

Ethics and digital health: What is the purpose of a digital health system and what must be its ethical commitments?

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Key points

- We don't talk enough about the **purpose** of a data aggregation activity
 - “Digital health” is not a monolithic activity
 - Why does that matter, ethically?
- Wide range of **ethics issues** in digital health
 - (aka, much more than privacy and security)
- Essential to keep **promises to stakeholders**
 - But what promises should be made?

Purpose of a digital health activity

- **Why are digital health data being collected?**
 - What is the purpose or reason for creating this data system?
 - To support care in a larger enterprise (e.g., “learning health system”- housed entirely within a health system) or stand alone data system or research getting and sharing data externally?
 - Will data be shared externally? Commercial interest in data?
 - System model may be relevant to whether any **direct benefit** is expected for those whose data included?
- **E.g., models**
 - Learning health system
 - Federal research programs/consortia (e.g., AoURP)

– Independent commercial data base- many purposes

(at least some of the...)

Ethics considerations in digital health

- **Transparency**
- **Consent and permissions**
- **Privacy and security**
- **Data access and sharing**
- **Ownership and governance**
- **Justice and fairness**
- **Benefits and purpose**

Ethics considerations in digital health-2

- **Transparency**

- Of course, but *about what topics?* (e.g., *all of below?*)
- Meaningful? Understandable? Format?

- **Consent and permissions**

- About what?
- Meaningful? Opt outs?

- **Privacy and security**

- Meet and constantly upgrade to current best practices?
- Transparency about which data are collected? Shared?
- Transparency about what is identifiable? Defined how?

Ethics considerations in digital health-3

- **Data access and sharing**

- Who has access and why? To improve health of data contributors or others like them? To commercialize? With what protections to meet all other ethics standards?
- Transparency about all of above

- **Ownership and governance**

- Who makes all of these decisions?
- Any engagement or governing board of

“participants”?

Ethics considerations in digital health-4

- **Justice and fairness**

- Whose data are included? Intentionality in this?
- What inferences can be drawn from data? (who benefits from this system and what's learned?)
- Which questions are examined? Require dedicated consideration of least well off?

- **Benefits and purpose**

- Do participants benefit? (P.S. Learning useful health info doesn't mean participants benefit)
- Do participants know data system purpose?

Promise keeping, trust, and integrity

- Integrity and trustworthiness require promises to participants to be kept
 - Any not kept must transparently be disclosed and explained
- Key is which promises to make
 - Commitments to transparency
 - Commitments to getting one's results
 - Commitments to ongoing engagement
 - Commitments to investigating health problems of those least often studied