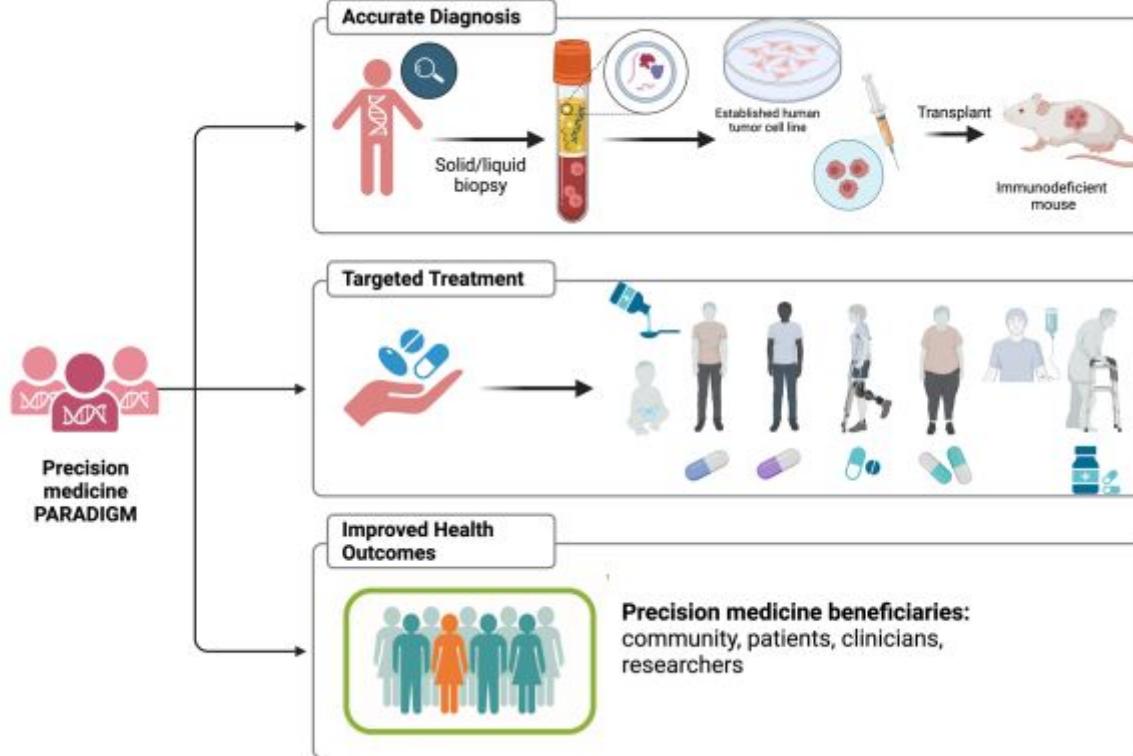


# Ethical Challenges of AI-Driven Personalized Medicine: Are Patients Aware of How Their Genomic Data is Used?

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# 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

