

Designing Technologies to Support Aging with Ethics in Mind

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THE PRODUCT DEVELOPMENT LIFECYCLE

PRE-LAUNCH

GENERATING IDEAS

- *Identify User Needs*

DESIGNING &
PROTOTYPING

- *Assess and Address Bias*
- *Consider Risk-Benefit Tradeoffs*
- *Protect User Privacy*
- *Consider Environmental Impacts*

VALIDATING &
CERTIFYING

- *Fulfill Your Value Proposition*
- *Conduct Ethical Human Subjects Research*
- *Seek Necessary Pre-Market Approvals*

POST-LAUNCH

COMMERCIALIZING

- *Educate Users*
- *Promote Equitable Access*
- *Manage Your Supply Chain*
- *Be Aware of Liability Questions*

ETHICAL & REGULATORY CONSIDERATIONS

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Identify User Needs

- Understand user needs and leverage this understanding throughout product development.
- Understanding user needs may reveal ways to promote justice and fairness.
 - Example – Increase Accessibility: *Deaf users might benefit from visual or vibrotactile alarms.*
 - Example – Reduce Disparities: *Disparities in access to memory care may inspire a technology that increases rural patients' access to specialists.*
- All ideas have limitations, and consultation with users may help identify them.
 - Example: *Purported benefits of products that allow caregivers to remotely monitor older adults' location and activities include promoting safety and independence. Yet, many were developed without older adults' input or consideration of their values (including privacy!), limiting adoption.*

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Assess and Address Bias

- Be aware of the potential for bias. Failure to assess and address it can result in unfairness, particularly to vulnerable and historically marginalized groups.
- Diversity matters! A team that is personally or professionally homogenous may lack awareness or understanding of biases in medicine and society that could adversely affect product development.
- Bias can manifest in various ways.
 - Example – Biased Training Data: *A study of AI-based chest X-ray prediction models found that patients belonging to two under-served subgroups were more likely to be misdiagnosed than those belonging to one or none.*
 - Example – Stereotype Threat: *A study of digital depression screening found that such tests can be subject to stereotype threat, leading to statistically significant changes in scores for women and non-binary participants.*

Consider Risk-Benefit Tradeoffs

- Identify potential benefits and risks of their product and determine whether benefits outweigh risks.
- Benefits depend heavily on particulars. Consider whether there are opportunities to increase benefits.
- Risks also depend on particulars and can be multifaceted (e.g., physical, emotional, economic, or social).
 - Example – Social: *Stalkers have used GPS-data from the fitness app Strava to track the whereabouts of their victims and harass them.*
 - Example – Legal: *After Dobbs, there was worry data from period tracking apps could be used to determine when a pregnancy had been aborted, exposing users to criminal liability.*
- Understanding of risks informs selection of appropriate risk-mitigation strategies.

Protect User Privacy

- There is a sense that information about an individual's body or health is private. This animates laws governing handling of protected health information.
- People expect their privacy will be similarly protected when using health-related products outside clinical or research contexts, but this usually isn't the case.
- Comply with any relevant privacy laws, but also be aware that your ethical obligations to protect privacy may exceed the obligations imposed by law.
- Privacy protections can take various forms.
 - Example – Cyber Security: *Developers might limit what user data is stored and processed or incorporate data security measures such as encryption or authentication to prevent unauthorized access.*
 - Example – User Control: *Digital pills for the remote monitoring of medication adherence allow users to share information with others. There is also a process for revoking that access.*

Consider Environmental Impacts

- Given the substantial environmental impact of the health care system – and the negative externalities for public health – there have been calls for the health sector to green itself and reduce its ecological footprint.
- Try to improve the ratio between a digital health tool's usefulness and its environmental impact.
 - Example – Repairability: *Increase a device's lifespan by designing it so it can be repaired.*
 - Example – Recyclability: *Increase the components that can be recycled while reducing the use of raw materials.*

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Fulfill Your Value Proposition

- Technologies might be evaluated along technical, clinical, usability, and cost dimensions.
- Validate your technology with diverse populations.
 - Example – Race and Ethnicity: *Early pulse oximetry validation studies were done in homogenous samples. Measurement bias has since been found for pts with darker skin tones.*
 - Example – Age: *A validation study of the Apple Watch's ability to detect atrial fibrillation found that the sensitivity was much lower in older adults than in younger adults.*
- Account for how the technology might change what is being measured.
 - Example – Norms: *Researchers have shown normative data for paper-and-pencil neuropsych tests can't be applied to digital tests, as performances aren't directly comparable.*
 - Example – Practice Effects: *A study of smartphone-based monitoring of MS patients found improvements in test performance due to repeated exposure to test materials on some cognitive and dexterity tests. This might exaggerate treatment effects or mask deterioration.*

Conduct Ethical Human Subjects Research

- If you interact with or collect information from living individuals to validate your technology, you are conducting “human subjects research.”
- Comply with relevant ethical and regulatory guidelines.
 - Example: *The Common Rule governs NIH-funded research and requires review by an IRB.*
- There may be special considerations when conducting research with older adults.
 - Example – Impaired Capacity: *If prospective participants are cognitively impaired, you will need a plan to assess decisional capacity and, if needed, identify a surrogate decision maker who can consent to research participation. It’s typically not appropriate to assume incapacity.*
 - Example – Institutionalization: *If prospective participants live where research will be conducted (e.g., in long-term care), the fact of institutionalization makes them vulnerable because of their dependence on others.*

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Educate Users

- Educating users is important for respecting their autonomy and enabling them to make an informed decision about whether a digital health tool is right for them, their families, their patients, or others whose interests may be implicated.
- Education should address many of the issues we've discussed, such as information about benefits and risks. This information must be shared in a way that promotes understanding, though this often isn't the case.
 - Example: *Researchers have shown that the terms of service and privacy policies for period-tracking apps are often neither easily accessible nor understandable.*
- Share any material information—that is, information that might reasonably be predicted to change how a consumer uses the technology—as it arises.
 - Example: *The terms of service change.*

Promote Equitable Access

- Although a potential use of technology is to advance equitable healthcare, there are barriers to accessing these technologies that must be addressed.
 - Example – Internet Access: *Lower-income households lag their middle- and upper-income counterparts. There are also significant racial disparities in access to high-speed Internet.*
 - Example – Education: *A study of patients at Federally Qualified Health Centers found a majority of respondents expressed interest in having a wearable activity tracker, but less than a quarter had such a tracker. Reported barriers included lack of information about trackers.*
 - Example – User Size: *Digital blood pressure cuffs that are not correctly sized may give inaccurate readings.*

Conclusion

- Technology has the potential to support aging and enhance the wellbeing of older adults.
- Ethical and regulatory challenges exist at each stage of the product-development life cycle.
- To realize the promise of these technologies, developers cannot simply acknowledge these challenges but must proactively address them.

