

DESIGN THINKING THROUGH THE BIG GAME

A CASE FOR CO-CREATION TO IMPROVE PATIENT EXPERIENCE IN OBSERVATIONAL CLINICAL RESEARCH

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PAPER ABSTRACT: Cincinnati Cohort Biomarker Programs (CCBP) are conducting qualitative research regarding biomarkers in patients with neurodegenerative diseases. The program is struggling to attract more participants and retain existing participants. This research investigates how to improve the engagement of participants in the program. The research conducted interviews with researchers from CCBP to gain insight into the program and subjects. It is found that a monetary incentive is provided but is not perceived by participants as necessary. In addition, participants are looking for more information regarding the disease and a connection to a community of those who share a similar experience. The Biomarker Idea Generation (BIG) Game is created and used as a co-creation method to generate ideas. This research proposes a new type of incentive in the form of an accessible physical input device connected to digital services. They are perceived to provide a better value than a monetary incentive and further the perception of the program. Due to time constraints, in-depth evaluation in terms of accessibility and production has not yet been reviewed. In the next step, the research is planned to evaluate the accessibility, price structure, cost-to-benefit ratio, and development timeline of the device.

Keywords: Healthcare, Multiple Stakeholders, Observational Clinical Studies, Co-creation, Interview, Game, Hardware, Interface, Incentive, Well-Being, Patient Engagement

1. INTRODUCTION

Cincinnati Cohort Biomarker Program (CCBP) is conducting qualitative research regarding Biomarkers in patients with certain neurodegenerative diseases some of which are Parkinson's or Alzheimer's disease (Sturchio et al., 2020). A biomarker is a biochemical, molecular, or cellular alteration measured in media like tissues, cells, or fluids (Hulka & Garrett, 1993). The program struggles to attract more participants and maintain engagement from existing participants. This happens mostly as many patients with these diseases experience decreased functional mobility (Bouça-Machado et al., 2018) and cognitive ability (McKhann et al., 1984), making it difficult to follow through with the program activities. This research looks into how to improve the quality and longevity of engagement of participants in the program by exploring an alternative to the monetary incentive, which is offered by CCBP at the time of this research. According to the interviews with six of the program's facilitators, we learned that participants seek more information regarding the disease and a connection to a community of those who share a similar experience to pursue needed activities of managing neurodegenerative diseases in a supportive environment. With research showing recurring patterns of challenges in recruiting study participants but not revealing a clear solution to them, we explore alternative perspectives to understand the problems by generating a wide variety of ideas that would positively contribute to the program. With that in mind, the 'Biomarker Idea Generation Game' ('BIG Game') is created and used as a co-creation method to offer a new way of looking at the issue and avoiding the pitfalls of solutionism, and to generate concepts of alternative incentives. The generated ideas were then collected, categorized, and evaluated using a feasibility map. This research proposes a new type of incentive in the form of a unique physical input device combined with a web application that provides information and communication experiences to the patients. They are meant to offer a better value than a monetary incentive and help with well-being aspects that influence program leaving rates. In what follows, we describe our research process and findings that lead to propose a collection of concepts that can engage participants with neurodegenerative diseases in long-term clinical research. An initial assessment of the selected concept will follow with discussions about its value propositions from multiple stakeholder perspectives.

2. PARTICIPATION CHALLENGE

The primary research consisted of semi-structured interviews with researchers from CCBP to gain insight into the CCBP system and how it works, the challenges that recruiters and facilitators are facing, patients' life with the condition, and their motivation for participating in CCBP's clinical research. The examination of biomarkers for neurodegenerative diseases necessitates patients' long-term consistent involvement. The primary objective of the program is to identify different types of neurodegenerative diseases by collecting blood, urine, and stool, and measuring gait, balance, cognitive function, and physical activity in each participant for a minimum of three years to match each one to correct distinct therapies ("For Participants," n.d.). As of this study, the CCBP has 750 active participants out of its goal of 3000. The majority are older adults, who are people over 60 years of age (Older Persons, 2020), comprising 80% of the current participants. Program-related activities must be done with a researcher once every year and last around two hours each time. Participants have to undertake certain tasks, which are sometimes challenging because of their condition, and with little rest to fulfill the requirements for research in the assigned time slot. Due to the nature of the diseases, patients may

