Empowering Patients to Share Patient-Generated Data through a Grid-Based User Interface

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Background

For individuals with health conditions that require caregivers and clinicians to assist with everyday life such as paralysis or post-surgery recovery, sharing data collected from wearable devices such as Fitbit could be useful for coordinating care and maintaining awareness. However, the detailed nature of the data raises privacy concerns.

Peter (patient)

Should I share my data with them?

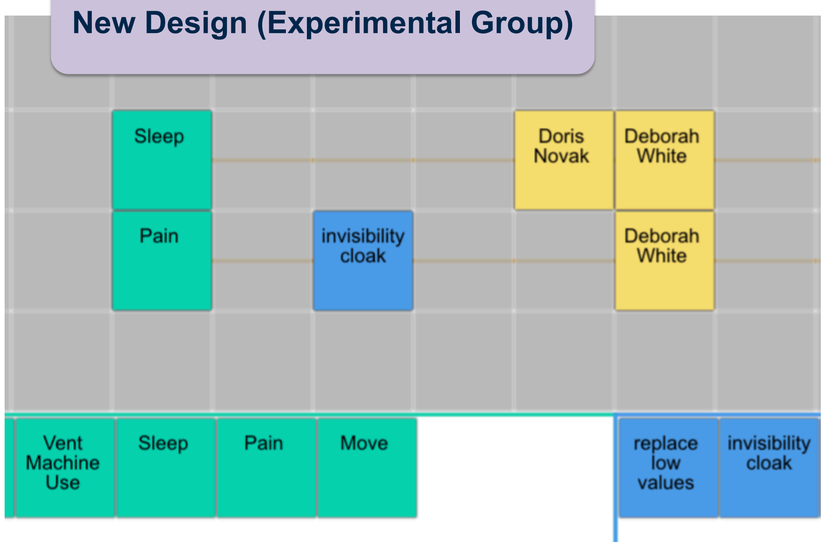
- Did Peter sleep enough yesterday? — Family Caregiver (Mom)
- Why did the heart rate skyrocket here… — Physician
- Peter didn't exercise last week… — Nurse

Proposal

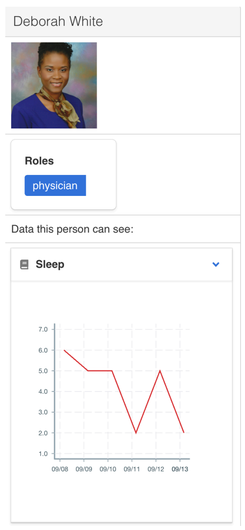
Through interviewing members of the care team and co-designing with a young adult with one such condition, we learned that patients needed the ability to control the details being shared to stakeholders with whom the patient have different relationships, to jump-start the sharing process, and to understand the effect of sharing decisions. Stakeholders were worried about a patient's independence and over-sharing. In other words, systems designed to support such care team arrangement should specifically allow fine-grained control of sharing policies, support easy reuse, and facilitate understanding of sharing policies through data preview [1].

Existing designs for authoring sharing policies are either over-simplified without the capability of fine-grained control, or too sophisticated and hard to master for regular users. We proposed a grid-based user interface that invokes a board game metaphor for users to manage sharing policies. The metaphor utilizes users' familiarity with board games where visual elements are shown on the board directly to represent the game state and can be directly re-arrange to change the state (sharing policies in our case).

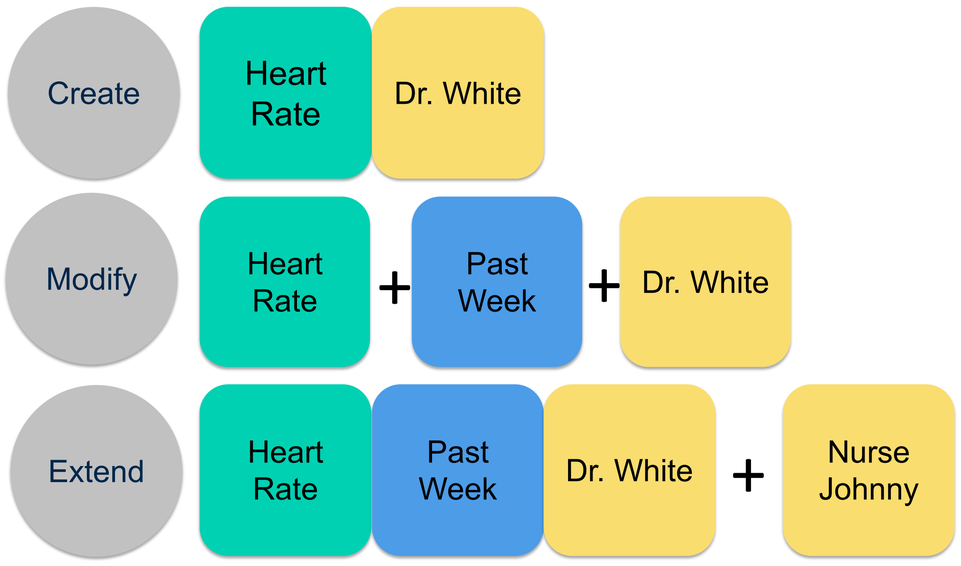
New Design (Experimental Group)



