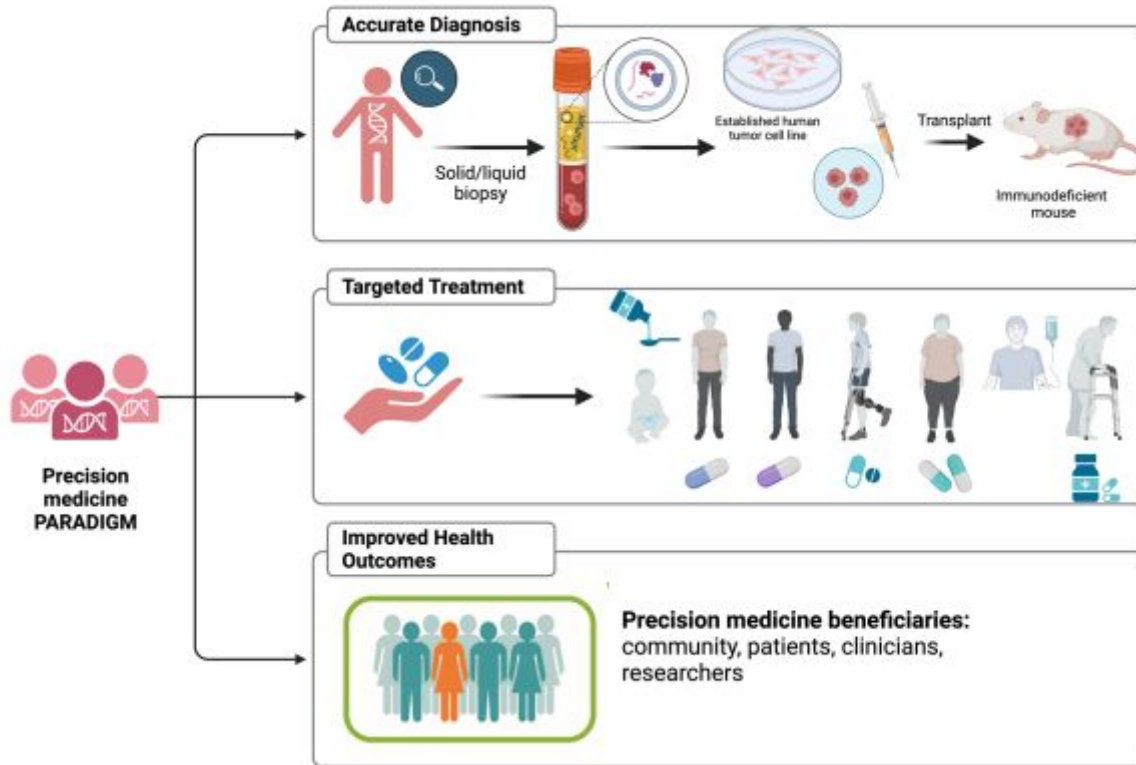


# Ethical Challenges of AI-Driven Personalized Medicine: Are Patients Aware of How Their Genomic Data is Used?

RICHARD LUC, MS MBA  
CANDIDATE, M.S. DATA SCIENCE  
EASTERN UNIVERSITY, '25G  
UNIVERSITY OF MAINE, '12, '14G, '17G

# OVERVIEW



**FIGURE 1**

# OVERVIEW

## INTRODUCTION

- Importance and relevance of ethical challenges in AI-driven personalized medicine
- Are patients aware of how their genomic data is used?
- Black boxes in AI-driven healthcare - recommendations without explanations?

## KEY THEMES

- Patient awareness and informed consent
- Data privacy and ownership
- Transparency and data sharing
- Equity and bias in AI models

