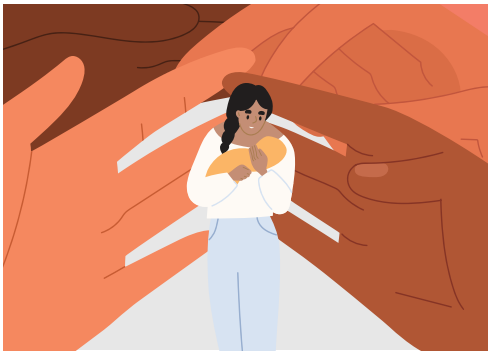
- Choosing where she wanted her prenatal care, but delivering in a place she originally didn't want to
- Emergency C-section where her daughter had to stay in the NICU
- Balancing school and being a mother

1. Cindy is a 19-year-old undergraduate student in college studying psychology but had to drop out and transition to vocational school when she learned she was pregnant with her baby daughter.

2. Her fiancé was immediately excited about her pregnancy, which led Cindy to become excited too. After that, her whole family eventually became excited and supported her, despite her fearing they wouldn't because she was 19.



6. Her daughter is still in the NICU but she's meeting all the milestones and Cindy is there often to check up on her, looking forward to the day when she can take her home.



7. Even though her delivery experience was difficult, she is so happy that she ended up delivering there as the NICU staff have been comforting and made her feel safe, which for her is rare to find nowadays.

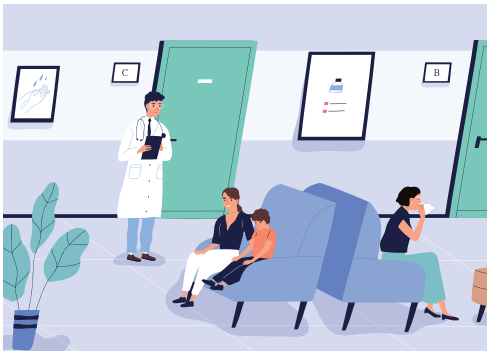
How does this story relates to the optimal clinical journey?

A. Cindy is younger than the majority of pregnant women in the US.

B. She took actions to support her mental health.

C. Cindy deliverd at 29 weeks (11 weeks before the ideal delivery time).

Cindy



3. She started attending prenatal checkups at the local clinic. She had some choices and ultimately chose there based on what her experience was as a patient at the hospital, where she remembered sitting for hours in a waiting room, not being taken care of.

4. Cindy has a history of mental health illnesses. Being in different types of therapies, seeing different psychologists and specialists, and learning different mindsets, she did everything to “not let the crown fall off [her] head”.

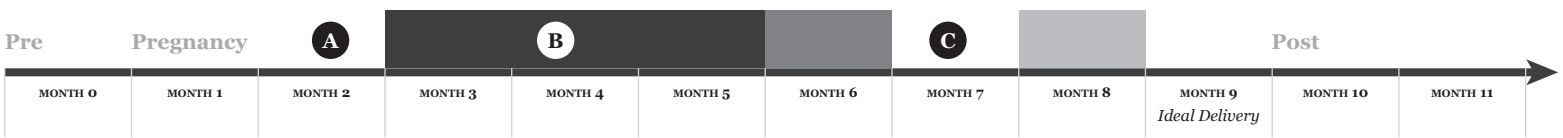
"I was afraid. All I remember is having a blue sheet covering down there."

5. She was admitted to the hospital due to abnormal fluid in her uterus. She thought she might be able to manage it without giving birth, but they decided to perform an emergency C- section because she was having major contractions and pain. Her baby was born at 29 weeks.

8. Despite currently fighting post-partum anxiety and depression, she’s taking it day by day. She is planning what it looks like when her baby is home. When a surge of feeling overwhelmed comes with making appointments and emails, she continues to push forward.

"Now I’m really happy and excited. She’s my biggest blessing.”

