Evaluating Maternal Participation in Mobile Health Research

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**Background**

With the advancement of digital technology, mobile health apps facilitate the routine collection of personal health data, constituting an invaluable asset of information to organizations (e.g., government and private). Such data is often easily accessed, raising an interest in utilizing such data for the public good; however, we do not know very much about people’s motivation to share data freely for research purposes. This study explores the willingness of mothers and children with Autism Spectrum Disorder (ASD) to share such information with researchers.

**Objectives**

- Evaluate the feasibility of collecting mobile health data (mHD) for research purposes
- Inform the design of future mobile health research studies

**Methods**

The Caregiver Health and Activity Monitoring Pilot Study (CHAMPS), was a 16-week study asking mothers in the Interactive Autism Network (IAN) – a community-powered research network that focuses on improving the lives on individuals with ASD and their families – to:

- Share their mHD with researchers by connecting their Fitbit to a secure online platform
- Complete 5 monthly brief online surveys about their own perceived physical health, well-being, and Fitbit use. At the beginning of the study, complete an initial survey about activity level. At the end of the study, complete a final survey asking participants to share their feelings and thoughts about their participation.
- Surveys were completed on a study-specific online portal or mobile app. Screenshots of the mobile app are below.

**Methods (continued)**

Eligible IAN mothers were emailed a study invitation to join CHAMPS. Eligibility included:

- Being the mother of a child or adolescent with ASD
- Participating in a previous questionnaire that asked mothers if they owned a Fitbit

Study invitations were sent to two groups as outlined below. A maximum of 60 participants per group were permitted to consent to join the study. All eligible mothers were invited.

- **Group A**: Mothers that currently owned a Fitbit
- **Group B**: Mothers that did not own a Fitbit
- A Fitbit was purchased for this group

**Results**

- **Enrollment**: 109 mothers joined the study. Group A mothers (established Fitbit users) were more likely to consent for the study than Group B (new Fitbit users).
- **Data Collection**: Monthly survey completion ranged from 60% to 100% for group A and ranged from 92% to 98% for Group B.
- **Fitbit use**: 43% of Group A mothers connected their Fitbit to the online platform while 100% of participants connected their Fitbit in Group B.
- **Study completion**: 91 mothers (83%) completed the study. Group B had a significantly higher completion rate than Group A (Group A=63%, Group B=98%; p<.001).
- **Feedback**: Group A concentrated on the positive aspects of contribution to research while Group B focused on their thoughts and experiences using the Fitbit.

**Conclusions**

- The novelty of having a Fitbit, or not, affects participant engagement in the study – completion rates were higher amongst the group that received a new Fitbit and 100% of participants connected their Fitbit to the online platform.
- Fitbit novelty also seems to influence how participants view their participation in research.
- The CHAMPS Study demonstrated the feasibility of collecting mHD from mothers of children and adolescents with ASD via questionnaires, using an online platform or mobile app, and an activity monitor; especially when the device was purchased for them.
- These study findings help guide the design of future health-related research that utilize digital technology.

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**References**