Hui International™

Perinatal Health Equity and Technology Convening

Creating a Baseline for Future Conversations and Collaborations

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Our Hui International team is deeply aware that our race, gender identities, socio-economic and cultural backgrounds have formed inherent biases within each of us. It is with this understanding that we strive to create a process and project where all voices matter. We believe perinatal health equity is possible through honest and multifaceted conversations, interdisciplinary commitment, innovation, and diverse stakeholder collaboration.

Lucy Morse Roberts

CEO, Hui International

Hui International – Where All Can Blossom and Thrive

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Convening Purpose

Hui International's mission is to create safe, stable, nurturing, and empowering relationships and environments where all can thrive. We focus on achieving our mission through parent/caregiver programs, podcasts, and health and wellbeing projects. The purpose of this project is to explore the possibilities of improving perinatal health equity through technological innovations. The emergence of artificial intelligence (AI) is transforming every aspect of how we operate in the world. We see this transformation as an opportunity to improve accessibility to health and wellbeing resources, reduce disparities, and improve outcomes. We envision a healthcare system free from structural racism and gender biases that is more accessible to all.

At Hui International, we recognize that effectively applying technology to enhance well-being requires the input of experts in perinatal health, technology, and those with lived experiences. To this end, we convened a small group of specialists from various fields to explore perinatal health needs, potential technological solutions, and possible collaborations.

Our first convening focused on the following questions:

#1

"What are the barriers to perinatal health equity?"

#2

"How can technology be used to improve perinatal health equity?"

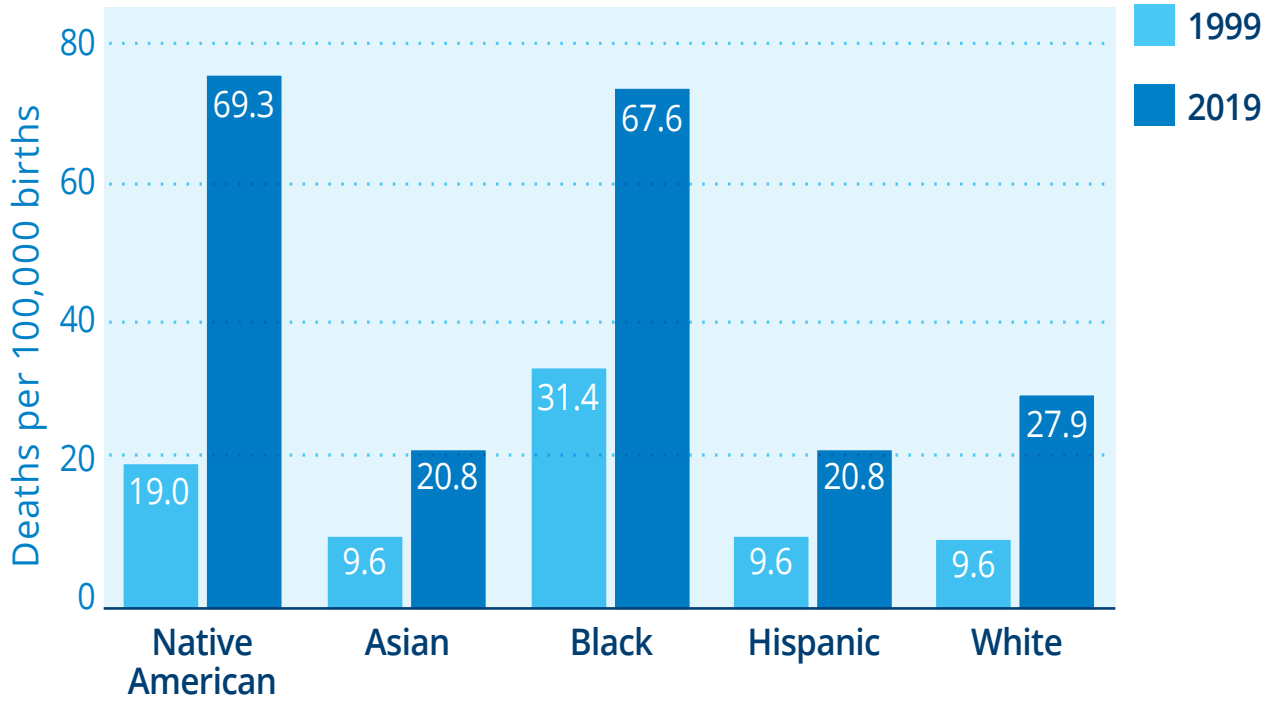
With these two prompts we created a baseline for future discussions and potential collaborations.