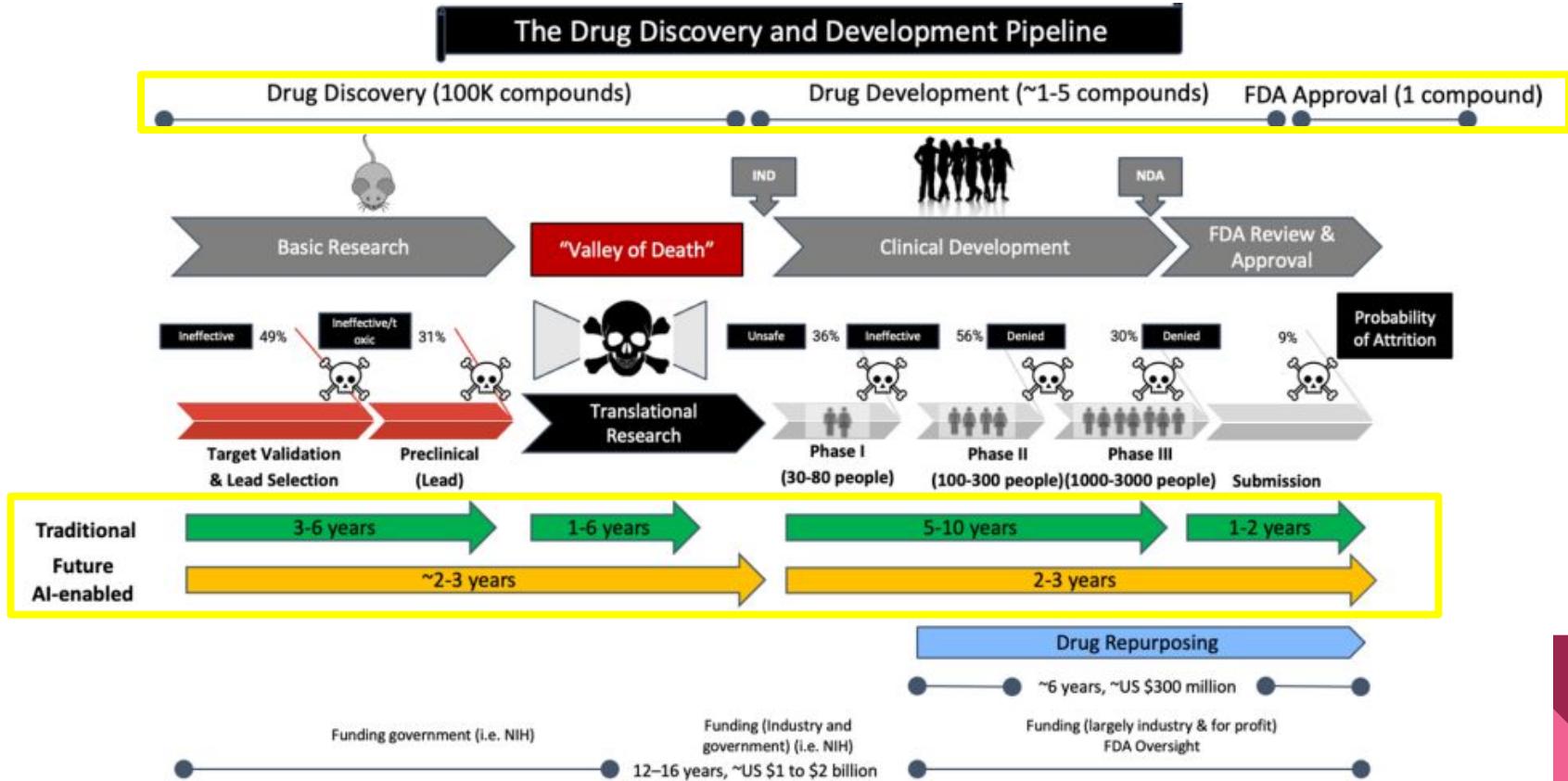
- 23andMe filing for bankruptcy: Is your genetic data safe?

