Evaluating Trustworthiness in AI-Based Diabetic Retinopathy Screening: Addressing Transparency, Consent, and Privacy Challenges

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Introduction and Objectives

Introduction:
- Artificial intelligence (AI) offers significant potential for enhancing individual well-being and societal progress
- The healthcare integration of AI brings complex ethical, legal, social, and technological challenges
- Trustworthy AI emphasizes the need for trust among individuals, organizations, and societies to ensure the responsible development and use of AI systems.
- Building trust in AI systems is crucial for their acceptance and effectiveness, ensuring equitable and ethical healthcare solutions.
- This study investigates the views of healthcare providers, policymakers, AI developers, ethical and legal experts to understand their concerns about trust and trustworthiness in AI development and deployment.

Methods

- **Study design**: Qualitative approach
- **Study participants:** Health system stakeholders, including ophthalmologists (Opth), retina specialists, program officers (PO), legal experts, bioethics experts, and industry partners (AI developers). (Table 1)
- **Study tools:** Pretested semi structured questionnaire
- Consolidated Criteria for Reporting Qualitative (COREQ) Research guideline for qualitative studies
- **Data analysis:** Qualitative data was analyzed using Atlas. Ti (https://atlasti.com/)

Results

Characteristics of the stakeholders	(n = 15)
Gender, n (%)	
Male	9 (60)
Female	6 (40)
Age (years), n (%)	
31-40	8 (53.3)
41-50	5 (33.3)
51-60	2 (13.3)
Age (years) (mean ± SD)	43.9 ± 6.8
Professional status, n (%)	
Retina specialist	1 (6.7)
Ophthalmologist	4 (26.7)
Program officer	4 (26.7)
Legal expert	2 (26.3)
Industry partner	3 (13.3)
Bio-ethics	1 (6.7)
Professional experience, years (mean ± SD)	12.3 ± 5.2

Total (n=15) participants were enrolled: 9 (60%) males and 6 (40%) females, with the majority aged 31-40 years (53.3%), average professional experience of 12.3 ± 5.2 years (table 1)

Six key themes emerged from the interviews regarding the perceived trustworthiness of AI: effectiveness of the AI algorithm, responsible AI concerning data collection, ethical consideration and approval, explainability, challenges of AI implementation, and accountability and liability.

Summary of key findings: The study revealed critical shortcomings in the AI company's data collection practices, including a lack of transparency, inadequate patient consent processes, insufficient attention to data privacy, and the absence of robust regulatory frameworks. These gaps have led to unchecked data privacy breaches and raised concerns about emerging data colonialism practices within the healthcare system.

Ophthalmologist
"The primary purpose of AI is its use for screening purposes, and it can cover up to 80 percent of all community diabetic retinopathy-related problems without a needless referral."

AI developer
*"We started going out into the **market conducting camps** on our own, and during the entire process, we've screened more than **94,000** people till date, and there is no ethics requirement to conduct camps"*

Legal expert in AI
*"Right now AI companies are quickly creating **large data sets.** They are **self-regulating** and saying we are anonymising, and not revealing it into public domain, don't get into trouble"*

AI developer
"The available ethical framework does not impose any compulsion to have any ethics clearances for AI training datasets"

Legal expert in AI
*"Regulatory policy regulations are **vague or gray or not completely well-defined** or not completely tested"*

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Conclusions and lessons learned

- The study provides a comprehensive overview of the various issues, gaps, and challenges related to AI development and deployment, making it a valuable reference and foundation for future research
- Trustworthy AI requires transparent data practices, robust patient consent, and adherence to ethical and privacy standards. Addressing these areas is crucial for overcoming current shortcomings and ensuring AI's reliable and ethical deployment in healthcare.

Policy Recommendation

- Development of AI needs access to high-quality and trustworthy data
- Robust data governance and privacy frameworks are critical for maintaining patient data safety and privacy
- Reviewing and updating current organizational data, governance framework and infrastructure to foster strategic collaborative partnerships is critical to implementing AI best practices

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