Background

Healthy perinatal care sets the foundation for physical, emotional, and cognitive health and well-being throughout one's lifespan. Ensuring healthy, thriving communities necessitates prioritizing perinatal health. Alarmingly, the United States' maternal mortality rate has more than doubled over the past two decades[1]. This tragic trend disproportionately affects women of color, ***(see Figure 1)*** with black and Native American and Native Alaskan women being 2-3x more likely to die from pregnancy or birth complications than white women[2].

Figure 1

Maternal mortality rates in 1999 versus 2019, by race [3]



** Data from Fleszar et al., 2023. "Asian" includes Pacific Islander and Native Hawaiian. "Native American" includes Native Alaskan.*

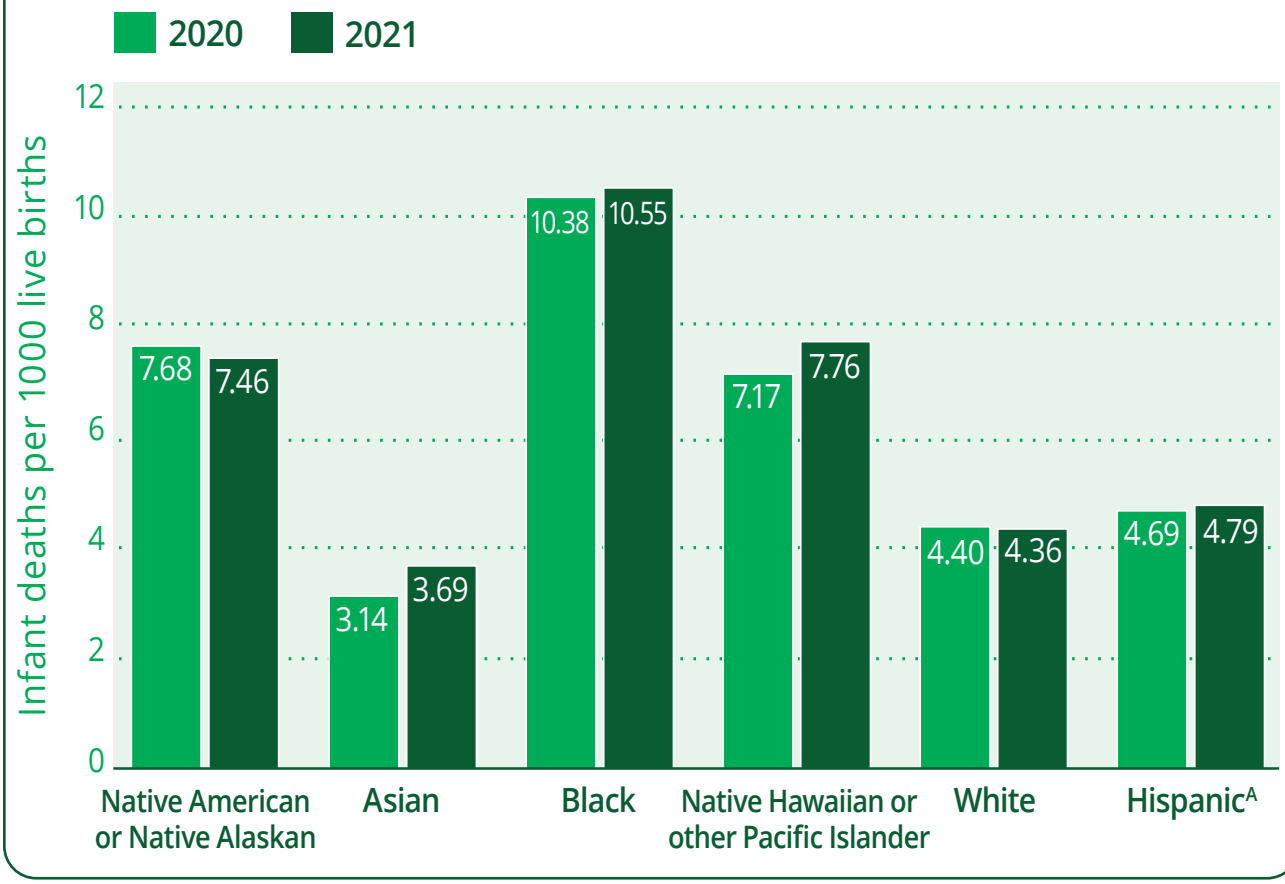
1 https://jamanetwork.com/journals/jama/article-abstract/2806661?resultClick=1