9. “I could have never imagined what pregnancy was until I went through it. This whole process really opened up my eyes. Creating life and going through the new experiences. It’s really a great thing.”



Insights

Synthesis Process

After we conducted our interviews with community members, we began to synthesize our learnings. Sifting through the many pages of notes, quotes and stories, we identified a number of universal themes that spanned across individual experiences.

We continued to categorize these themes while remaining grounded to the mom's perspective and truth through continued engagement with several moms.

Additionally, to ensure that was these larger themes rang true and representative of the lived experiences from which they were gleaned, we dedicated weeks to confirm, re-affirm, and finally share with community resources and moms.

The Primary Insights from Moms

While these women's experiences are not a monolith, we heard similar themes in the stories they shared. In an effort to synthesize the voice into key areas of potential impact, we developed the following insights. We found that:

1. Moms do not feel seen or heard

Moms don't want to learn ad hoc. They want information before the last minute. *(Moms don't know what they need to know until they need to know it. Sometimes that's too late.)*

Many of the expectant moms we met with stated that they didn't have enough understanding or support before, during, and after pregnancy. There was a lack of clarity in what to expect, what is "normal" or not, and what resources were appropriate or even available to them. One mom said, "We don't need to learn as we go, we need to be taught beforehand." They pointed out that it's more than not having education, it's that they didn't even know they needed education on certain things. Moms noted that some of this can be attributed to new experiences, and that it's difficult to know what you need before you're experiencing it. The other component is that services and resources are not built around the lived, real experiences of the pregnancy journey, particularly in Paterson.

They feel they are being seen as a pregnant person of color first, rather than a human.

The majority of expectant moms we met with called out that many providers don't seem to care about their lives beyond their pregnancy. It was noted that this happens at every hospital, not just St. Joseph's. One mom said, "I wish they would just ask, 'How are you doing?'" And, many moms expressed experiences of racism and stereotype perpetuation such as feeling judged for being a young black mom or having a lot of kids. Moms are saying don't judge me based just on what you see. I am here, I am a mom who needs help. I am a human being first and foremost.

2. Moms have difficulty managing and navigating the existing systems

They are forced to choose between immediate life and future pregnancy care decisions.

Most of the moms we spoke with said that they had to make hard decisions every day, such as choosing between keeping their jobs or going in for their prenatal visit. A mom actually had to quit her job in order to attend visits, while another felt she would be fired for going, so she decided to keep her job instead. They called out that, more than just at work and school, a lot of things around life don't line up with times that the clinic appointments are available, and they don't have the privilege to choose options. Other moms have difficulty planning for the future, with one saying, "how can I plan when I'll probably get shot in the next few years?"

They carry the full weight of fighting and advocating for their own care.

We heard from many moms that the pregnancy process feels incredibly isolating. That there is no support network and moms are often left to fend for themselves. One mom shared a story about losing custody of her first child because she didn't know how to get help. With her second child, she said, "I will never let that happen again, I will educate myself and fight since no one else will." The systems in place make it incredibly difficult to change one's trajectory and current life circumstances. Another example is that if a mom goes through months of finally receiving benefits, if she tries to improve her situation, she will immediately lose those benefits. This is a catch-22 that these moms are burdened with, because the systems don't/won't work together for an expectant mom's benefit.

Our Problem Statement

There is a gap between what providers, community resources, and funders are working towards and what moms are experiencing and feel that they need.

Many of the intentions between expectant moms and those who serve them are the same. In general, all parties want a healthy baby delivered full-term, to be empowered to make choices, and options to make a mom's life easier. There is, however, a misalignment of expectations and experiences in many services that are provided for expectant moms.

Expectant Moms

Are confused about what they need to know, what's normal, and where to go.

Clinical Providers, Community Resources, & Funders

Provide a broad range of perinatal services and truly care about creating a great experience for women.