Board Game Inspired grid-based sharing policy management UI that allows fine-grained control and visual grouping



Data preview to facilitate understanding of sharing policies

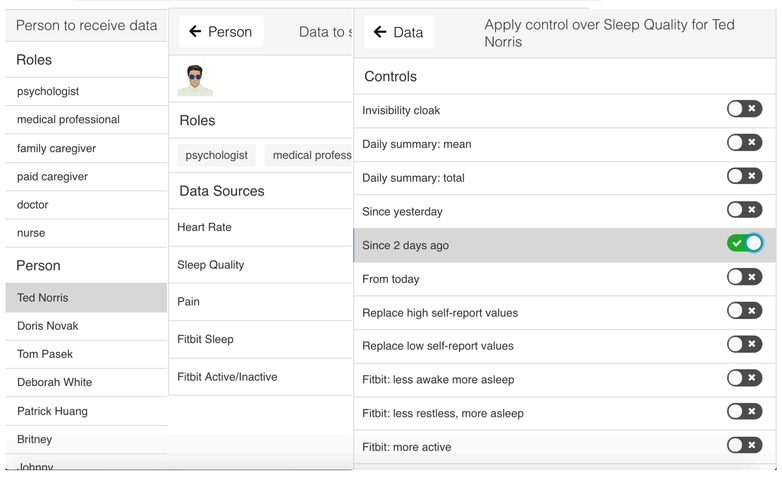


Intuitive support for modification and reuse (e.g., extend to another person) of sharing policies through visual composition

Evaluation

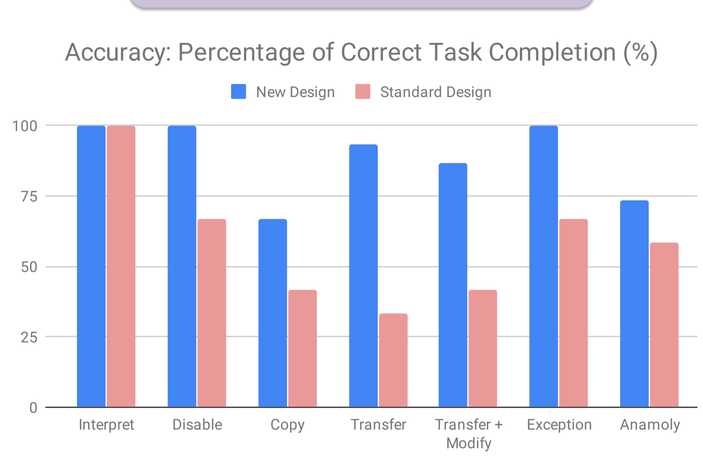
We use a between-subject study design to evaluate our UI design against the one proposed by Bahirat et al. [2], which uses conventional graphic user interface (GUI) widgets. The goal is to see whether people can use the new design to visually manage sharing policies by performing the following tasks: interpret policies, disable policies, copy policies, modify policies, extend policies, make an exception, and find the anomaly. Preliminary analysis shows that participants using new design perform generally better than those using standard design in terms of accuracy rate and speed. Data preview also garners positive feedback to support participants to verify whether they have configured their policies correctly.

Standard Design (Control Group)



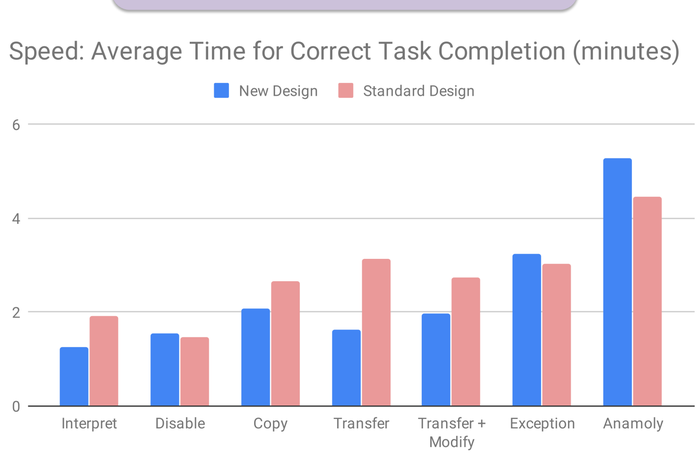
Adapted version of the layered design by Bahirat et al.: each layer provides options to fine-tune data sharing.

Accuracy Rate: New vs. Standard



The new design outperforms standard design by allowing users to correctly completing more of the tasks.

Time to Task Completion: New vs. Standard



The new design outperforms standard design by allowing users to completing tasks correctly quicker.

References

1. Ayse G. Buyuktur, Pei-Yao Hung, Mark W. Newman, and Mark S. Ackerman. 2018. Supporting Collaboratively Constructed Independence: A Study of Spinal Cord Injury. Proc. ACM Hum.-Comput. Interact. 2, CSCW: 26:1–26:25.
2. Paritosh Bahirat, Yangyang He, Abhilash Menon, and Bart Knijnenburg. 2018. A Data-Driven Approach to Developing IoT Privacy-Setting Interfaces. In 23rd International Conference on Intelligent User Interfaces (IUI '18), 165–176.

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