**Commonwealth of Massachusetts**

**Department of Developmental Services**

**Research Review Committee Meeting Minutes**

Date: September 22, 2023

By Teams: Erin Brown (Chairperson), Kathleen Gallagher, Patricia Shook, Joshua Greenberg, Rosalie Edes, Joseph Weru, and Freddy Torbey (observer/minutes)

Additional Attendees: Sofia Langman, Victoria Gill, Tina Ranalli, Krishna Venkatasubramanian

**Agenda Items**

1. Administrative matters.
2. “User study of a self care app prototype specifically designed for people with intellectual and developmental disabilities (I/DD),”

Krishna Venkatasubramanian, PhD, Assistant Professor, Department of Computer Science and Statistics, University of Rhode Island; Tina-Marie Ranalli, PhD, Independent researcher and consultant

**HOUSEKEEPING**

* Chair established quorum
* Chair summarized requirements for approval of research proposals pursuant to 115 CMR 10.08
* Chair presented proposal for discussion

**“User study of a self care app prototype specifically designed for people with intellectual and developmental disabilities (I/DD),”**

Krishna Venkatasubramanian, PhD, Assistant Professor, Department of Computer Science and Statistics, University of Rhode Island;

Tina-Marie Ranalli, PhD, Independent researcher and consultant

Discussion

* RRC discussed Massachusetts’ consent and competency standards for individuals and guardians
* RRC discussed the grade and comprehension levels of proposed assent and consent forms, and possibility of continuous withdrawal of consent
* RRC discussed longevity of data retention, through what software data will be collected, and where it will be stored
* RRC discussed inclusion criteria for participants and the proposed exclusion of non-English speaking individuals, as well as usability of self-care app for non-communicative and non-English speaking persons
* RRC discussed lack of proposed hypothesis, as well as proposed communication software’s own independent retention of recorded data

Issues

* Proposal requires additional assurance clarifying adherence to Massachusetts legal standards as to individuals’ consent and competency in participating
* Proposed documents need to explicitly clarify that data will be retained for no longer than 5 years, that data collected will only be used for this study, and researchers would need to return to RRC for further use of data

Outcome

* Chair moved, and RRC members agreed, to approve proposed study on condition of provision of written assurances regarding adherence to Massachusetts legal competency standards; assurances regarding data and consent form destruction within a 5 year limit; and assurances that data collected will be used exclusively for the purposes of this study

### CONDITIONALLY APPROVED RESEARCH

**“User study of a self care app prototype specifically designed for people with intellectual and developmental disabilities (I/DD),”**

**Krishna Venkatasubramanian, PhD, Assistant Professor, Department of Computer Science and Statistics, University of Rhode Island;**

**Tina-Marie Ranalli, PhD, Independent researcher and consultant**

### NON-APPROVED RESEARCH

None