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Young People's Barriers, Motivations and Contributions towards MY GENE: Mixed-Methods Approach

Beatriz Sofia Martins Alves

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Beatriz Sofia Martins Alves

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Resumo

Este estudo investiga o impacto da participação de jovens em estudos sobre a Experiência de Utilizador (UX), focando-se tanto nas suas contribuições específicas para o *design*, impacto emocional e usabilidade da plataforma *MY GENE*; como nas barreiras e motivações gerais que influenciam a participação de jovens em estudos de investigação científica. Os dados foram recolhidos através de uma combinação de tarefas de avaliação de UX; da versão em português europeu da *System Usability Scale* (SUS); da versão portuguesa reduzida da Escala de Afetos Positivos e Negativos (PANAS-VRP); e de perguntas abertas complementares a estas escalas. A recolha de dados foi realizada online através da plataforma Loop 11.

Os resultados revelam que os jovens forneceram novos *insights* e ideias para a melhoria da plataforma, resultando em contribuições que não tinham sido previamente sugeridas pelos participantes adultos. A plataforma recebeu uma classificação de usabilidade "C", indicando um nível de usabilidade moderado, tendo sido associada a um impacto emocional predominantemente positivo. O estudo identifica desafios logísticos como a principal barreira para a participação dos jovens em estudos de investigação científica no geral, enquanto recompensas extrínsecas foram identificadas como o principal fator motivacional para essa participação.

Estes resultados enfatizam a importância de envolver jovens em estudos de UX de modo a englobar as suas perspetivas únicas, cruciais para o desenvolvimento de plataformas mais intuitivas e apelativas. As conclusões deste estudo servem de base para melhorar a plataforma MY GENE e fornecem recomendações para futuras estratégias que incentivem a participação de jovens em investigação científica.

Palavras-chave: Experiência de Utilizador, saúde digital, envolvimento jovem, co-criação, experiência emocional, psicologia, motivação.

Abstract

This study investigates the impact of involving young people in User Experience (UX) research, focusing both on their specific contributions to the design, emotional impact, and usability of the MY GENE platform; and on the general barriers and motivations that influence young people´s participation in scientific studies. Data was collected through a combination of UX evaluation tasks; the european portuguese version of the System Usability Scale (SUS), the portuguese reduced version of the Positive and Negative Affect Schedule (PANAS-VRP); and supplementary open-ended questions. The data collection was performed online via Loop 11 platform.

The results reveal that young participants provided new insights and ideas for the platform's improvement, resulting in contributions that had not been previously suggested by adult participants. The platform received a usability grade of "C," indicating moderate usability, and was associated with a predominantly positive emotional impact. This study identifies logistical challenges as the most significant barrier to youth involvement in scientific research in general, while extrinsic rewards were identified as the main motivational factor for that participation.

These findings emphasize the importance of involving young people in UX research to capture their unique perspectives, which are crucial for developing more user-friendly and engaging platforms. This study's insights serve as a foundation for improving MY GENE platform and to offer recommendations for future strategies to encourage youth participation in scientific research.

Keywords: User Experience (UX), digital health, youth engagement, co-creation, emotional experience, psychology, motivation.

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1. Introduction

1.1. The Rise of Digital Health

Recent advancements in technology have profoundly transformed numerous sectors, with healthcare being one of the most significantly impacted. Digital health, as defined by the World Health Organization (WHO), encompasses the use of digital technologies to enhance health and well-being. This includes tools such as mobile health (mHealth) applications, wearable devices, telemedicine, and electronic health records (World Health Organization & International Telecommunication Union, 2020).

For instance, mHealth applications empower individuals to monitor their health metrics, receive medication reminders, and access educational resources, thus promoting proactive health management and potentially reducing the need for hospital visits (Wong et al., 2020). Wearable devices provide continuous health data crucial for managing chronic conditions and improving preventive care, while telemedicine expands access to healthcare services, particularly benefiting individuals in remote areas, including those needing mental health support (Ghose et al., 2021). The COVID-19 pandemic of 2020 served as a catalyst for unprecedented advancements in the field of digital health, accelerating its development out of necessity as healthcare systems adapted to new challenges and the urgent need for remote care solutions (Ahmed et al., 2022).