encounter limitations in cognitive functions (McKhann et al., 1984) and functional mobility (Bouça-Machado et al., 2018). This limits the possibility of participants scheduling and remembering the appointments, but also of arriving at the physical location of the research, which is currently a necessity, as they start to depend on their families, friends, caregivers, or others to transport them. Within three years, participants may experience a decline in their memory and muscle strength, or even develop other illnesses, leading to the termination of their involvement in the program because of their inability to fulfill all of the program obligations. These factors significantly impact the number of participants who can provide continuous data throughout the program, realized after a three-year involvement. These obligations are mostly necessary for the scientific goals of the project but can be rethought. Telehealth, a way of delivering healthcare via remote technologies (What Is Telehealth, n.d.), could be one of the solutions. It is not a single technology. It is a collection of clinical practices, technologies, and organizational arrangements (Medicine & Services, 2012). But even this way of providing access does not help all of the patients if not provided inclusively. How can the Program goals be achieved while better caring for patients' capabilities and needs? Along with the facilitation, can that additional care be an incentive for participation?

3. CURRENT RECRUITMENT STRATEGY AND CORE VALUE

The recruitment strategy for the program at the time of this research involves a combination of physical and digital communication channels. This includes websites, social media platforms, email newsletters, banners, and hospital networks. A significant portion of the program's current participants is recruited through the hospital networks. More precisely, through the ongoing health programs involving personnel like medical doctors who know best the state their patients are in and if they necessary prerequisites to participate in the program. They are in the best position to contact potential recruits discreetly and effectively. They have their patients' trust, which is a significant factor in people with neurodegenerative illnesses and their caregivers. Conversely, the program's social media presence has been sporadic and has yet to yield significant results thus far. Nevertheless, the program intends to enhance its social media presence and be more proactive in leveraging social media for recruitment in the future, with the remaining hurdles of insufficient employees to work systematically on such media presence and insufficient funds to compensate those employees for additional work.

The program offers only a monetary incentive of 100 USD for each visit and to all participants to encourage their involvement. However, primary research conducted with the researchers has documented participants expressing that while they appreciate the incentives, they put a larger value on being a part of a program that is set to potentially help them and future generations of patients. Moreover, they have expressed a keen interest in gaining more knowledge about the disease, including its effects on their bodies and how to live a happier life despite it. They have also indicated a desire to connect with others who share similar experiences, as many are socially isolated. Creating a community for these individuals could improve their overall well-being and is proven to be beneficial to their health and life expectancy. To better understand the needs of such communities, the study looked into social media groups for caregivers. Caregivers are usually patients' family members, friends, or they are professionals in the field because the patients themselves are mostly not in the condition to participate.

These groups were found to be highly active, with patients and caregivers alike sharing their experiences and seeking guidance from others who have been through similar situations.

4. CO-CREATION METHOD

As a quick fix cannot be offered for such a complex problem, and without knowing some of the aspects that would require far longer and more strenuous research, nine members of CCBP research and staff were included again not to solve the problems but to develop a shared understanding and goals by generating ideas together with the four members of the design team. This was done through a solutionist game we called ‘BIG Game’. A co-creation method like that can highlight play, irony, and the limitations of technology before it is misused in a solutionist manner (Blythe et al., 2015). The Biomarker Idea Generation game has been developed based on insight to help researchers generate concepts. The game consists of five components that are randomly selected and combined. The goal is to provide a broad spectrum of scenarios from the least challenging to the most challenging.



Figure 1. Neurodegenerative disease patient persona cards and caregiver persona cards.

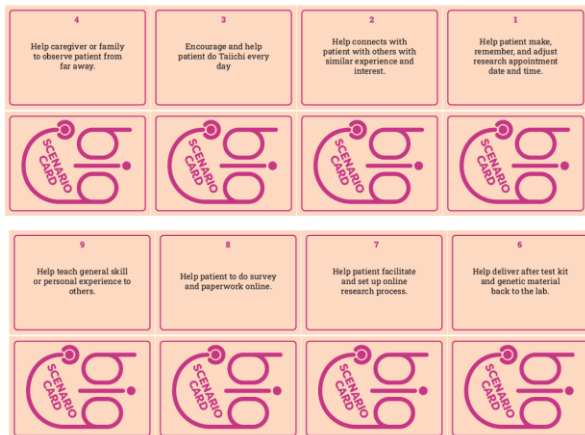
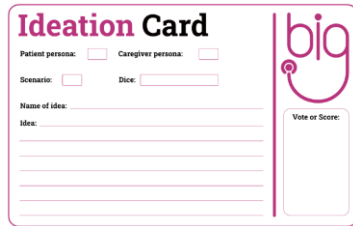


Figure 2. Scenario cards.