## CASE STUDY 23andMe

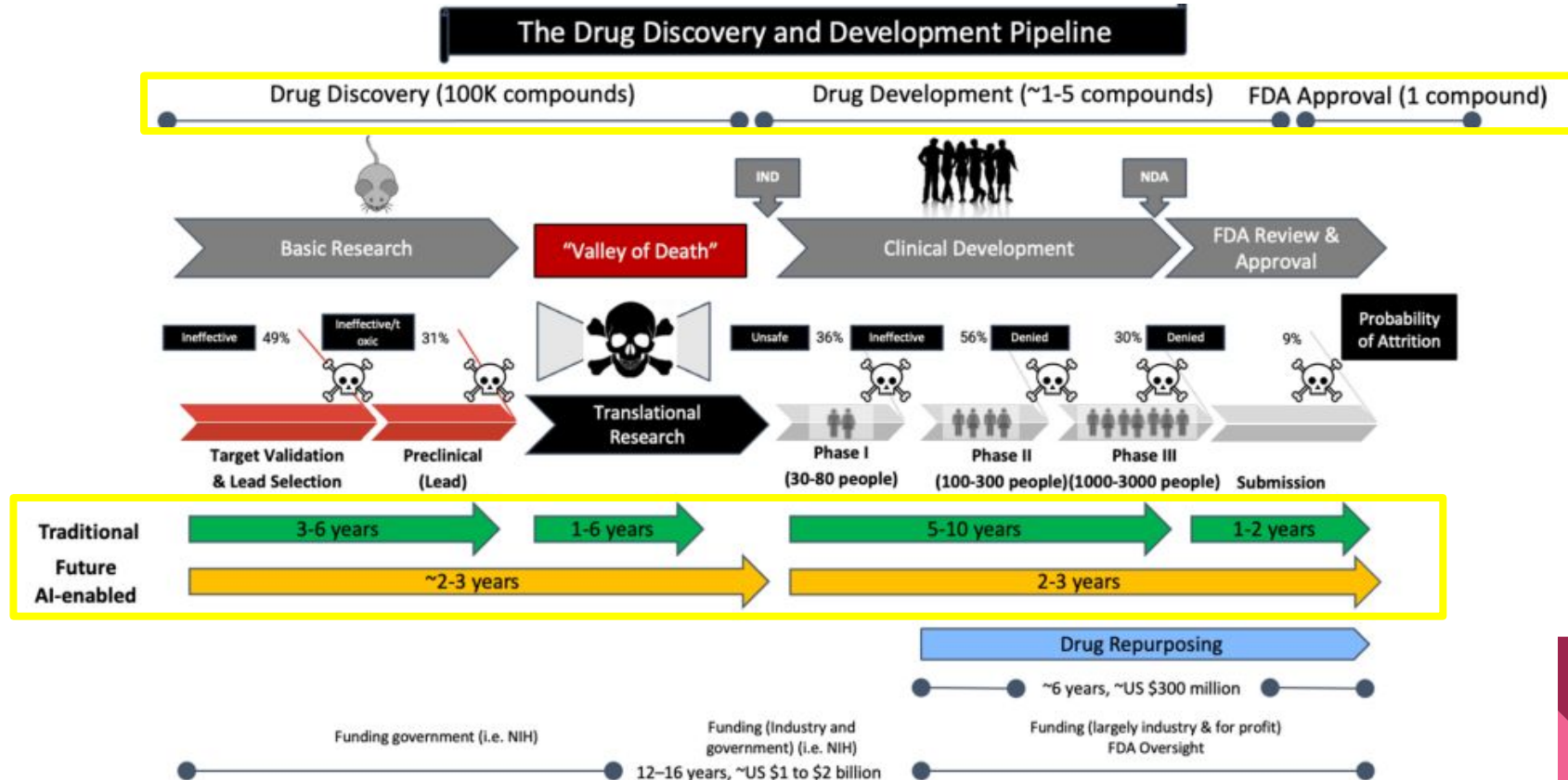
- 23andMe filing for bankruptcy: Is your genetic data safe?

## CONCLUSION

- Summarize ethical challenges identified by research and literature
- Directions for future research