2 https://everymothercounts.org/unitedstates

3 https://www.cdc.gov/nchs/data/hestat/maternal-mortality/2020/maternal-mortality-rates-2020.htm

Historical injustices have fostered a climate of distrust among marginalized communities, complicating efforts to increase access to care. Trust is crucial for individuals to engage in health-promoting behaviors and seek care. Women from Native American, Black, and Hispanic backgrounds, as well as those facing social complexities and injustices, are at heightened risk for poor perinatal outcomes, including preterm births and maternal and perinatal morbidity and mortality[4] ***(see Figure 2)***.

Figure 2
US Infant Mortality by race from 2020-2021 [5]



A People of Hispanic origin may be of any race.
Source: National Center for Health Statistics, National Vital Statistics, linked birth/infant death file.

4 Khan, Z., Vowles, Z., Fernandez Turienzo, C. et al. Targeted health and social care interventions for women and infants who are disproportionately impacted by health inequalities in high income countries: a systematic review. Int J Equity Health 22, 131 (2023). https://doi.org/10.1186/s12939-023-01948-w

5 https://www.cdc.gov/nchs/data/nvsr/nvsr72/nvsr72-11.pdf

Additionally, the U.S. healthcare system harbors biases that create barriers to care, evident in public health information that

relies heavily on literacy skills and neglects oral and visual methods. An analysis of over 1,000 studies shows that current health education materials fail to effectively communicate with their intended audiences[6]. Compounding the issue is the complex and fragmented nature of the healthcare system, making it especially difficult for individuals with limited English proficiency and diverse cultural backgrounds to navigate[7]. Addressing these systemic issues and fostering trust in healthcare is essential to improve perinatal outcomes and ensure healthier futures for all communities.

Discussion Summary

1. Build and Be Worthy of Trust

A dominant barrier to perinatal health equity is the lack of trust in the healthcare system due to systemic racism[8]. The resulting low psychological safety experienced by patients, particularly those from minority or immigrant

6 Rudd, Rina. "Health Literacy Research Findings and Insights: Increasing Organizational Capacity for Shaping Public Health Messages." CDC. https://youtu.be/4N8QxVkjHRY

7 Girardi, G., Longo, M. & Bremer, A.A. Social determinants of health in pregnant individuals from underrepresented, understudied, and underreported populations in the United States. Int J Equity Health 22, 186 (2023). https://doi.org/10.1186/s12939-023-01963-x

8 Learn more about the negative psychological wellbeing on black families in "Weathering & Age Patterns of Allostatic Load Scores"

communities, has detrimental health consequences[9]. Firstly, individuals are less likely to engage with or seek out services, with

some declining aid even when it is offered. Secondly, women in underrepresented communities continue to experience a lack of perinatal health information and access to care. To address these challenges, the healthcare system must become worthy of trust through engaging in activities that dismantle systemic biases, such as bridging diversity in culture and language.

