THE ETHICS OF INTEGRATING MEDICAL AI INTO RESEARCH, PRACTICE, AND EDUCATION

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10.17.2022
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4 PRINCIPLES OF BIOMEDICAL ETHICS

- Autonomy
- Beneficence
- Non-Maleficence
- Justice
“acknowledge that person’s right to hold views, to make choices, and to take actions based on personal values and beliefs”

• Voluntary Participation
  • No conflict of interest
  • No coercion or undue influence

• Informed Consent
  • Capacity to consent
  • Responsibilities of participant & researcher
  • Risks & benefits
  • Confidentiality, privacy & data storage processes
“forms of action intended to benefit other persons.”

- obligation to protect persons from harm
- A social/health value, desired outcome
- Maximize benefits and minimize risks
- Ensuring favorable risk-benefit ratio
- To individuals, community, scholarship
Federal Policy for the Protection of Human Subjects
('Common Rule')

Harm or discomfort not greater than that “ordinarily encountered in daily life or during routine physical or psychological examinations or tests”
NON-MALEFICENCE

Obligation “not to inflict harm intentionally”

Physical risks
• Bodily contact, side effects, falls

Psychological/emotional risks
• Feeling uncomfortable, embarrassed, upset

Social risks
• Loss of status, privacy and/or reputation

Legal risks
• Apprehension or arrest, subpoenas
EXAMPLES

- **Anonymity**
  - Anonymous participant data
  - Notions around privacy (person-centered)

- **Confidentiality**
  - Security of data (data-centered)
  - Who has access to your data
  - Safeguards and procedures
  - Limitations of confidentiality
  - An extension of privacy
“fair, equitable, and appropriate treatment in light of what is due or owed to persons”

- Historically excluded groups are not exploited
- Fair distribution of the benefits and burdens of research
- To ensure equitable and culturally competent research
- That all populations are included in research designs
What is Vulnerability?

There is no one definition for vulnerability

- Susceptibility to coercion or exploitation
- Increased risk of harm
- Diminished autonomy
- Capacity to protect own interests
- Historically excluded populations (systems of oppression)
- Balance need for protection with benefits of access, knowledge, ownership and protection
Aspects of Vulnerability

• Capacity to participate in research
• Population (mental illness, children, pregnant women)
• Experiences of marginalization and unethical research (e.g., LGBTQ, Indigenous, economically disadvantaged)
• Power differentials between researcher and subject
NUREMBERG CODE (1947)

Nazi Experimentation on Human Subjects

- Informed Consent
- Absence of Coercion
- Beneficence
DECLARATION OF HELSINKI (1964)

World Medical Association
(Most Recent Revision: 2013)

- Respect for the Individual
- Right to self-determination
- Right to make informed decisions
- Privacy & Confidentiality

Milestone to the IRB Process
NATIONAL RESEARCH ACT (1974)

*Created the National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research*

- Guidelines for human subject research
- Oversee and regulate medical experiments
- Formularized regulations through local IRBs (Office of Human Research Protections)
BELMONT REPORT (1978)

The National Commission for the Protection of Human Subjects of Biomedical and Behavioral Research

- Tuskegee Syphilis Experiment
- Respect for Persons, Beneficence and Justice
- Informed Consent
- Assessment of Risks & Benefits
- Selection of Subjects
Current AI Trends in Healthcare Industry

This slide contains information regarding the current trends that are prevailing in healthcare industry in context to artificial intelligence. The present AI healthcare trends aims in improving overall patient and medical practitioner relationship, reduces clinical services cost.

**Patient Centric Approach**
- AI assisted high quality care to patients
- Electronic healthcare reports and smartphone apps offers at home health solutions
- Add text here

**Data Driven Healthcare**
- AI allows data compilation and for clinical purpose - medical research and review
- Detecting effective treatments based on patient’s relevant health history data
- Add text here

**Enhanced Healthcare Communication**
- AI assisted apps aiding patients to chat with doctors, appointment booking
- Decreased medical errors
- Add text here

**Medical Diagnostic Imaging**
- AI assisted imaging useful for detecting and screening vision threatening eye diseases, serious heart and brain strokes, lesions in lungs and liver
- Add text here
- Add text here
ETHICAL BENEFITS

• Reduce administrative tasks of physicians
• Facilitate workflow
• Accurate and earlier diagnoses and treatment options
• Reduce human error and bias
• AI can be used to predict risk factors
• Can obtain information about social contexts that influence care
• More personalized and value driven care
• Can reach rural or remote communities through eHealth platforms and telehealth
• Older adults, disabled persons
Medical AI Ethics