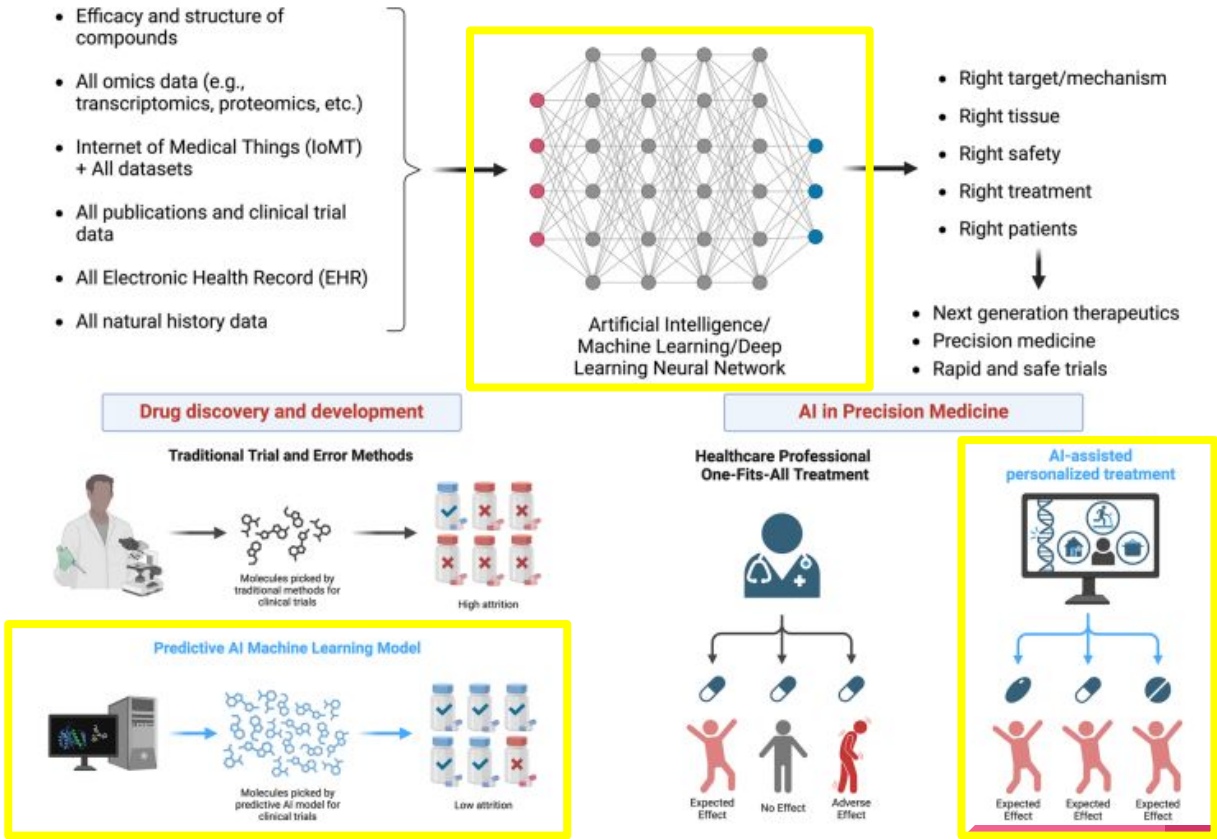
# INTRODUCTION

## INTRODUCTION



Source: Carini and Attila (2024)

# INTRODUCTION



# PATIENT AWARENESS AND INFORMED CONSENT IN AI-DRIVEN GENOMICS

# PATIENT AWARENESS AND INFORMED CONSENT IN AI-DRIVEN GENOMICS

## ETHICAL DILEMMA

- Awareness that genomic data is being used in AI healthcare
- Manner in which genomic data is collect and processed
- Educated on and obtaining informed consent

## POINTS OF CONSIDERATION

- Consent issues, sharing of data, misuse potential
- Multilayer understanding and trust in AI - need for clear communication and consent process

## QUESTIONS

- Are current consent protocols enough in AI healthcare?
- Are there ways to improve communication regarding informed consent?