Digital health innovations not only reshape healthcare delivery but also enhance the accessibility, personalization, and outcomes of patient care (Wong et al., 2020). They play a critical role in public health education, enabling individuals to access a wide variety of health-related information, which empowers informed decision-making and promotes greater self-efficacy (Jokisch et al., 2022). However, the vast amount of information available online raises concerns regarding its accuracy and trustworthiness, as misleading information can lead to poor health decisions and outcomes (Ghose et al., 2021). Therefore, it is imperative that digital health tools provide reliable, evidence-based information to ensure users can make informed choices about their health.

1.2. User Experience (UX) and Emotional Design

A critical determinant of the success of digital health interventions is the quality of User Experience (UX). The International Organization for Standardization (ISO) defines UX as the "perceptions and responses that result from the use or anticipated use of a product, system, or service" (ISO 9241-210, 2010). This definition underscores the importance of understanding not only how users interact with digital tools but also how they perceive these interactions. Key attributes within the UX framework include usability, which refers to the effectiveness with which a product can be used, incorporating factors such as ergonomics and accessibility (Capdevila et al., 2021).

In the context of UX, "engagement" refers to the degree of attention, interest, and emotional connection users experience with a product (Oyedele et al.,, 2018). Effective UX design must address cognitive, emotional, and behavioral needs, extending beyond mere visual and functional elements (Norman, 2008). According to Self-Determination Theory (SDT), individuals are most motivated and engaged when their needs for autonomy, competence, and relatedness are fulfilled (Ryan & Deci, 2024). When users feel their input is valued and that they have control over their interactions with technology, their intrinsic motivation and satisfaction with the product can increase.

Donald Norman (2008) emphasizes the significance of emotional design, which involves creating products that evoke positive emotional responses, enhancing user engagement and satisfaction. Hassenzahl and Tractinsky (2006) further illustrate how emotional experiences impact user satisfaction, demonstrating that designs that elicit positive emotions foster better engagement. Given the influence of emotional factors on UX, it is essential to integrate emotional design alongside usability in digital health interventions (Norman & Verganti, 2014).

1.3. Design Thinking and Co-Creation in Psychology

The Design Thinking model provides a practical framework for integrating these psychological principles into UX design. This user-centered approach comprises five iterative phases: Empathize (understanding user needs), Define (articulating the problem), Ideate (brainstorming solutions), Prototype (developing concrete products), and Test (evaluating prototypes with users for refinement) (Brown, 2008). This process enhances UX design's ability to meet users' needs and improve engagement.

An effective strategy for enhancing UX is co-creation, which refers to the process where users actively participate in the design and development stages of a product (Ind & Coates, 2013). By fostering close collaboration, co-creation ensures that the final product aligns with user needs and preferences, leading to more relevant and effective digital tools (Abbate et al., 2019). Despite increasing focus on UX in digital health, psychological research has often concentrated on design and engineering aspects, neglecting a deeper understanding of users' psychological motivations and engagement strategies. Although much is known about how design elements affect user satisfaction, there is a notable gap in understanding how to effectively engage users in the design process itself (Hassenzahl, 2010; Norman, 2002).

This gap is particularly significant concerning the involvement of young people in co-creation efforts. Engaging youth in developing digital health tools is vital, as their perspectives and experiences can yield valuable insights for creating more effective and inclusive solutions. However, young people are often underrepresented in these processes (WHO, 2020), resulting in missed opportunities to address their needs and preferences. This study will explore the role of youth engagement in co-creation, focusing on the MY GENE platform, designed to enhance family communication regarding genetic cancer risk.

1.4. Psychosocial Genetics and MY GENE Platform

Psychosocial genetics is the intersection of genetic information and the psychological, social, and emotional factors that influence how individuals process and respond to genetic risks. This concept is particularly relevant for families with a genetic predisposition to diseases such as cancer, where communication, coping strategies, and decision-making are significantly affected by the emotional complexities surrounding genetic information (Etchegary et al., 2010). One of the primary challenges in this context is disclosure—the process of sharing genetic risk information with family members. Parents often struggle with how much to disclose to their children, balancing the desire to protect them from distress with the need to promote informed decision-making regarding health (Klitzman et al., 2011).