Ecosystem of Stakeholders

"There's really no such thing as the 'voiceless'. There are only deliberately silenced, or the preferably unheard"

- Arundhati Roy, Author & Activist

Voice

All industries, government sectors, and non-profits collect voice in some manner. Whether it is through passive strategies like community needs assessments or more active strategies such as participatory decision making, it is a priority of many organizations. However, there is still a disconnect with people feeling their voices are not heard or not represented. Based on what we learned from the people we interviewed, the following frameworks and insights put forward some opportunities to develop a more active approach to elevating voice.

Key Stakeholders

As voices are elevated and amplified, it's important to consider the ecosystem of where that message is going and how it is being received. In Paterson, the perinatal health ecosystem consists of four main stakeholder groups:

1. Moms & Pregnant Women

Includes Black and brown women living in Paterson who are currently pregnant and/or already have children. We also include the women's family support system, including dads, grandparents, and extended family and friends.

2. Community Resources

Includes the community organizations based in Paterson that provide services and resources for expectant moms and parents.

3. Clinical Providers

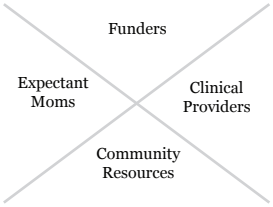
Includes OBGYN physicians, nurse midwives, nurses, and other ancillary staff in the outpatient and inpatient clinical settings.

4. Funders

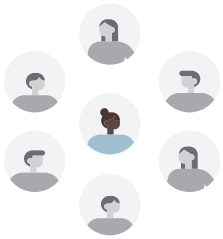
Includes foundations, mostly based in NJ, that provide funding for perinatal health initiatives and services in Paterson.

Developing a Framework

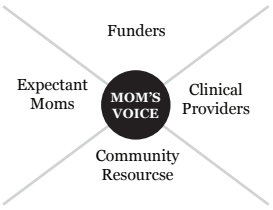
To better understand and speak to the complexity a mom must navigate, we developed a diagram mapping the keystakeholder groups.



Many times this ecosystem is represented with the moms in the middle of a circle and all of the stakeholders surrounding them with their services, care, and/or funding.



We included the moms as an equal stakeholder group rather than a group of people receiving a service, and to push the concept further, we have centered all stakeholders around the mom's voice. Elevating a mom's voice shows that they should be the drivers of this ecosystem.



It also emphasizes the importance of not only identifying and understanding the mom's circumstances and needs, but also hearing their lived experiences and desires for how they want to receive better care and resources for their families.

To achieve our goals, we must work to elevate and center our solutions around an expectant mom's voice.