# PATIENT AWARENESS AND INFORMED CONSENT IN AI-DRIVEN GENOMICS

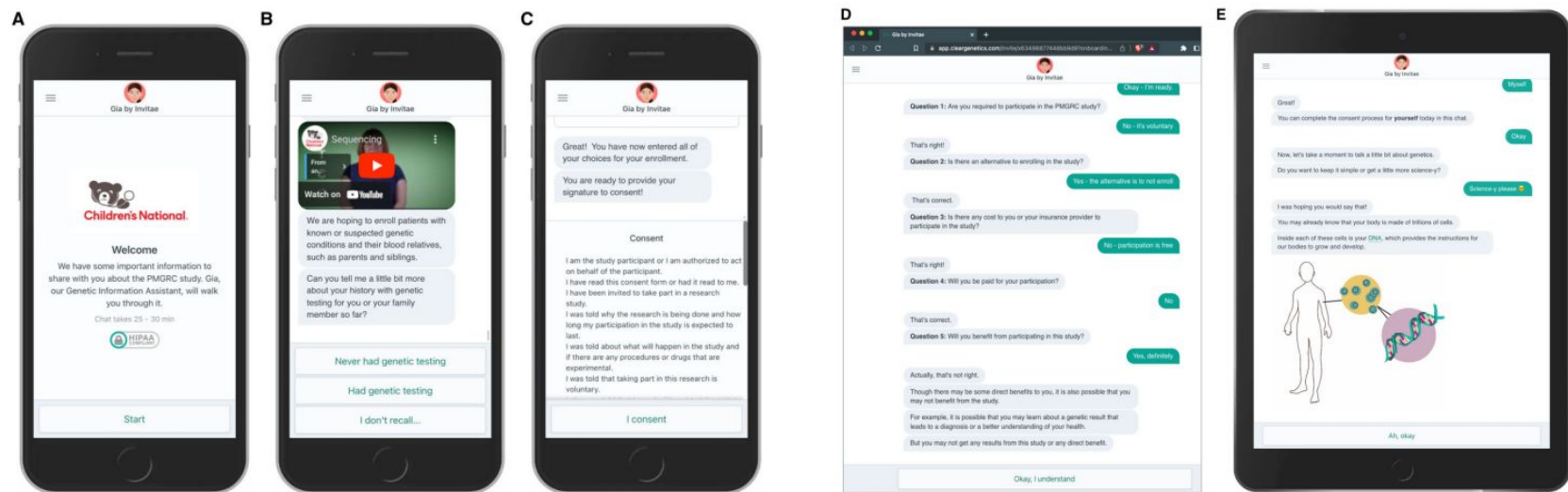


FIGURE 4

# DATA PRIVACY AND OWNERSHIP IN PERSONALIZED MEDICINE

# DATA PRIVACY AND OWNERSHIP IN PERSONALIZED MEDICINE

## ETHICAL DILEMMA

- AI / ML require large amounts of data
- Data breaches and hacking are becoming increasingly concerning
- Unauthorized data sharing or selling