Effective communication about genetic risks is vital, as it influences both the psychological adjustment of individuals to this information and the adoption of preventive health behaviours that can mitigate these risks. In certain hereditary cancer syndromes, patterns of cancer occurrence often reflect one another, highlighting the need for clear communication regarding the potential for developing related diseases. Research indicates that open, informed discussions about genetic risk within families can lead to positive outcomes, including reduced anxiety and an increased likelihood of children adopting preventive health measures (Abad et al., 2024).

However, communicating genetic risk to younger individuals presents unique challenges. Adolescents and children may struggle to understand complex genetic information, which can lead to misunderstandings and increased anxiety in the face of uncertain health risks. This challenge is often exacerbated by variations in family dynamics, educational backgrounds, and cultural contexts that influence how genetic information is shared and comprehended (Werner-Lin et al., 2012). Families frequently report feeling under-equipped to navigate these emotionally charged discussions, heightening their anxiety and uncertainty (Werner-Lin et al., 2018).

Given these challenges, tools that facilitate supportive, age-appropriate conversations about genetic risk are invaluable. Families require resources that not only convey accurate information but also guide them through the emotional intricacies of discussing genetic risks (Werner-Lin et al., 2018). The MY GENE platform was developed to address this need as part of the "PLAY-THE-ODDS" exploratory project. Funded by the FCT- Fundação para a Ciência e Tecnologia (EXPL/PSI-GER/1270/2021) and conducted by the Centro de Psicologia da Universidade do Porto, this initiative brought together experts in genetic counselling, psychology, communication design, and gamification to co-create solutions for improving parent-child communication about genetic cancer risk.

Designed as a digital city, the MY GENE platform includes various features to facilitate conversations between parents and children about genetic risks. Although the tool was developed using a co-creation approach, it is essential to note that young people were not included in the initial design process, which primarily involved adults. This exclusion creates a need to explore how integrating young people's perspectives can enhance the platform's effectiveness.

1.5. Research Objectives

This study aims to address the gap created by the exclusion of young people in the design process by integrating their perspectives into the platform's development. In line with the goals of this research, the following research objectives were established: (1) evaluate the usability of the MY GENE platform from the perspective of young people; (2) assess the emotional impact of the MY GENE platform on young users; (3) gather relevant feedback from young participants to improve the MY GENE platform; (4) identify barriers to youth engagement in research; and (5) identify motivations for youth engagement in research, with the aim of promoting better future practices.

2. Method

2.1. Empirical Study

A mixed-methods approach was selected for this study to thoroughly address the research objectives. This approach integrates both quantitative and qualitative methods, enabling a richer and more comprehensive analysis of the results. This combination of methods facilitates the exploration of the meanings and reasons behind the quantitative findings, as qualitative insights provide valuable context to the numerical data (Clark & Ivankova, 2015).

The quantitative component consisted of UX evaluation tasks; a usability assessment using the System Usability Scale (SUS); and an assessment of the platform's emotional impact on users, measured by the Positive and Negative Affect Schedule (PANAS-VRP). In contrast, the qualitative aspect involved open-ended questions, allowing participants to express their thoughts in their own words, providing deeper insights into their experiences.

2.2. Participants

Although 17 young people expressed interest in participating, seven of them and/or their legal guardians did not fill out the informed consent forms (*Appendix A),* which prevented them from accessing the link to participate in the study. Consequently, the study included only 10 participants, aged between 14 and 17 years (M = 15.8, SD = 0.92), with 60% identifying as female and 40% as male.

Inclusion criteria for this study were: (1) participants being aged between 13 and 17 years old; and (2) participants not belonging to a family with a known genetic cancer risk. The second criterion was guided by ethical guidelines that emphasize that individuals should have the option to make informed decisions about genetic testing (European Society of Human Genetics, 2009). Since predictive genetic testing for adult-onset conditions is generally recommended to be delayed until adulthood (18 years or older in Portugal), adolescents from families with known genetic risks were excluded from the study, to prevent including individuals who may not yet know whether they carry a genetic mutation. Recruitment was conducted using convenience and snowball sampling techniques, chosen for their practicality in reaching the targeted age group within limited time and resources (Leighton et al., 2021).

Despite the small sample size, research by Nielsen (1999), a leading expert in UX, indicates that testing with just five users can uncover approximately 85% of usability problems. These findings highlight the efficiency of small-scale usability testing in identifying key issues and guiding improvements.