The Stakeholder Map Centered on the Moms' Voice

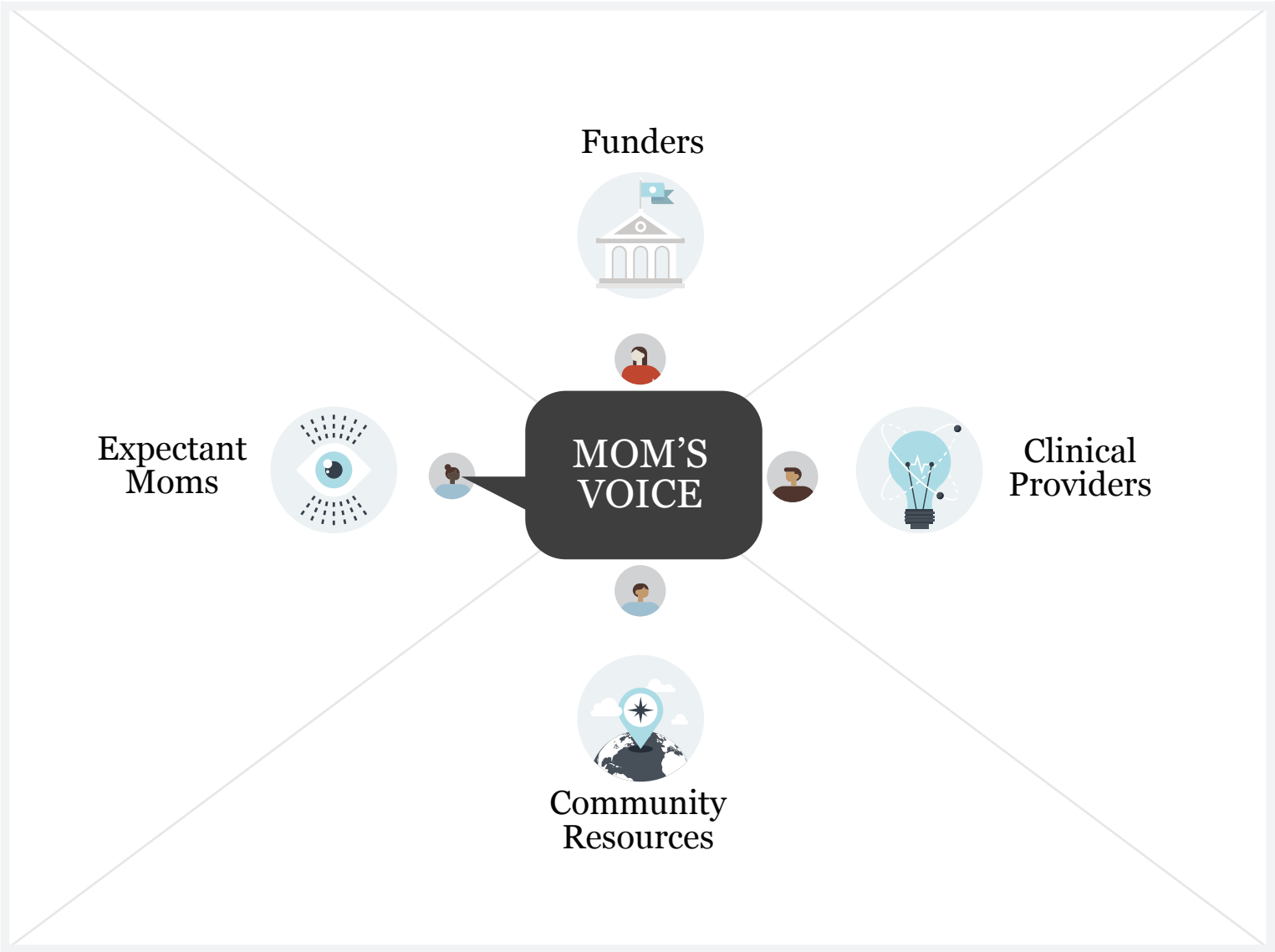
A stakeholder map visualizes the ecosystem in which a product or service operates from a specific perspective.

It helps to understand who is involved, to reveal existing formal and informal relationships between stakeholders, to identify frictions between them, and to find new business opportunities by establishing new relationships, fostering existing ones, or creating alternatives.

Designing Resilient Systems

With a stakeholder map you can easily identify relationships or partnerships that could be formed so that your organization leverages several parts of a system and does not rely just on one.

Stakeholder Map



Expectant Moms Inter-relationships

Other Moms:
Learn from each other and build the community of Paterson

Community Resources:
Partner to find resources they need

Clinical Providers:
Attend clinic to have a healthy baby

Funders:
Receive services supported by funders & may also engage to tell them what they need

Community Resources Inter-relationships

Moms:
Provide resources to moms

Other Community Resources:
Work together to ensure community is being served

Clinical Providers:
Share with clinics resources they can provide for moms in need