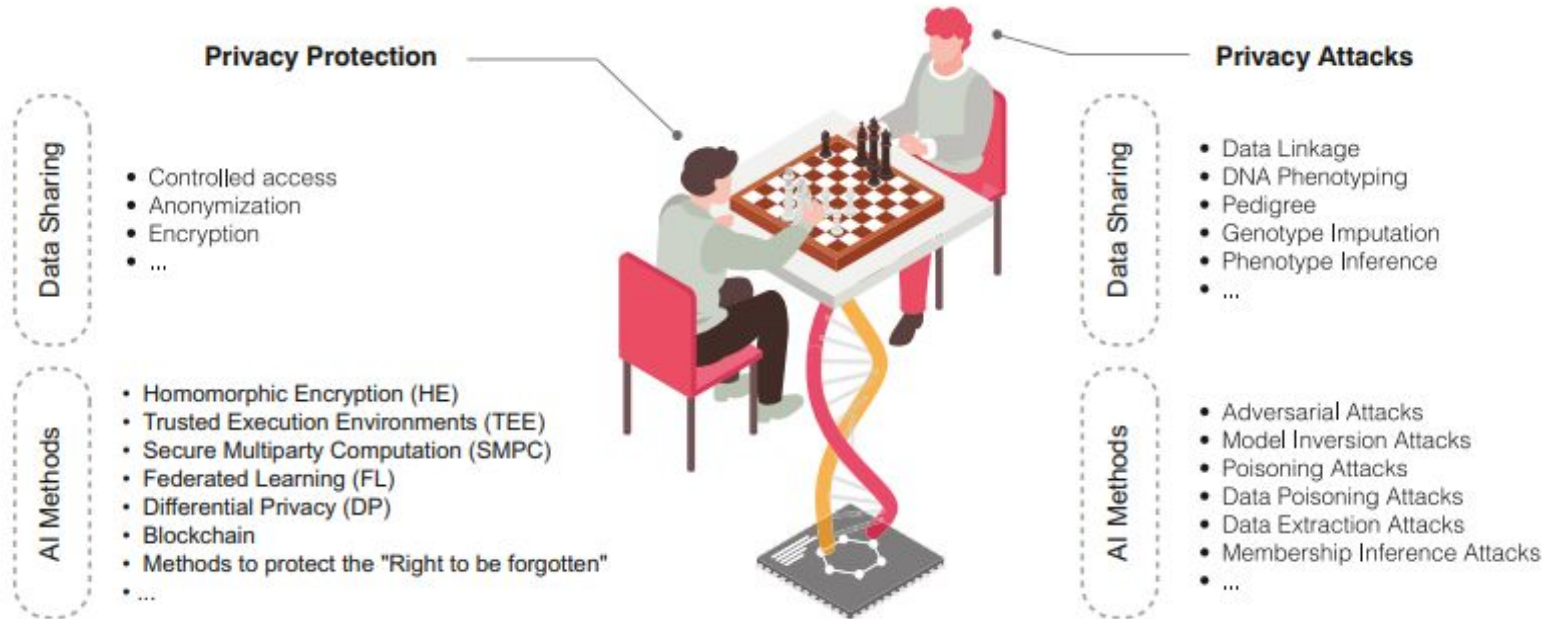
## POINTS OF CONSIDERATION

- Data breaches, user authentication, inherent risks
- Need for stringent data protection when handling genetic information

## QUESTIONS

- Is it possible to balance advances in personalized medicine with the strongest security measures?
- Encrypted models and governance policies regarding data security

# DATA PRIVACY AND OWNERSHIP IN PERSONALIZED MEDICINE



**FIGURE 5**

# TRANSPARENCY AND DATA SHARING IN AI-DRIVEN HEALTHCARE

# TRANSPARENCY AND DATA SHARING IN AI-DRIVEN HEALTHCARE

## ETHICAL DILEMMA

- Focus on Black Box - is it even useful if patients and doctors can't understand/interpret how AI/ML arrive at the conclusions that is output?