## CONCLUSION

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

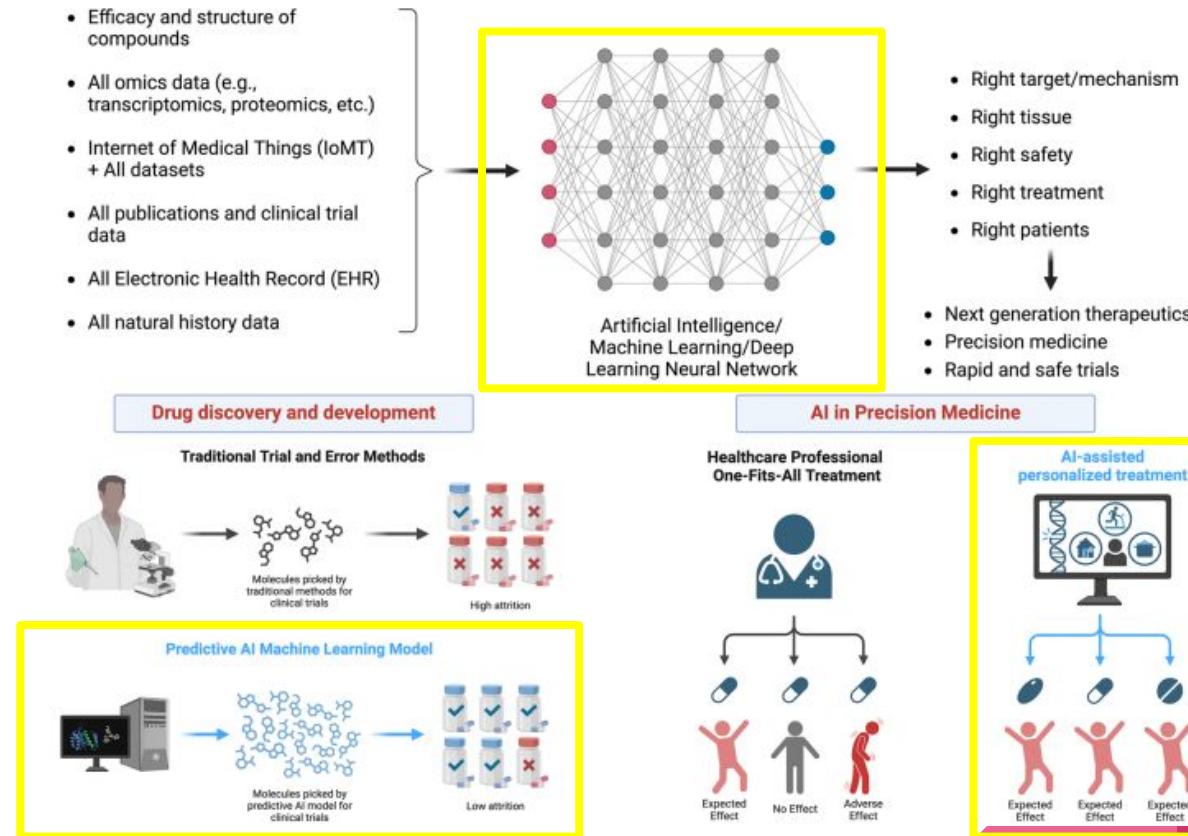
# INTRODUCTION

# 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

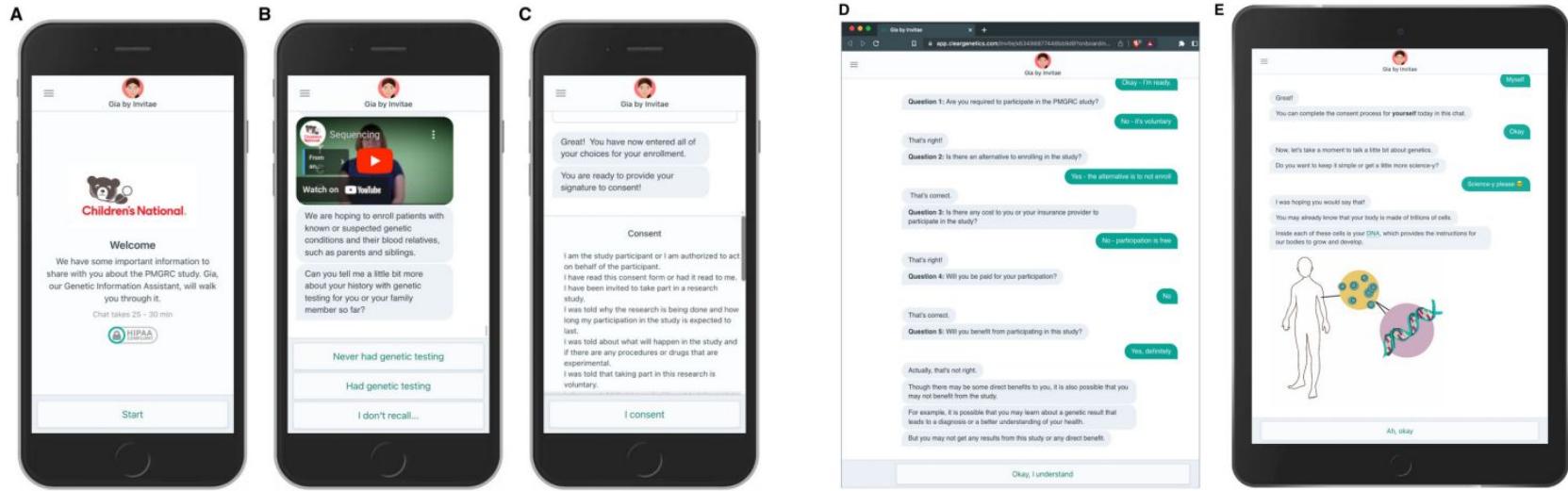
## POINTS OF CONSIDERATION

- 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

Source: Savage et al. (2024)