2.3. Informed Consent and Right to Privacy

This study followed ethical guidelines outlined in the Declaration of Helsinki (World Medical Association, 2014) and national legislation. Participants and their legal guardians signed an informed consent (*Appendix A*) before participating and were informed of their right to withdraw from the study at any time without penalty. Participants who did not complete the consent form, or whose responsible guardians did not provide consent, were excluded from the study.

Google Meet was selected as the platform for holding the online meeting due to its secure communication features, including end-to-end encryption (Google, n.d.). To ensure privacy, screen sharing and recording were disabled. All data collected via the Loop 11 platform were encrypted and protected, as the platform complies with strict security protocols (Loop 11, n. d.). Participants were assigned random unique identification numbers to ensure confidentiality during data analysis.

2.4. Instruments

The data were collected through an online questionnaire specifically developed for this dissertation (Appendix B). The questionnaire combined and adapted validated instruments for the Portuguese population.

2.4.1. Demographic Data

The initial section of the questionnaire collected demographic information to contextualize participants' background, focusing on age and gender. No additional sociodemographic data was collected since it was not relevant to the analysis or to address the study objectives.

2.4.2. UX Evaluation Tasks

Participants performed four evaluation UX tasks, which were adapted from a validation session of the MY GENE platform, conducted in November 2023 with adult users. These tasks aimed to assess platform usability (Research Objective 1) by focusing on typical user actions. The specific tasks were: “Navigate the platform map to find the city” (UX task 1); “Navigate the city map to find the hospital” (UX task 2); “Navigate the city map to find the library” (UX task 3); and “Navigate the library to find genetic testing information” (UX task 4).

2.4.3. System Usability Scale (SUS)

The usability of the MY GENE platform was evaluated not only through UX tasks but also using the System Usability Scale (SUS). The SUS is a widely utilized usability-assessing tool consisting of 10 items rated on a 5-point Likert scale (1 = Strongly Disagree to 5 = Strongly Agree). This instrument was chosen due to its extensive validation and ease of administration, making it a suitable tool for usability evaluation (Research Objective 1), even with small samples (Brooke, 1996; Sauro & Lewis, 2016).

For this study, the European Portuguese version of the SUS (Martins et al., 2015) was utilized, as all participants were Portuguese speakers. To better align with the context of the study, the term "produto" (product) in the original translation was replaced with "plataforma" (platform). Research shows that replacing terms in SUS items (such as "system" with "website" or "product") does not affect the scores significantly (Lewis & Sauro, 2009).

2.4.4. Positive and Negative Affect Schedule (PANAS-VRP)

The Positive and Negative Affect Schedule (PANAS) was employed to assess the emotional impact of the MY GENE platform on young users (Research Objective 2). Developed by Watson, Clark, and Tellegen (1988), PANAS measures two dimensions of affect: Positive Affect (PA) and Negative Affect (NA). It is important to note that, although all emotions are important and no emotions are inherently positive or negative, the terms “positive emotions” and “negative emotions” are used in this study for practical reasons. These terms specifically refer to the PANAS-VRP subscales and related work, following the original terminology of the instrument.

The PA score reflects the extent to which participants experience five “positive emotions”: “interessado/a” (interested); “entusiasmado/a” (entushiastic); “inspirado/a” (inspired); “ativo/a” (active) and “determinado/a” (determined). According to the authors who developed the original PANAS, scores in the higher ranges indicate stronger positive emotional experiences. On the other hand, NA score indicates the extent to which participants feel “nervoso/a” (nervous); “amedrontado/a” (apprehensive); “assustado/a” (frightened); “culpado/a” (guilty); or “atormentado/a”(distressed), typically perceived as “negative emotions”. Lower scores are indicative of reduced negative emotional impact, whereas higher scores suggest more intense negative feelings, according to the same authors.

For this study, the Portuguese Reduced Version (VRP) of PANAS (Galinha et al., 2014) was chosen due to its shortness and relevance to Portuguese speakers. This version's brevity was particularly useful in maintaining participants' attention during the study since multiple scales were administered (Alwin & Beattie, 2016).