2. Break Down Cultural and Linguistic Barriers

Bridging cultural and linguistic barriers is crucial in addressing healthcare inequities. The healthcare system often relies on text-heavy, jargon-rich informational delivery platforms, which assume a high level of literacy. This approach leaves pre- and non-literate and non traditionally educated learners uninformed. For immigrants and the undocumented, this issue is exacerbated by their unfamiliarity with the U.S. healthcare system. Efforts to bridge these barriers include translated resources[10] and community-based programs targeting specific populations. Ultimately, employing communication methods that resonate with diverse cultural and linguistic backgrounds is a crucial initial step to achieving health equity and creating a healthcare system that is trustworthy and accessible.

9 2020 Narrative Review on "Involvement in maternal care by migrants and ethnic minorities."

10 2020 systematic review on "Implications of Language Barriers for Healthcare"

3. Partner with Existing Community Networks and Foster New Networks of Support

An essential aspect of establishing a more accessible pipeline between communities and healthcare systems is the integration of local communities[11]. This can be achieved through various means, including physical outreach efforts such as establishing smaller clinics or implementing traveling healthcare programs. Additionally, fostering community partnerships, particularly with local elders, "aunties", and respected centers, can serve as catalysts for health initiatives. This approach is exemplified by emerging programs led by the Agency for Healthcare Research and Quality (AHRQ).

4. Foster Community

Health decisions largely occur within homes and beyond traditional healthcare settings[12], highlighting the need to foster support networks. Health services must intervene proactively during crucial times, such as the early stages of pregnancy and during the lactation period. This involves providing education on perinatal health, ensuring women have access to accurate and comprehensive information, and articulating the importance of community involvement in health decisions[13].

Equally important to this endeavor of network building is helping women forge connections with other women, irrespective of location. This can be achieved

11 2023 Scoping Review on "Addressing Health Disparities through Community Participation"

12 Learn more about Social Determinants of Health and how they are changing public health landscape

13 Read 2024 Narrative Review that imagines a "Human Rights Based Approach to Care"

by offering platforms of communication that connect women facing similar perinatal challenges, enabling them to share experiences, offer mutual support, and build a sense of unity and solidarity beyond their immediate communities. Consider the IRTH app, designed to connect women of color by providing access to reviews of pediatric physicians from other women within their

own ethnic community. Through these collective efforts, we can establish a healthcare system that truly serves and uplifts every individual woman and community.

5. Restructure the Healthcare System

The United States healthcare system faces numerous challenges, including poor organization, high healthcare premiums, and limited service in rural areas[14]. Despite having the highest maternal healthcare expenditure per capita[15], the United States has the highest rates of infant and maternal mortality among high-income countries[16]. Care management plans and electronic medical record systems represent key problems in the healthcare system.

a. Medi-Cal Managed Care Plans

Medi-Cal, California's healthcare assistance program, provides support to over a third of the state's residents. Despite its statewide coverage, each of California's 58 counties has the authority to establish its own managed care plan, facilitating services for Medi-

14 2013 Review on US Healthcare

15 https://everymothercounts.org/unitedstates

16 Okobi et al., 2023

Cal beneficiaries through a network of healthcare providers. However, this decentralized approach can lead to restricted access to providers within the managed care plan's network, prolonged wait times, and difficulties in communication

and coordination among providers, ultimately resulting in fragmented care and potential gaps in treatment. A unified state-managed Medi-Cal is a potential solution that could help provide consistent care across counties, simplify transitions, improve communication, and boost efficiency for better healthcare outcomes.

b. Electronic Medical Records

Electronic medical records (EMRs) are digitized versions of patient charts, providing physicians with easy access to a patient's medical history. While EMRs were initially seen as a convenient alternative to paper charts, they often fail to prioritize user experience, making them difficult for physicians to navigate. Additionally, the lack of standardization across EMR systems between hospitals and reluctance from EMR providers to cooperate complicates patient data sharing. In order to allow patients to receive the best possible care, it is imperative that we create an interoperable system of EMRs to allow physicians access to a patient's comprehensive medical history and information.