Funders:
Receive grant based funding to secure resources needed for moms

Clinical Providers Inter-relationships

Moms:
Form bonds during prenatal care to ensure a healthy pregnancy and baby

Community Resources:
Connect mothers to groups to provide additional support

Other Clinical Providers:
Work as a team to make sure optimal care is delivered

Funders:
Partner to implement new services through funding programs

Funders Inter-relationships

Moms:
May connect via grant programs

Community Resources:
Partner to implement community-based programs and services

Clinical Providers:
Partner to implement new services through funding programs

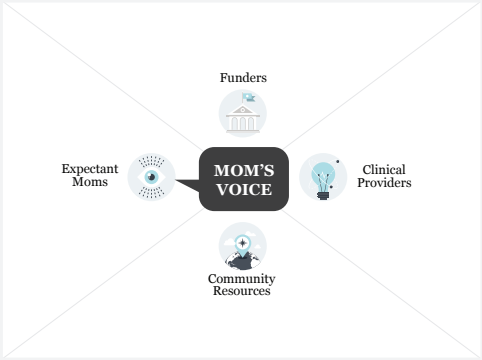
Other Funders:
Collaborate to exchange best practices and strategies for program sustainability

Key Stakeholders

An Ecosystem

A stakeholder is an individual person, a group, an organization that has a certain interest in or a relationship to a specific topic or business.

Stakeholder maps can be used to analyze and understand who is involved in a problem space, and how these people, organizations and aspects are connected. Understanding their perspectives and how they are connected can help to better manage the different expectations.



Relationships

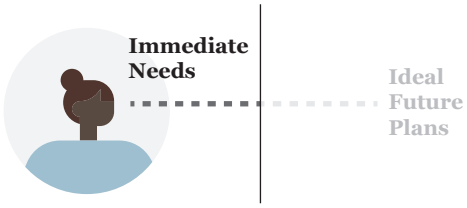
Stakeholders have certain relationships with each other. In many cases, a transaction or value exchange takes place between them. Use the stakeholder map to illustrate these relations. This will help you to see which stakeholders are connected, and to discover lacks or synergies.

A Expectant Mom's Perspective

The group of moms we met with were representative of what many expectant moms in Paterson's highest risk zip codes experience during their pregnancy journey. A common thread we found is that many of these expectant moms do not feel seen or heard. They do not feel empowered, they feel a lack of human compassion, and they are often struggling with many other life/systemic concerns.

How is an expectant mom expected to plan, if it's hard to see past today? We heard: why should I plan when I'll probably shot dead in the next year?

While not every expectant mom has this exact concern, every mom is navigating the cost-benefit of each decision she makes. A mom may miss her appointment because she values working to feed her family over seeing her doctor.



If you want to communicate with an underresourced expectant mom, care must be taken in considering her individual cost-benefit analysis.

Key Stakeholders

Community Resource Perspective

Meeting with community resource groups that focus on services for expectant moms along their pregnancy journey, we found that each is passionate about improving a mom's life, and wants to get them services that they need. Many seek to go beyond their job duties to meet a mom's needs. We found that moms approached our interviews with expectations that reflected the service delivery of the community resource that referred them. If a community resource was more transactional, the mom would more so ask about an incentive; if a community resource was more relational, the mom immediately had more of a rapport and were more willing to have an in-depth conversation.

One is not superior to another. There are benefits and disadvantages to both.

T ← → R

Transactional: strictly providing a product or service	Relational: providing a service with a long-term relationship
↑ volume ↓ cost ↓ time investment	↓ volume ↑ cost ↑ time investment
Some expectant moms just want what they've come for, and don't want a relationship.	Some expectant moms don't want to feel like a number, and want to build a relationship.

Questions to ask to see where your group lies on the Transactional and Relational spectrum:

1. Does a mom know the name of someone at the Community Resource?
If a mom knows the name she engages with, this suggests the CR is more relational.

2. Does the design of the physical & virtual space evoke feelings of an office or a home?
If a mom feels like they are in an office, this suggests the CR is more transactional

Clinical Caregiver Perspective

After meeting with clinical providers at SJH, we found that they are truly dedicated to providing the most compassionate and comprehensive care to their patients. They are mission oriented and are proud to work for an organization that doesn't turn anyone away based on ability to pay for the services. Working cohesively as a team, they follow and support patients outside of their visits in the office to make sure they can answer questions and come to appointments. At the same time, they feel the pressure of working inside of a system that is, in large part, still volume based and is set up to provide episodic care. The OBGYN clinical field is one of the most intensive practices of medicine as it includes surgery, pregnancy care, gynecologic care, oncology, and primary health care for women. In order to maintain consistent quality, clinicians base their high-level care plan for patients around national guidelines.