The image shows a form titled "Ideation Card" with a "big" logo on the right. The form includes fields for "Patient persona" and "Caregiver persona" (each with a checkbox), "Scenario" and "Dice" (each with a dropdown menu), "Name of idea" (with a text input field), and "Vote or Score" (with a large empty box for writing). There are also several horizontal lines for writing the idea.

Figure 3. Ideation card.

- Neurodegenerative disease affected patient persona card: A set of cards that provide information about the lifestyle and limitations of the patients.
- Caregiver persona card: A second set of cards that provide information about the caregiver to create unique scenarios when combined with the patient persona.
- Activity card: A set of cards that provide activities that, when combined with both personas' cards, create a unique challenge specific to each combination of the personas.
- Ideation card: Cards that provide a template for players to write down their scenario and generate their final idea.
- Technology dice: When rolled, a die provides technological direction that the player must follow to solve the scenario.

In every round, each player randomly selects a patient, caregiver, and task card, and then rolls the dice. The four are combined into a scenario, and the player then has 15 minutes to generate a concept solution and write it into the ideation card. After the timer is up, each player is tasked to present their idea and try their best to persuade other players to vote for their idea. The players then anonymously vote for the idea they think is the most helpful to the research and record their vote into their ideation card. The card is then collected for another round. The game is played for three rounds, and each player's accumulated vote is counted. Those who get the most votes will be named the session's winner. Four different CCBP members and design team members played each session with three rounds to see how different players understand the prompts and their connection to the program.

There are two main reasons that we came up with the point system. Firstly, the game was devised to be challenging and fun to play so that the players feel engaged and interested in producing and presenting their best ideas and realize the level of playfulness and irrationality maintained throughout the process. But more importantly, a way to quickly evaluate the ideas was needed, as the game was designed to be generative and quantitative, more specifically to facilitate the generation of a large number of ideas. We believe that the ideas that have received more votes from participants are the ideas that are more feasible or needed in practice based on the players' collective experience.

5. RESULTS

The game's results showed 36 ideas, of which eight were voted as winning concepts, and another five were assessed as equally or more feasible than winning ones and added to the consideration for the final concept. These results have proven the co-creation game design successful based on the

requirements developed. Some of the ideas leaned more towards a novel use of technology like a caregiver camera system, some towards organized social activities like practicing Taiichi or having a friend-finding system, and some towards granting a specific set of information to the user. The number of different perspectives on what could help with their problem finally made it easy for the design team to begin to flesh out something systematic. The ideas were evaluated through feasibility mapping by being put on the usability-cost matrix. The matrix showed a high range of cost per idea but relatively high usability of all of the ideas. Moreover, as many ideas were narrowed down into a social or information space, and one idea of a simple button for patients' needs was evaluated as very usable and averagely costly, it was taken as a vessel to implement the rest of the ideas into a single concept.



Figure 4. 32 out of the total 36 ideas generated through the gameplay.

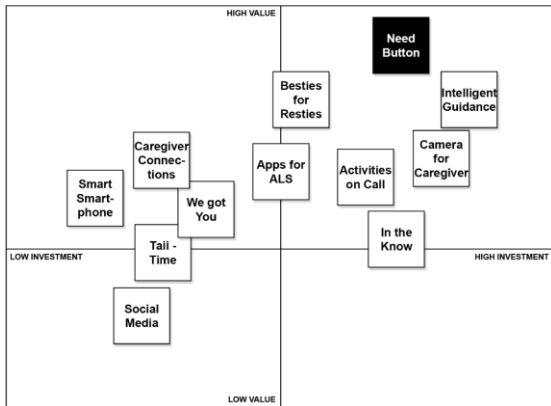


Figure 5. Feasibility mapping of generated ideas.