# 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

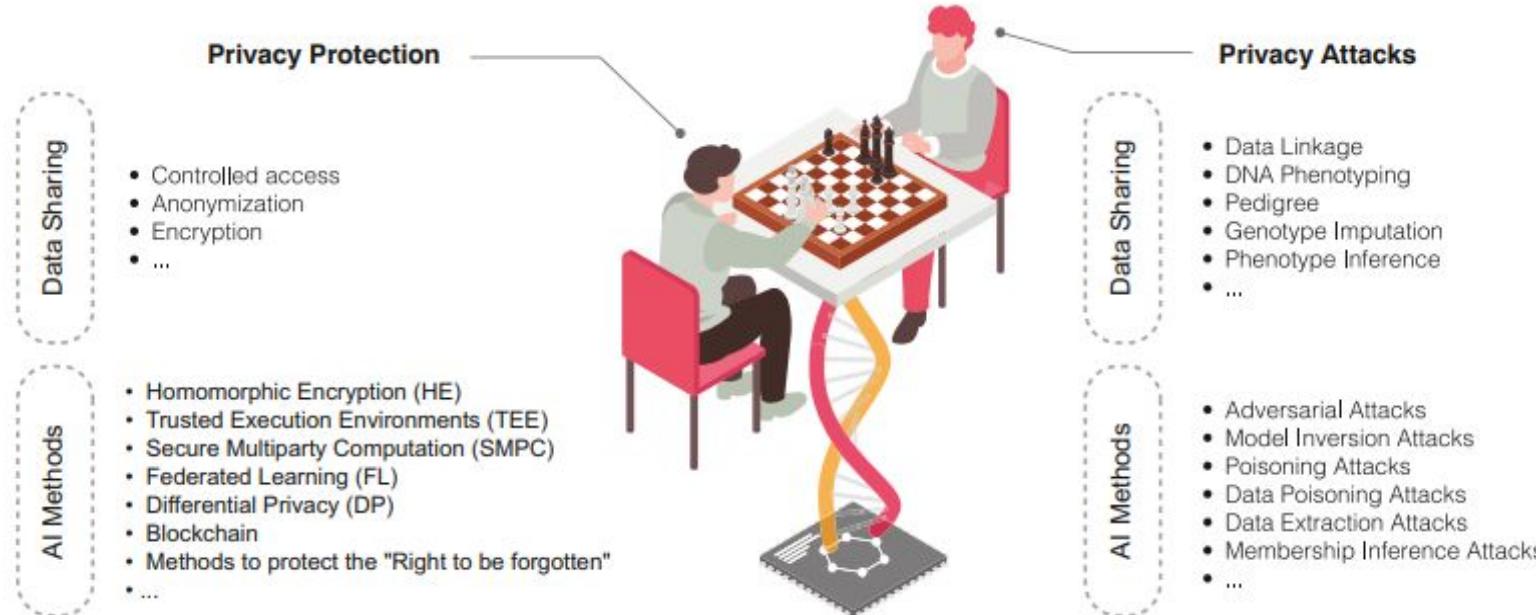
## POINTS OF CONSIDERATION

- 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**

Source: Zhou et al. (2024)