With providers and patients sharing the same goal for a healthy pregnancy and baby, it can be frustrating for providers when patients are non-compliant with the plan of care, which can set up challenges within the clinician/patient relationship. The diagram below depicts this shared goal but also emphasizes the importance of communication.

An expectant mom meeting with clinical providers is an episodic experience.

CLINICAL PROVIDERS

X

EXPECTANT MOMS

Communication is vitally important.

Funders Perspective

Having met with various funders, it is clear that they take their role in the perinatal health ecosystem as leaders and investors very seriously. They understand the power and opportunity that money can bring to a community and/or program. They are also keenly aware of the need to invest well in areas of focus that will bring the biggest return. The "return" is often measured in terms of measurable outcomes including pre-term birth rates, low risk C-section rates, and number of women breastfeeding. In order to show improvement in these statistics, they tend to focus in on very specific geographic, demographic, and service level initiatives and programs. Funders are driven by the desire to make systems-level changes, and therefore must go deep into certain areas and stay invested long enough to bring their programs to sustainability. To that end, they are extremely strategic and visionary when it comes to ways to build sustainability, especially through state policies, laws, and Medicaid coverage.

By design, funders are typically one step removed from the recipients of the services they fund, relying on their grantees to deliver on the program objectives. The framework below illustrates how funders might create more of a through line that incorporates a mom's voice in order to measure impact.

ROI	+	**HCROI**
ROI: 1. # of People Served 2. Revenues/Cost 3. Health Outcome Data		Human Centered ROI: 1. Satisifaction Surveys 2. Real-time feedback 3. Net Promoter Score

Opportunity Spaces

Opportunity Spaces

To achieve our goals, we must work to elevate and center our solutions around an expectant mom's voice.

Building on the insights from the moms and all of the stakeholders in the ecosystem, we have identified three opportunity spaces to begin responding to the call to action of elevating the mom's voice: self-efficacy, listening & response, and advocacy.

While these are represented as individual opportunity spaces, we recognize they are not mutually exclusive. In fact, they are deeply connected and work in a cyclical nature. As moms experience more self-efficacy and use their voice, they are expressing needs that are received by other stakeholder groups through listening and responding.

Once needs are heard, the ecosystem works together to put these in place through advocacy.

1. Self-Efficacy

Psychologist Albert Bandura, describes self-efficacy as a person's belief in their ability to succeed in a particular situation.[23] These beliefs are made up of how people think, behave and feel. A key way to increase self-efficacy is by building skills and mastery through experiences. Observing others such as yourself succeed in similar situations is also critical to building self-efficacy.

WHAT IT IS

Providing opportunities for a person to build their skills and mastery through experiences with both mentor and peer support.

WHAT IT ISN'T

Dehumanizing someone as an "other", or someone that must be served rather than an active participant. This can be done even with good intentions. This leads to disconnected approaches that can build someone up, but it doesn't create systems for them to be successful.

ANALAGOUS EXAMPLES

Alcoholics Anonymous support groups
Graduate education programs

2. Listening & Response

Active listening is the process of listening attentively while someone else speaks, paraphrasing and reflecting back what is said, and withholding judgment and advice. It is a technique used to promote healthy communication between individuals. A step further is move beyond listening by providing an appropriate response that includes an action step to close the loop.

WHAT IT IS

Opening emotional and mental safe spaces for people to share their experiences and ideas to the organizations and/or people that can implement changes.

WHAT IT ISN'T

Finding a surrogate person or group to represent the needs of your users. Holding another focus group or non-representative community advisory committee.