2.4.5. Open-Ended Questions

Qualitative data were collected through open-ended questions integrated into the SUS and the PANAS-VRP scales. After completing PANAS-VRP, participants were asked two questions: “While using the MY GENE platform, please tell us what brought up the most positive emotions and why” and “While using the MY GENE platform, please tell us what brought up the most negative emotions and why” (Research Objective 2). Following the completion of the SUS, participants where asked: “If you could change something in the platform to improve it, what would it be and why?” to obtain specific feedback regarding the MY GENE platform (Research Objective 3).

At the end of the questionnaire, participants answered two additional open-ended questions to explore their motivations and barriers regarding participation in scientific research: “What obstacles could prevent you from participating in a scientific research study, even if it is different from this one?” (Research Objective 4) and “What are your main motivations for participating in a scientific research study, even if it is different from this one?” (Research Objective 5).

2.5.Procedure

2.5.1. Data Collection Procedure

Data were collected through the Loop 11 platform via an online questionnaire, administered during two synchronous group video calls held on July 26th and July 28th at 3 PM (Lisbon time). Although the initial plan was to conduct a single session, the data collection was expanded to two separate sessions to accommodate participants' availability and maximize overall participation. Each session included different participants who had no prior interaction, minimizing potential bias. To ensure the reliability of the findings, both sessions were conducted under consistent conditions. The researcher remained in the same location, utilized the same online platform and materials, and scheduled the sessions at the same time of day to improve control over environmental factors.

The study link was initially distributed through personal networks and shared on social media (Facebook, Instagram, WhatsApp). Given the participants were minors, the link requested the email addresses of their legal guardians, to whom informed consent forms were subsequently sent (*Appendix A*). The video call link was provided to participants only after the signed consents of both the participants and their guardians were received via e-mail.

Each video session opened with a personal introduction from the researcher, followed by a brief slide presentation (*Appendix C*) on genetic cancer risk and family communication, to help contextualize the MY GENE platform for participants. The participants were then directed to the study link and completed the questionnaire without any time limits, fostering thoughtful and reflective responses.

2.5.2. Data Analysis Procedure

The UX tasks were evaluated based on predefined criteria: "success" (completing the task) and "failure" (not completing the task). Task completion time and errors were not measured. According to Nielsen (1992), a failure rate above 30% typically indicates significant usability issues, which was the chosen benchmark for this analysis.

To evaluate the SUS score, participants' individual responses were converted to a single score between 0 and 100. Positive items (1, 3, 5, 7, 9) had 1 subtracted from their raw score, and for negative items (2, 4, 6, 8, 10), the raw score was subtracted from 5. These scores were then summed and multiplied by 2.5 to obtain a final score. Individual SUS scores do not have a statistical meaning. To analyse the final SUS value from a richer perspective, a combination of three common interpretation methods were used: the Benchmark Method, where scores above 68 are considered above average (Brooke, 1996); the Grading Scale Method, where scores are translated into letter grades (A to F) to rank usability (Bangor et al., 2008); and the Percentile Ranking Method, where SUS scores are compared to broader distributions of usability scores via percentiles (Sauro & Lewis, 2016).

In what concerns the PANAS-VRP, the PA and NA scores were calculated by summing participants' responses to each subscale. PANAS authors considered that scores above the mean of 8 on the Negative Affect scale were considered high, indicating a substantial presence of negative emotions, which was established as this study benchmark. Regarding the positive affect (PA) subscale, the authors suggested that scores above the mean of 15 are indicative of high levels of positive affect, while scores below this range reflect lower levels of positive emotions, which was considered the reference for that analysis. Cronbach’s Alpha was used to evaluate the reliability of both PA and NA subscales and a Pearson Correlation analysis was conducted to explore relationships between PANAS-VRP scores and SUS scores. Data obtained from these instruments were entered, coded, and analysed using IBM Statistical Package for the Social Sciences (IBM SPSS®), version 29 for Windows.

Responses to open-ended questions were analysed using thematic analysis, following Braun and Clarke's (2006) guidelines. Themes were identified by coding responses and grouping them into broader categories relevant to the research objectives. Following the recommendation of Creswell and Poth (2016), the analysis focused on three to five key themes to maintain clarity and avoid excessive fragmentation. Given the small dataset, qualitative responses were analysed manually without specialized software.