6. Tech Integration Ideas

Below are additional shared methods for elevating healthcare delivery via the integration of technology:

- Technology can aid in pinpointing

local disparities and fostering dialogue between communities and healthcare providers. Concrete data can turn abstract ideas into actionable solutions for healthcare inequalities.

- Technology is useful for evaluating the effectiveness of programs and providing access to non-traditional methods for pre- and post-assessment comparisons. Get Well Loop digital care platform is a potential platform to model after.
- Currently available social media platforms can be utilized to facilitate more equitable and accessible distribution of information. This can include using YouTube videos like Hui International's work on *The Ulysses Syndrome* and *Ways to Heal* project and/or delivering healthcare information through platforms popular with target communities, such as Tik Tok videos[17] or Instagram posts[18].
- User-friendly digital platforms can facilitate connections among individuals who share similar experiences, as evidenced in the platform designed for individuals with rare diseases, 'Patients Like Me.' Data gathered from these networking platforms can be used to tailor specific programs for communities, as modeled by the IRTH app, which offers services catered to black and brown communities.

17 Tik Tok search for "Maternal, Infant, and Reproductive Health"

18 Example accounts include "MotherhoodUnderstood" & "EveryMomCounts"

Next Steps

Addressing perinatal health equity requires a fundamental change in perspective and a radical shift in the underlying framework of the healthcare system. The convening in May 2024 marked the start of this effort by creating a foundation for future discussions and potential collaborations. However, it is important to acknowledge that the voices of individuals with lived experiences were absent from this meeting. Recognizing this gap, we plan to hold a second convening that includes community partners with lived experiences as well as community leaders and advocates. The inclusion of these voices is crucial, as our work can only be truly relevant and impactful when informed by their expertise, interests, and partnerships. Our goal is to find a common language between partners, identify needs and set goals with those most impacted by disparities, gain a deeper understanding of barriers, and explore opportunities for solutions. Our goal is the genuine transformation of perinatal healthcare so all can blossom and thrive.

Special Thanks to the Following Attendees

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To those who attended, thank you for joining us and contributing to this initiative. For those interested in this vital work, please reach out to Lucy Morse Roberts, Hui International CEO

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Glossary

Health Terms

One finding from our convening is the need to better understand the terms related to each field. Each industry has its own terminology. An expert in one field may not know the verbiage of another. The following glossary contains terms relevant to perinatal healthcare and AI with the hope that knowing these terms will help foster more effective collaborations in the future.

Agency for Healthcare Research and Quality: Reference to specific organization

Antenatal: Pertaining to the period before childbirth; often used synonymously with prenatal

Antenatal Depression: A form of clinical depression that occurs during pregnancy, characterized by persistent sadness, anxiety, and changes in sleep and appetite*

BioBART: (Biomarker And Risk assessment Tool) is a diagnostic tool used to identify and assess biomarkers for evaluating health risks and disease progression*

Breastfeeding: The practice of feeding a baby breast milk, recommended by healthcare professionals for its numerous health benefits for both mother and baby

Capitation[19]**:** A type of healthcare payment system in which a physician or hospital is paid a fixed amount per patient for a prescribed period by an insurer or physician association

Cesarean Section (C-Section): A surgical procedure in which the baby is delivered through incisions made in the mother's abdomen and uterus

19 https://www.verywellhealth.com/capitation-the-definition-of-capitation-2615119

20 https://www.sciencedirect.com/topics/social-sciences/commodification

* ChatGPT

Commodification of Healthcare[20]**:** Description of how people, products, and services in healthcare are utilized as a commercial product and mass-produced, often at the cost of authenticity

Doula: A trained professional who provides physical, emotional, and informational support to women before, during, and after childbirth