• Data Ownership (who owns the data; right to ownership)
• Data Protection (confidentiality and privacy; HIPAA)
• Data Sharing
• Accuracy (efficiency, reliability, consistency)
• Transparency (to whom)
• Bias
• Informed Consent (patient autonomy and self-determination)
• Trust (patient-provider)
• Cost (implementation of AI)
• Accountability and Responsibility (of researchers, physicians, developers)
• Legislation and Regulation
Medical AI Ethics And Social Justice

**Bias**: How do biases influence practice?

**Trust**: How does AI influence the patient-provider relationship?

**Fairness**: Who will have access to AI technologies?
Bias of Medical AI

- Humans’ implicit and explicit biases filter into AI algorithms
- Historical exclusion in clinical trials (back to research ethics)
- Biobanks that uphold samples from predominantly white men
- Questions that are normative and do not consider complex, intersectional identities
- Limited knowledge, training
- So how will AI/ML integrate these experiences without prior knowledge?

How do we then transition to applying these algorithms to diverse populations?
Intersectionality

- Individuals belong to multiple social categories/identities
- Interconnectedness of social categorizations (race, class, gender)
- Overlapping experiences of discrimination and privilege
# Health Disparities are Driven by Social and Economic Inequities

<table>
<thead>
<tr>
<th>Economic Stability</th>
<th>Neighborhood and Physical Environment</th>
<th>Education</th>
<th>Food</th>
<th>Community, Safety, &amp; Social Context</th>
<th>Health Care System</th>
</tr>
</thead>
<tbody>
<tr>
<td>Employment</td>
<td>Housing</td>
<td>Literacy</td>
<td>Food security</td>
<td>Social integration</td>
<td>Health coverage</td>
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<tr>
<td>Income</td>
<td>Transportation</td>
<td>Language</td>
<td>Access to healthy options</td>
<td>Support systems</td>
<td>Provider &amp; pharmacy availability</td>
</tr>
<tr>
<td>Expenses</td>
<td>Parks</td>
<td>Early childhood education</td>
<td></td>
<td>Community engagement</td>
<td>Access to linguistically and culturally appropriate &amp; respectful care</td>
</tr>
<tr>
<td>Debt</td>
<td>Playgrounds</td>
<td>Vocational training</td>
<td></td>
<td>Stress</td>
<td>Quality of care</td>
</tr>
<tr>
<td>Medical bills</td>
<td>Walkability</td>
<td>Higher education</td>
<td></td>
<td>Exposure to violence/trauma</td>
<td></td>
</tr>
<tr>
<td>Support</td>
<td>Zip code/geography</td>
<td></td>
<td></td>
<td>Policing/justice policy</td>
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</tr>
</tbody>
</table>

**Health and Well-Being:**
Mortality, Morbidity, Life Expectancy, Health Care Expenditures, Health Status, Functional Limitations
COVID-19 Hospitalization and Death Rates among Active Epic Patients by Race/Ethnicity

Rate per 10,000, as of July 2020

<table>
<thead>
<tr>
<th>Race/Ethnicity</th>
<th>Hospitalization Rate</th>
<th>Death Rate</th>
</tr>
</thead>
<tbody>
<tr>
<td>White</td>
<td>7.4</td>
<td>2.3</td>
</tr>
<tr>
<td>Black</td>
<td>24.6</td>
<td>5.6</td>
</tr>
<tr>
<td>Hispanic</td>
<td>30.4</td>
<td>5.6</td>
</tr>
<tr>
<td>Asian</td>
<td>15.9</td>
<td>4.3</td>
</tr>
</tbody>
</table>

Total Active Patients (millions):
- White: 34.1
- Black: 7.0
- Hispanic: 5.1
- Asian: 1.4

NOTE: Rates for Black, Hispanic, and Asian patients are statistically significantly different from White patients at the p<0.05 level. Persons of Hispanic origin may be of any race but are categorized as Hispanic; other groups are non-Hispanic. Data for other racial groups not shown due to insufficient data.

SOURCE: Epic and KFF analysis of Epic Health Record System COVID-19 related data as of July 2020.
So Back to AI....