The concept of “Big Button” was chosen for further development. It consists of a hardware input device that provides simpler access to digital telemedicine and well-being services as an incentive to participate in clinical studies. The big button interfaces offer accessibility based on primary research insights from facilitator interviews, and cognitive and emotional familiarity to the study participants with neurodegenerative diseases. This was achieved through market research of input devices from the 1970-1990 era, which were assessed as more familiar and more emotionally impactful to individuals who were children or young adults in that time period. By benchmarking similar products in the market,

the development team was able to ensure that the cost structure of the device was feasible, meaning that it could be produced at a reasonable cost, more specifically at a cost lower or similar to the monetary incentive used by CCBP at the time of research.

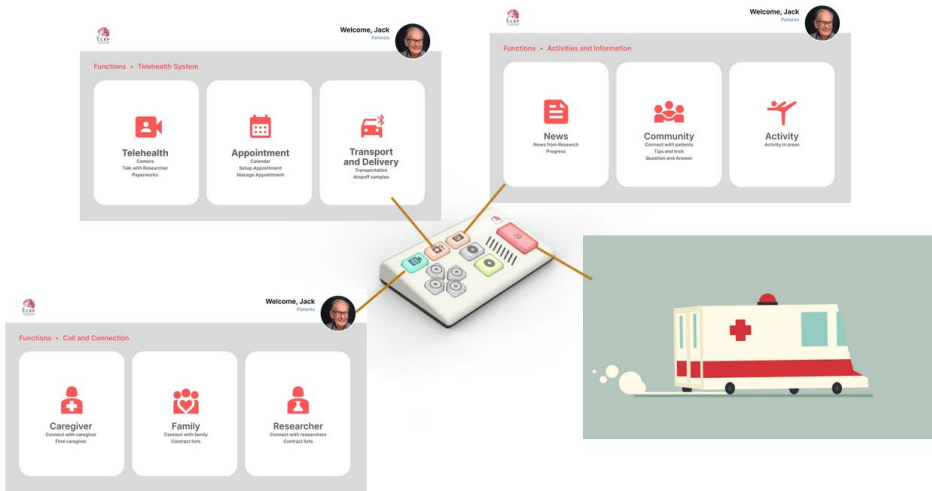


Figure 6. BIG Button product scheme.

The resulting concept is a simple input device that connects to any of the user’s computing devices and features enlarged, spaced-out buttons with descriptive icons. This interface works in conjunction with a software program consisting of local or web applications that allow patients to access various functions, such as telehealth appointments and calendars, from within the program. It is also an accessible connector to various well-being applications, such as video calls, social media, and information databases for neurodegenerative illnesses and CCBP progress, providing patients with easy access to these resources.

Even though it requires of the user to have some kind of a computing device and a screen, one key advantage of the "Big Button" is that it mainly acts as a low-barrier access point to already existing digital services that can provide constant access to medical knowledge bases and reminders of study participation. This means that the development and maintenance are not connected to the physical device and thus can be done at a lower cost. This allows for an interesting, cost-effective solution for research programs such as CCBP, providing significant accessibility, peace of mind, and daily well-being benefits to patients. We expect the Big Button would be well integrated into patients’ life context to remind their connection to the CCBP community of support, eventually contributing to a positive impression of CCBP as a program for patients, families, and caregivers alike and reminds them of the program and its values of positive change daily rather than only once a year. Consequently, this should improve the program's patient recruitment numbers and retention of the patients in the program through the years.

6. CONCLUSION AND NEXT STEPS

The co-creation of the BIG game was a success in idea generation, and the game design choices, like the rounds being timed and ideas being voted for, have been fruitful with the total number of ideas and

with the winning ideas being the best ones in later assessment. The initial evaluation with CCBP suggested that implementing the "Big Button" device could potentially improve participation and engagement with the program. This is because the device offers a more meaningful and usable incentive for patients to participate in the program, as it provides them with easier access to their personal devices and allows them to engage with various functions and applications.

Our research has contributions to adopting a generative method and exploring alternative perspectives through ideating and prototyping conceptual design systems by involving clinical researchers and program facilitators. In other words, we take a service design approach to develop a shared understanding of the problem and explore alternative solutions from multiple stakeholder perspectives. This paper focuses on the process of idea generation and initial proof of concepts. Based on the positive feedback from the stakeholders in CCBP, future work will follow to develop a high-fidelity prototype to assess its usability, accessibility, price structure, and cost-to-benefit ratio for further development. A deployment study with patients, especially the ones unable to continue with the program, will also be conducted to investigate the impact of the proposed design system as an alternative incentive to participate in clinical research.

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