Eclampsia: A severe complication of preeclampsia characterized by the onset of seizures in a pregnant woman with high blood pressure, often leading to serious health risks for both mother and baby*

Electronic Medical Record (EMR)[21]**:** Electronic record of a patient's medical history including patient data, diagnosis, and treatment

Equity[22]**:** Refers to systems and practices that are fair and just, based on a recognition of individual differences and/or sociopolitical contexts that disproportionately advantage or disadvantage some people more than others

Fetal Health: The health and development of the fetus during pregnancy

Gestational Diabetes: A type of diabetes that develops during pregnancy, characterized by high blood sugar levels that can affect the health of both mother and baby*

Home Visiting Programs: Community-based interventions where trained professionals provide support, education, and resources to families in their homes to promote child health, development, and well-being. These programs aim to improve maternal and child health outcomes by addressing various needs, including prenatal care, parenting skills, and connections to other community services*

Lactation Consultant: A healthcare professional trained to assist mothers with breastfeeding

Lactation Period: Period of milk production and secretion (aka: breastfeeding)

21 https://digital.ahrq.gov/electronic-medical-record-systems

22 https://www.aspanet.org/ASPA/ASPA/About-ASPA/Social-Equity-Center/Definitions.aspx

23 https://seniors.insurance.ca.gov/hc/Medicare-and-MediCal.cfm#:~:text=Medi%2DCal%20is%20California's%20Medicaid,eligible%20participants%2065%20or%20over.

* ChatGPT

Maternal Health: The health and well-being of pregnant and postpartum women, encompassing physical, mental, and social aspects

Medicaid[23]**:** A federally funded insurance program for citizens over the age of 65 meeting certain eligibility

Medi-Cal[24]**:** California's Medicaid system which provides certain medical services to eligible children and adults

Midwifery: The practice of assisting women in childbirth, including prenatal and postnatal care, often emphasizing a more holistic and natural approach

Morbidity[25]**:** Refers to having a disease or a symptom of disease, or to the amount of disease within a population; also refers to medical problems caused by a treatment

Mortality[26]**:** Death rate, or the number of deaths in a certain group of people in a certain period of time

Neonatal Health: The health of newborn infants, typically referring to the first 28 days of life

Obstetrician: A physician who specializes in obstetrics, including prenatal care, childbirth, and postpartum care

Obstetrics: The branch of medicine concerned with childbirth and the care of women giving birth.

Perinatal[27]**:** The period surrounding childbirth, typically encompassing the last few weeks of pregnancy and the first few weeks after birth

Perinatal Health Equity[28]**:** Relates to the absence of disparities in

24 https://www.coveredca.com/health/medi-cal/

25 Cancer.Gov

26 Cancer.Gov

27 Partially generated by ChatGTP

28 WHO

controllable areas of health needs for women during pregnancy through post delivery

Perinatologist: A medical doctor who specializes in high-risk pregnancies and fetal medicine

Placenta Previa: A condition where the placenta covers the cervix either partially or completely, which can cause severe bleeding during pregnancy and delivery*

Postnatal: Referring to the period after childbirth, including both the immediate postpartum period and the weeks or months following

Postpartum Depression: A mood disorder that can affect women after childbirth, characterized by feelings of sadness, anxiety, and exhaustion

Preeclampsia: A pregnancy complication characterized by high blood pressure and signs of damage to other organs, most commonly occurring after 20 weeks of gestation*

Premature Birth: Birth that occurs before 37 weeks of pregnancy have been completed

Prenatal: Relating to the period before birth, typically referring to the care and medical attention given to pregnant women

Program of All Inclusive Care (PACE) Programs: Program offered to eligible members of Medical and Medicaid

Promotora: A community health worker who provides culturally and linguistically appropriate health education, outreach, and support to underserved communities*

Stillbirth: The birth of a baby who has died in the womb after 20 weeks of pregnancy

VBAC (Vaginal Birth After Cesarean): A delivery method for women who have previously had a cesarean section but are attempting to deliver subsequent babies vaginally

* ChatGPT

Artificial Intelligence Terms

AI Ethics: The study of ethical issues arising from the design, development, deployment, and use of AI systems. It involves considering the societal impacts, fairness, accountability, transparency, and other ethical dimensions of AI technologies.