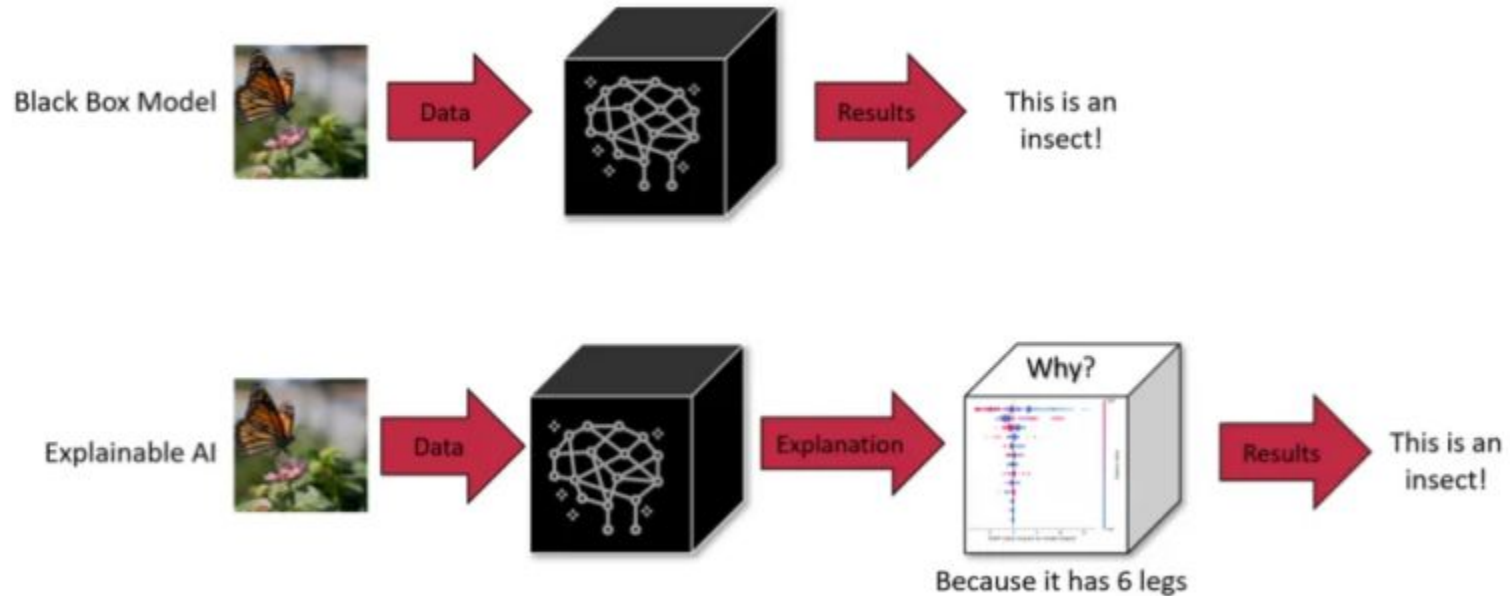
## POINTS OF CONSIDERATION

- Interpretability, privacy, security, equity, intellectual property
- Emphasize need for frameworks and policies to manage data sharing and privacy concerns

## QUESTIONS

- Should doctors blindly accept the results of AI/ML models when it comes to human diseases and personalized medicine?
- Are there ways that we can make AI more explainable, e.g. Explainable AI (XAI)

# BLACK BOXES IN AI PERSONALIZED MEDICINE



**FIGURE 6**

# TRANSPARENCY AND DATA SHARING IN AI-DRIVEN HEALTHCARE

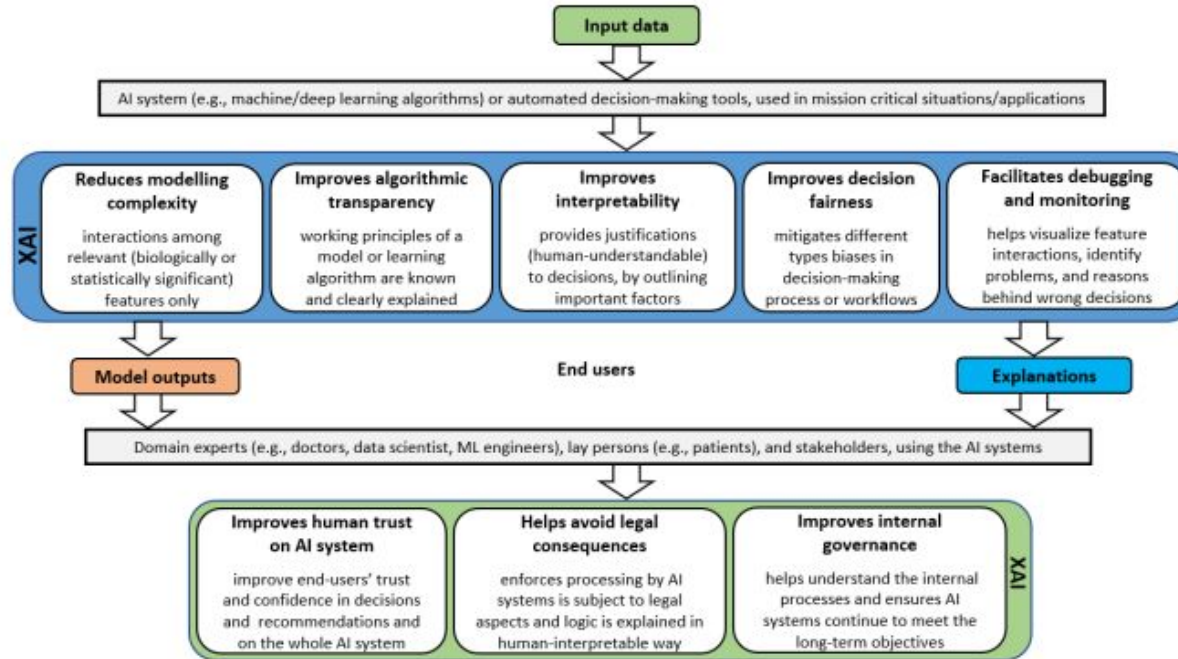


FIGURE 7



# EQUITY AND BIAS IN AI MODELS FOR PERSONALIZED MEDICINE

# EQUITY AND BIAS IN AI MODELS FOR PERSONALIZED MEDICINE

## ETHICAL DILEMMA

- While intent is admirable, just like in regular medicine, AI-driven personalized medicine has potential to worsen disparities between patients, e.g. minorities and underrepresented
- If human input is biased, AI/ML will be biased as well

## POINTS OF CONSIDERATION

- Importance not only in personalized medicine, but public health - requires community engagement, inclusive data practices, transparent algorithms for equitability
- Need to address algorithm biases to ensure equitable diagnostic outcomes in medicine

## QUESTIONS

- How can AI-driven personalized medicine be more equitable and unbiased?
- Are there ways to ensure that even if human input is biased, algorithms could be unbiased?
- How can biased data be collected and processed?