# 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?

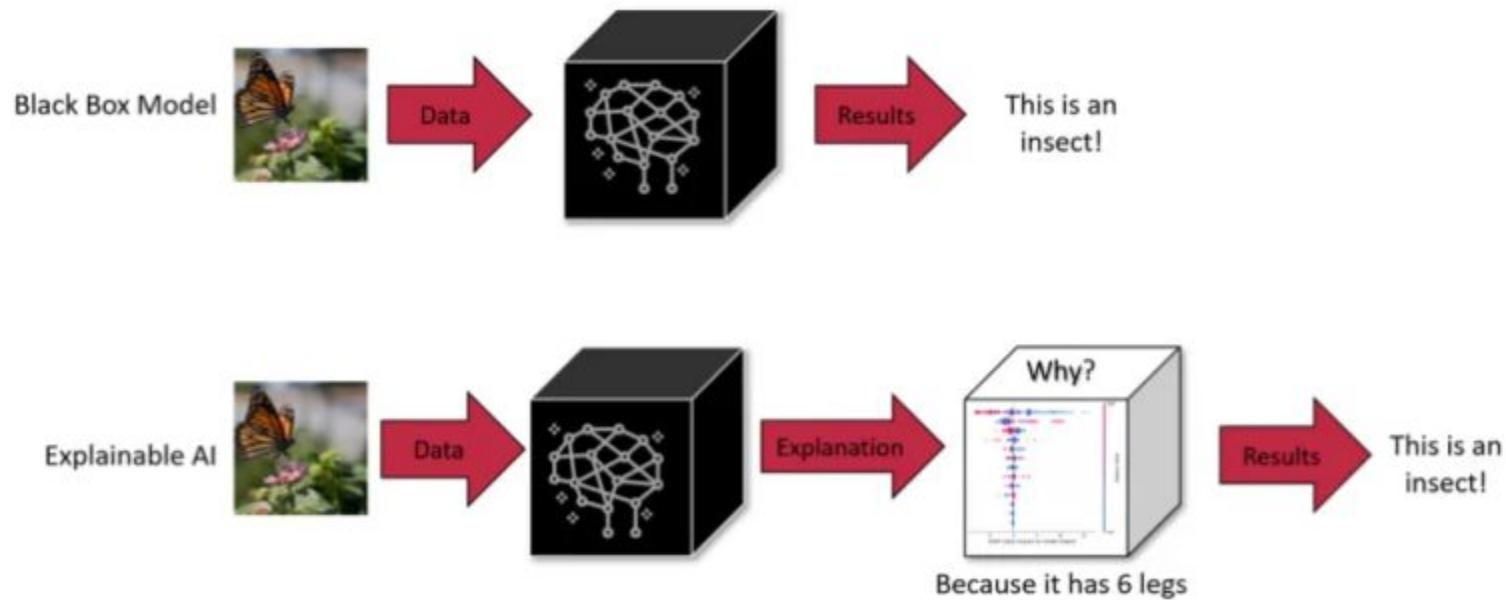
## POINTS OF CONSIDERATION

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

## QUESTIONS

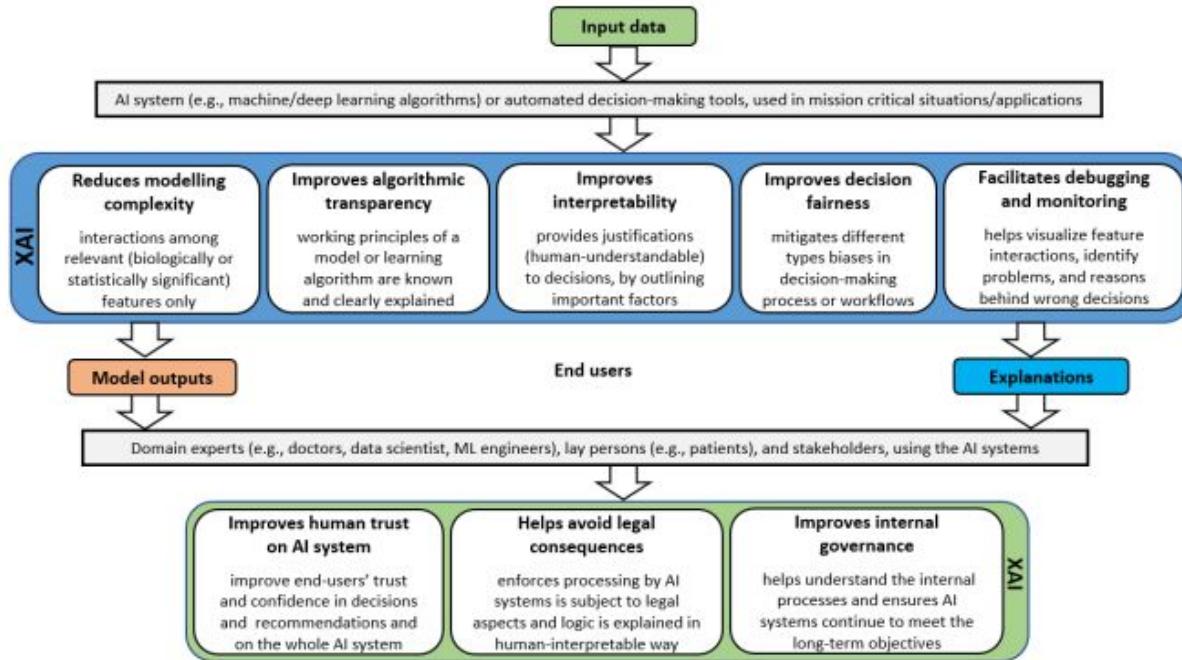
- Should doctors blindly accept the results of AI/ML models when it comes to human diseases and personalized medicine?
- Are there ways that we can make AI more explainable,  
e.g. Explainable AI (XAI)