- With inherent biases related to algorithms that may overlook:
  - Diverse health-related experiences
  - Social determinants of health
  - Health disparities and health inequities
  - Actual follow-up and preventative care
  - The complexities of care – it is not a single solution
**Trust in Medical AI**

- Bias of AI stems from bias of providers
- Distrust in healthcare, fears of discrimination, avoidance of care
- Lack of training and education
- LGBTQIA+ persons, people of color, disabled persons (e.g.)
- Will bias of AI further distrust in healthcare?
- We know that physician-provider trust is KEY to preventative care
- We see this with vaccine hesitancy

**Two Issues:**
(1) AI/ML may reduce provider autonomy – lessen relationship
(2) The bias of AI/ML may further distrust prior to the office visit
Black, Hispanic Adults Most Likely To Want To “Wait And See” Before Getting a COVID-19 Vaccine

Percent who say they will get a COVID-19 vaccine:

- Already gotten/As soon as possible
- Wait and see
- Only if required
- Definitely not

<table>
<thead>
<tr>
<th></th>
<th>Already gotten/As soon as possible</th>
<th>Wait and see</th>
<th>Only if required</th>
<th>Definitely not</th>
</tr>
</thead>
<tbody>
<tr>
<td>Total</td>
<td>47%</td>
<td>31%</td>
<td>7%</td>
<td>13%</td>
</tr>
<tr>
<td>Black</td>
<td>35%</td>
<td>43%</td>
<td>8%</td>
<td>14%</td>
</tr>
<tr>
<td>Hispanic</td>
<td>42%</td>
<td>37%</td>
<td>9%</td>
<td>11%</td>
</tr>
<tr>
<td>White</td>
<td>53%</td>
<td>26%</td>
<td>5%</td>
<td>14%</td>
</tr>
</tbody>
</table>
Larger Share Of Younger Hispanic Adults Express Vaccine Hesitancy

When a vaccine for COVID-19 is approved and widely available to anyone who wants it, do you think you will...?

- Get the vaccine as soon as possible
- Only get the vaccine if required
- Wait and see
- Definitely not get the vaccine

Total Hispanic adults

- 26% Get the vaccine as soon as possible
- 43% Only get the vaccine if required
- 11% Wait and see
- 18% Definitely not get the vaccine

Hispanic adults 18-49

- 20% Get the vaccine as soon as possible
- 45% Only get the vaccine if required
- 11% Wait and see
- 22% Definitely not get the vaccine

Hispanic adults 50+

- 38% Get the vaccine as soon as possible
- 39% Only get the vaccine if required
- 10% Wait and see
- 11% Definitely not get the vaccine
How will medical AI impact the trustworthy relationship to strengthen preventative care?

How will AI/ML consider the complex lived experiences?
Fairness in Medical AI – Health Care Settings

- Who will have access to AI/ML developments?
- Less resourced hospital settings (community hospitals) that are predominantly utilized by historically excluded populations?
- 1 out of 5 people use a community hospital
- Large highly resourced academic medical centers
2021 – Pew Research Report:

7% of Americans (23 million people) do not use the Internet
23% do not have access to broadband connection at home
27% do not own a laptop or desktop
44% of households with incomes below $30,000 don’t have broadband
40% of schools lack broadband connections
60% of health care facilities outside metropolitan areas
Fairness in Medical AI – Patient-Centered Care

- Issues connected to the digital divide
- The digital divide: technology, internet access, digital literacy
- Cost for companies and cost to individuals (classism)
- Seniors who report chronic health conditions, disability, or physical limitations that prevent them from full utilization (ageism)
- AI may have restrictions for those living with disabilities (ableism)
Digital Divide

Social
- Literacy skills
- Disability vs. fit
- Age: Old vs. young
- Family background (income and education)
- Ethnicity and language (non-English speaking)

Economic
- Under-developed nations vs. first world countries
- Poverty, i.e., unaffordability
- Lack of international investment and funding in poorer countries

Geographical
- Rural areas vs. suburban
- Under-developed nations vs. first world countries

Approach
- Fear of technology, or 'technophobes'
- Lack of motivation or objective
IMPLICATIONS

- Training on public health and health equity
- Social determinants of health conversations
- Diversity in bioethics, in AI/ML developers, in healthcare
- Community advisory boards
- Collaboration of AI with patient-centered care
Cultural Humility In Medical AI

- Developing trust, familiarity and mutual respect
- Capacity building
- Stages & Types of Informed Consent
- Data Collection Approaches and Methods
- Community-Based Research
- Context-specific resources
- CABs: Community Advisory Boards
- Dissemination Practices & Knowledge Mobilization
Understanding cultural competence and cultural humility

Becoming culturally competent and practicing cultural humility are ongoing processes that change in response to new situations, experiences, and relationships. Cultural competence is a necessary foundation for cultural humility.

CULTURAL HUMILITY

Holding systems accountable
- How can I work on an institutional level to ensure that the systems I’m part of move toward greater inclusion and equity?

Understanding and addressing power imbalances
- How can I use my understanding of my own and others’ cultures to identify and work to disrupt inequitable systems?

CULTURAL COMPETENCE

Gaining cultural knowledge
- What are other cultures like, and what strengths do they have?

Developing cultural self-awareness
- What is my culture, and how does it influence the ways I view and interact with others?

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Q&A

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