ANALAGOUS EXAMPLES

Parent/Teacher Association
Parish/Pastoral Councils

3. Advocacy

The Alliance for Justice defines advocacy as any action that speaks in favor of, recommends, argues for a cause, supports or defends, or pleads on behalf of others.[24] There are very powerful examples of advocacy to elevate voice in grassroots social justice movements, in policy development, and in more individual examples (i.e. legal defenses).

WHAT IT IS

Connecting to end users while speaking in favor of, recommending, arguing for, supporting/defending, or pleading on the behalf of them.

WHAT IT ISN'T

Adding another link in a chain holding a broken system. This often occurs by not understanding the nuanced needs and what is already being done in a community.

ANALAGOUS EXAMPLES

Governmental lobbyists for a company
Attorney representing a case
Black Lives Matter campaigns

What Next?

We're not going to solve problems the way we've always done it, or else we'd have already solved them.

Sharing Out

The goal of this share out was to have a facilitated dialogue about which of the three opportunity areas to activate in our next phase.

Fundamentally, what we've done with all of our perinatal health services and ecosystems to date has been built on a network of experts (outside/in), but we need to push further by elevating the mom's voice (inside/out) to continue bridging the current gap and building more effective and sustainable services.

Our first step was a shareout of this report on September 27, 2021 to the key stakeholders we identified in the perinatal health ecosystem.

Worksheet

Your Name:

A worksheet we asked various perinatal health stakeholders to fill out on our September 27, 2021 shareout.

Which best describes you? (Choose one)

Drawing 1

Drawing 2

We're not going to solve problems the way we've always done it, or else we'd have already solved them.

What are the opportunities?

Define

Pick one thing you're working on that you believe help's expectant moms?

What problem does it solve?

Why is that important?

Learn

We heard from moms about how they are experiencing services in Paterson.

Moms do not feel seen or heard

They don't know what they need to know until they need to know it, at which point it's too late.

They feel they are being seen as a pregnant person of color first, rather than a human.

Moms have difficulty managing and navigating the existing systems

They are forced to choose between immediate life and future pregnancy care decisions, and these choices aren't made voluntarily.

They carry the full weight of fighting and advocating for their own care.

Make

Based on the learnings, brainstorm unconsidered, new opportunities:

1.
2.
3.
4.
5.
6.
7.

Map the number to the Venn Diagram

Conclusion

Debriefing

Over the past year, we have seen communities struggling to cope with an unprecedented pandemic. We have seen healthcare workers be heroes as well as suffer from long-term post-traumatic stress disorder. We have seen expectant moms try to do the best they can with overburdened systems that were already difficult to navigate.

Through this, we applied our human centered innovation approach to better understand the perinatal health ecosystem in Paterson.

We worked with many community-based organizations to understand the services and the unique perspectives needed to provide love and care to Paterson moms.

We communed with Paterson moms and dads to provide a safe space while lending an ear to understand their experiences while seeking opportunities to meet their needs.

We met with SJH OB/GYN clinicians to learn how they're able to maintain passion, drive, and empathy while caring for moms with difficult prenatal challenges in New Jersey.

We sat with some of the most driven and caring foundations in New Jersey to understand what motivates and drives their strategies and funding.

Summary

First and foremost, women in Paterson are people: each with their own beliefs, culture, and biases which inform their perception and motivation. While the pregnancy journey is centered on the mom, other various stakeholders are critically involved either directly or indirectly to impact the mom's care, all of whom are united by their goal to have healthy births for expectant moms.

We sought to create a framework that represents how each stakeholder group can work together, with the mom's voice in the center, to make the most effective and sustainable changes to perinatal health in Paterson.

If we are able to meet expectant moms where they are, and in ways that they want to engage; if we can work together to solve for the experience gaps everyone knows exist; if we can take the first steps to ask ourselves to change, and not ask expectant moms to change, we will not only elevate a mom's voice, but also begin the long journey to racial health equity.

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St. Joseph's Health
THE CENTER FOR INNOVATION

2019-2021

The Center for Innovation at SJH

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