# BLACK BOXES IN AI PERSONALIZED MEDICINE



**FIGURE 6**

# TRANSPARENCY AND DATA SHARING IN AI-DRIVEN HEALTHCARE



**FIGURE 7**

Source: Karim et al. (2022)

# 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-drive 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

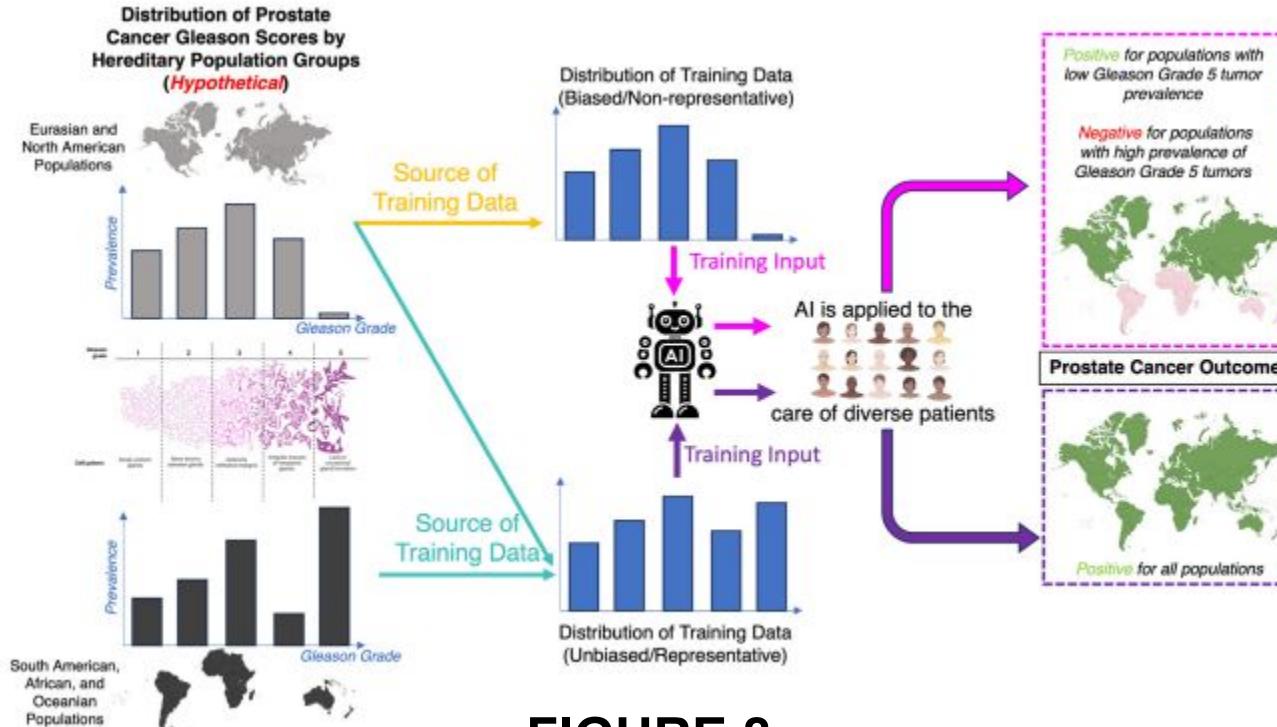
## POINTS OF CONSIDERATION

- 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**

Source: Hanna et al. (2024)

# 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?

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