# EQUITY AND BIAS IN AI MODELS FOR PERSONALIZED MEDICINE

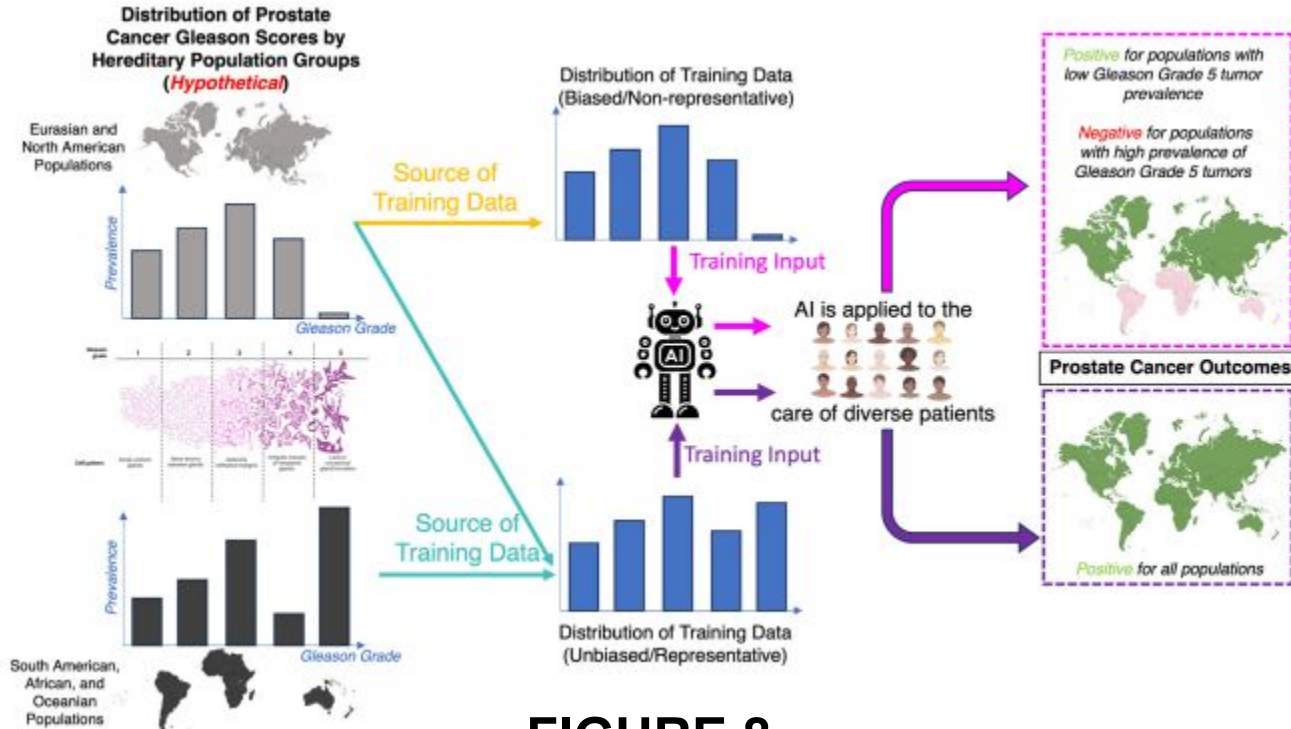


FIGURE 8

# CASE STUDY - 23ANDME



Ancestry  
Service



Health + Ancestry  
Service



23andMe+  
Premium™



23andMe+  
Total Health™

# CASE STUDY - 23ANDME

## History

- 2023: breach exposed data from almost 7 million users and revealed vulnerabilities in third-party login reuse and lack of multi-factor authentication (MFA).
- 2025: the company filed for bankruptcy prompting patients to frantically delete any data they had control over.

## Ethical Dilemmas

- Users may not have fully understood secondary uses of their genomic data.
- Once breached, individuals couldn't easily control, remove or manage exposed genomic info.