Algorithm: A set of rules or instructions designed to solve a specific problem or perform a specific task. In the context of AI, algorithms are used to train machine learning models and make predictions or decisions based on data.

Artificial Intelligence (AI): The simulation of human intelligence processes by machines, especially computer systems. These processes include learning (the acquisition of information and rules for using it), reasoning (using rules to reach approximate or definite conclusions), and self-correction.

Automation of Systems[29]**:** The technique of making an apparatus, a process, or a system operate automatically

Bias: Systematic errors or prejudices in data or algorithms that can lead to unfair or discriminatory outcomes. Addressing bias in AI systems is a critical consideration in AI ethics and responsible AI development.

Big Tech[30]**:** major multinational technology companies collectively as a sector of industry

Computer Vision: A field of AI focused on enabling computers to interpret and understand visual information from the real world. It involves tasks such as object recognition, image classification, and image segmentation.

Curated AI Content: Digital material generated or refined by artificial intelligence and selected or organized by human curators to ensure relevance, accuracy, and quality. This process combines the efficiency of AI with human judgment to create engaging and reliable content for various audiences*

Data Mining: The process of discovering patterns and relationships in large datasets. It involves techniques from

29 https://www.isa.org/about-isa/what-is-automation#:~:text=The%20dictionary%20defines%20automation%20as,delivery%20of%20products%20and%20services.%E2%80%9D

30 Oxford Dictionary

* ChatGPT

machine learning, statistics, and database systems to extract useful information from raw data.

Deep Learning: A subset of machine learning that uses neural networks with many layers (deep neural networks) to learn representations of data. It has been particularly successful in tasks such as image and speech recognition.

Ethical AI: The practice of designing and deploying AI systems in a way that is fair, transparent, accountable, and respects fundamental human rights and values. Ethical AI aims to mitigate potential harms and ensure that AI benefits society as a whole.

Explainable AI (XAI): The ability of AI systems to explain their reasoning, decisions, and predictions in a human-understandable manner. XAI is important for building trust and transparency in AI systems, especially in high-stakes applications.

Huggy Face: An AI and machine learning platform that provides tools and resources for building, training, and deploying machine learning models*

Hyperemesis Gravidarum: A severe form of morning sickness that involves persistent nausea and vomiting during pregnancy, often leading to dehydration and weight loss*

Machine Learning (ML): A subset of AI that provides systems the ability to automatically learn and improve from experience without being explicitly programmed. It focuses on the development of computer programs that can access data and use it to learn for themselves.

Natural Language Processing (NLP): A field of AI focused on the interaction between computers and humans through natural language. It involves tasks such as language understanding, language generation, and machine translation.

Neural Network: A computational model inspired by the structure and function of the human brain, composed of interconnected nodes (neurons) that process information. Neural networks are a fundamental component of deep learning.

31 https://www.in.gov/fssa/ddrs/files/003_Comp-Quality-Improv-Plan-Guide-Ex-BQIS-01182018.pdf

* ChatGPT

Quality Improvement Plan[31]**:** An organization's framework for developing and improving processes

Reinforcement Learning: A type of machine learning where an agent learns to make decisions by interacting with an environment. It receives feedback in the form of rewards or penalties and adjusts its actions to maximize cumulative reward over time.

Small Tech: Innovative and inexpensive technological solutions

Supervised Learning: A type of machine learning where the model is trained on a labeled dataset, meaning each input data point is associated with a corresponding output label. The model learns to make predictions based on input-output pairs.

Unsupervised Learning: A type of machine learning where the model is trained on an unlabeled dataset and must find patterns or structures in the data on its own. It aims to learn the underlying structure of the data without explicit supervision.

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