Research Ethics Cultivating Conversations Recap

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The Potential of Digital Health to Improve Brain Health in Older Adults

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Have you thought about how to conduct ethical and responsible digital health research with older adult participants?

In our October *Cultivating Conversations* seminar, Dr. Zvinka Zlatar, Associate Professor of Psychiatry, spoke about how older adults might promote their brain health and lower their risk of dementia by modifying their lifestyle – specifically, physical activity.

This recap includes: (1) Summary, (2) Questions to Consider, (3) Resources.

Link to the <u>Zoom recording</u> to learn more about Dr. Zlatar's work.

Join the <u>CORE Platform</u> for Discussion

Using Digital Health Tools to Help Promote Physical Activity Among Older Adults

Dr. Zlatar and colleagues conducted a pilot randomized controlled trial with older adults. A goal was to learn if a digital health behavioral intervention that provided just-intime feedback could help older adults to increase moderate to vigorous physical activity (MVPA) to the recommended 150 minutes weekly over a 12-week period in their natural environments.

Participants (average age of 72, mostly women) were randomized into two conditions. In the intervention condition, 21 participants were provided with a wrist-worn digital health band with real-time heart rate tracking. The band provided just-in-time feedback (vibrating and flashing lights) to participants when they deviated from their own individualized heart rate targets during unsupervised exercise. The control group (N=22) completed readings on various aspects of healthy aging, including topics on nutrition and social isolation, and were quizzed weekly about the materials via online survey. Results indicated that participants in the exercise group significantly increased their MVPA, meeting or surpassing the recommended 150 minutes of weekly exercise.

Dr. Zlatar's research showed that an individualized digital health intervention that provides just-in-time feedback about exercise intensity can help older adults successfully achieve the physical activity recommendations in real-world contexts.

A key aspect of our Cultivating Conversations seminars is to explore the ethical, legal and social implications (ELSIs) of research. Dr. Zlatar discussed the challenges her team faced when using digital health technologies to measure participant behavior in the wild. She conducted an exit interview to examine participant experience with the wrist-worn sensor and offered recommendations to overcome these issues. Similarly, she discussed issues related to using digital health devices with Hispanic/Latinx older adults within the context of physical activity interventions to improve brain health. You can find a recap summarized below and a related paper published here.

Participant Perspectives and **Recommended Tips**

- 1. Privacy Concerns:
- Participants agreed that fitness apps should not share their information with third parties without their consent.
- Participants prefer not to share email or name with the apps.
- Participants want to know how their data are being used.

Recommended Tips

- Research teams are responsible for reading the terms of service of the device.
- Make sure that participants are aware of who can access the data, how the data are shared, and any risks and benefits associated with data management practices.
- The research team can suggest that the participant register the device using an alias email that is not connected to their personal account.

2. Access and Usability:

- Participants indicated that the devices were hard to use.
- Commercially available devices may be discontinued or no longer supported during the process.
- The research team had no direct access to the data. As a result, the researchers asked participants to export their data from the device to the research database. This was a major hurdle.

Recommended Tips

- Select commercial devices that have continued support and require minimal user effort.
- Establish a plan to directly access • participants' data from the device.
- Learn more about participants' • comfort level with technologies and create short training videos to show participants how the app works and how to set up their devices.
- Have research staff ready to answer any questions and troubleshoot via phone.
- Maintain regular contact with • participants and ensure the proper use of the device.
- Incorporate participants' feedback • and continue to improve future research.

3. Data Management:

- Participants wanted to know the results of the research using their data.
- Participants expect fitness apps to • ask for permission to use participants' data for internal, educational, research, or advertising purposes.

Recommended Tips

- Select devices that can provide real-• time feedback to participants.
- Offer individualized data reports to • participants.

Questions to Consider: 🚢



1. What can the Institutional Review Board or Office of Research Administration do to help researchers evaluate commercial devices for research use?

2. What are some innovative strategies to increase transparency of the informed consent process?

3. How can researchers ensure that participants understand the terms and services of the commercial device used in research?

Resources

-> Check out the Digital Health Checklist from ReCODE Health to guide research teams in making responsible and ethical decisions

Learn more about Dr. Zlatar and her colleagues' work:

-> Zlatar, Z. Z., Hays, C. C., Mestre, Z., Campbell, L. M., Meloy, M. J., Bangen, K. J., Liu, T. T., Kerr, J., & Wierenga, C. E. (2019). Dose-dependent association of accelerometermeasured physical activity and sedentary time with brain perfusion in aging. *Experimental gerontology*, *125*, 110679. https://doi.org/10.1016/j.exger.2019.110679

→ Bangen, K. J., Calcetas, A. T., Thomas, K. R., Wierenga, C., Smith, C. N., Bordyug, M., Brenner, E. K., Wing, D., Chen, C., Liu, T. T., & Zlatar, Z. Z. (2023). Greater accelerometermeasured physical activity is associated with better cognition and cerebrovascular health in older adults. *Journal of the International Neuropsychological Society : JINS*, 29(9), 859– 869.

https://doi.org/10.1017/S1355617723000140

→ Hays Weeks, C. C., Moore, A. A., Allison, M., Patrick, K., Bondi, M. W., Nebeker, C., Liu, T. T., Wing, D., Higgins, M., Hartman, S. J., Rissman, R. A., & Zlatar, Z. Z. (2023). The Independent Walking for Brain Health Intervention for Older Adults: Protocol for a Pilot Randomized Controlled Trial. *JMIR research protocols*, *12*, e42980. https://doi.org/10.2196/42980

Selecting and Testing a Digital Health Technology – Clinical Trials Transformation Initiative

→ How to read the terms and conditions Gelinas, L., Morrell, W., & Bierer, B. E. (2023). Terms and conditions apply: an ethical analysis of mobile health user agreements in research. *Journal of law and the biosciences*, *10*(2), Isad021. <u>https://doi.org/10.1093/jlb/Isad021</u> -> Tools and techniques to help ensure data privacy and security

Filkins, B. L., Kim, J. Y., Roberts, B., Armstrong, W., Miller, M. A., Hultner, M. L., Castillo, A. P., Ducom, J. C., Topol, E. J., & Steinhubl, S. R. (2016). Privacy and security in the era of digital health: what should translational researchers know and do about it?. *American journal of translational research*, *8*(3), 1560–1580.

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