## Solutions

- Implement tiered consent models that let users choose how their data is reused and to what level/extent they so choose.
- Strengthen regulatory oversight for AI-driven not only genomic, but healthcare platforms, ensuring transparency and accountability from government and business/industry leaders.

# CONCLUSION

# CONCLUSION

## SUMMARY

- Patient awareness and informed consent
- Data privacy and ownership
- Transparency and data sharing
- Health equity and data bias

## FUTURE DIRECTION

- How can we improve patient understanding of AI-driven decisions involving their genomic data?
- What new technologies can ensure data privacy without compromising model performance, especially in personalized medicine?
- How can we increase clinician and patient trust in black-box AI systems?
- How do we identify and reduce hidden biases in AI models trained on genomic and clinical data?

THANK YOU!

QUESTIONS?



# WORKS CITED

1. Bernal, Jose, and Claudia Mazo. "Transparency of Artificial Intelligence in Healthcare: Insights from Professionals in Computing and Healthcare Worldwide." *Applied Sciences*, vol. 12, no. 20, 2022, article 10228, <https://doi.org/10.3390/app122010228>.
2. Carini, Claudio, and Attila A. Seyhan. "Tribulations and Future Opportunities for Artificial Intelligence in Precision Medicine." *Journal of Translational Medicine*, vol. 22, 2024, article 411, <https://doi.org/10.1186/s12967-024-05067-0>.
3. Dankwa-Mullan, Irene. "Health Equity and Ethical Considerations in Using Artificial Intelligence in Public Health and Medicine." *Preventing Chronic Disease*, vol. 21, 2024, <http://dx.doi.org/10.5888/pcd21.240245>.
4. Fothergill, B. Tyr, et al. "Responsible Data Governance of Neuroscience Big Data." *Frontiers in Neuroinformatics*, vol. 13, 2019, <https://doi.org/10.3389/fninf.2019.00028>.
5. Hanna, Matthew G., et al. "Ethical and Bias Considerations in Artificial Intelligence/Machine Learning in Pathology and Laboratory Medicine." *Modern Pathology*, vol. 38, no. 3, 2025, article 100686, <https://doi.org/10.1016/j.modpat.2024.100686>.
6. Holthouse, Ryan, et al. "The 23andMe Data Breach: Analyzing Credential Stuffing Attacks, Security Vulnerabilities, and Mitigation Strategies." *arXiv*, 2025, <https://arxiv.org/pdf/2502.04303>.
7. Karim, Md. Rezaul, et al. "Explainable AI for Bioinformatics: Methods, Tools, and Applications." *arXiv*, 2022, <https://arxiv.org/abs/2212.13261>.
8. McGuire, Amy L., et al. "Research Ethics and the Challenge of Whole-Genome Sequencing." *Nature Reviews Genetics*, vol. 9, no. 2, 2008, pp. 152–156, <https://doi.org/10.1038/nrg2302>.
9. Mittal, Aayush. "The Black Box Problem in LLMs: Challenges and Emerging Solutions." *Unite.AI*, 1 Dec. 2023, [www.unite.ai/the-black-box-problem-in-llms-challenges-and-emerging-solutions/](http://www.unite.ai/the-black-box-problem-in-llms-challenges-and-emerging-solutions/).
10. Park, Hai Jin. "Patient perspectives on informed consent for medical AI: A web-based experiment." *Digital health* vol. 10 20552076241247938. 30 Apr. 2024, doi:10.1177/20552076241247938.
11. Savage, Sarah K., et al. "Using a Chat-Based Informed Consent Tool in Large-Scale Genomic Research." *Journal of the American Medical Informatics Association*, vol. 31, no. 2, 2024, pp. 472–478, <https://doi.org/10.1093/jamia/ocad181>.
12. Yang, Guang, et al. "Unbox the Black-Box for the Medical Explainable AI via Multi-Modal and Multi-Centre Data Fusion: A Mini-Review, Two Showcases and Beyond." *Information Fusion*, vol. 77, 2022, pp. 29–52, <https://doi.org/10.1016/j.inffus.2021.07.016>.
13. Zhou, Juexiao, Chao Huang, and Xin Gao. "Patient Privacy in AI-Driven Omics Methods." *Trends in Genetics*, vol. 40, no. 5, 2024, pp. 383–386, <https://doi.org/10.1016/j.tig.2024.03.004>.