3. Results

3.1. UX Evaluation Tasks

The results of the UX evaluation tasks are shown in *Table 1*. Tasks 2 and 3 showed a perfect success rate of 100%. While tasks 1 and 4 had slightly lower success rates—90% for task 1 and 80% for task 4—these values still exceeded the established benchmark for usability concerns. According to this benchmark (which identifies usability issues when the failure rate exceeds 30%, meaning success rates below 70%), none of the tasks raised critical usability problems.

Table 1

Success Rate of UX Evaluation Tasks

Task Number	Success Rate (in %)
Task 1	90
Task 2	100
Task 3	100
Task 4	80

3.2. SUS Scores

The individual and total SUS scores for the MY GENE platform are shown in *Table 2*. The final SUS score for the MY GENE platform was 74, on a scale from 0 to 100. This score indicates above-average usability according to Brooke's (1996) benchmark of 68. Based on Kortum and Miller's (2008) grading scale, the score corresponds to a "C" grade, or "good" usability, since it falls within the 70–79 range. Finally, Sauro and Lewis's (2016) percentile ranking places the platform in the 70th percentile, meaning it outperforms 70% of systems evaluated with the SUS.

Table 2

SUS Scores- Individual and Total

Participant Code	Odd-numbered items adjusted sum	Even-numbered items adjusted sum	Individual Total	Score (Individual Total x 2.5)
1	15	14	29	72.5
2	15	18	33	82.5
3	15	15	30	75.0
4	13	15	28	70.0
5	10	16	26	65.0
6	15	13	28	70.0
7	13	13	26	65.0
8	17	16	33	82.5
9	14	15	29	72.5
10	17	17	34	85.0
				74.0

3.3. PANAS-VRP

3.3.1. Positive Affect Subscale

The results for the Positive Affect score are summarized in *Table 3.* .For this subscale, the Cronbach's Alpha coefficient was 0.86, indicating excellent internal consistency and demonstrating that the items within this subscale are highly correlated and effectively measure the Positive Affect construct. The mean Positive Affect score was 16.80 (SD = 2.74), with a range from 13 to 21. This score falls within the higher range, considering the stablished benchmark of 15 (Watson et al., 1988), suggesting that participants experienced a high level of positive emotions while using MY GENE platform.

Table 3

PANAS-VRP Scored- Positive Affect Items

Participant Code	Positive Affect Items
1	17

2	14
3	18
4	21
5	14
6	21
7	16
8	17
9	13
10	17
	16.80

Following the PANAS-VPR scale, participants were asked to describe what generated the most positive feelings while using the platform. The results are summarized in *Table 4*.

Table 4

What Generated More Positive Emotions (PANAS-VPR)

Category	Subcategory	Definition	Quotes
Successful Task Completion	Personal Achievement	Sense of pride derived from successfully completing tasks and feeling capable.	"Whenever I was able to complete the tasks required, it was a good feeling (…) I felt confident that I could do what was expected." (P3)
	Self-Efficacy	Emotional satisfaction and improved confidence as a result of self-worth successfully completing the tasks.	"(…) gave me a nice sense of pride for doing it on my own." (P7) "I was relieved to realize that I did all

			the tasks without help even without knowing the topic (…).” (P4)
Learning Something	Discovering something new	Satisfaction from learning about different concepts	“(…) I felt excited because I was exploring something new and different (…)” (P1)
	Overcoming a Challenge	Personal satisfaction from successfully learning something perceived as difficult.	“(…) I was learning something new, which made me feel smart because it’s a difficult topic to understand.” (P9)
Contribution to a Meaningful Cause	Altruism	Satisfaction from contributing to a cause that aims to help other people	“I was happy to contribute to something that could really help.” (P10)
	Personal Relevance	Satisfaction from contributing to a cause that is similar to causes that may help the participant or someone they know	“ (…) health issues made me feel more connected to the project, as I have a brother with diabetes so I know how important this is.” (P2)

When the participants were asked about what brought up more positive emotions while using MY GENE platform, three main categories where identified: “Successful Task Completion”; “Learning”; and “Contributing to a Meaningful Cause”.

"Successful Task Completion" refers to how successfully completing tasks on the platform positively impacted participants' emotions. Participants reported a sense of "Personal Achievement", feeling proud and intellectually satisfied from successfully completing the tasks (P3). This category also includes "Self-Efficacy", where users reported experiencing cognitive fulfilment not only from completing the tasks successfully but specifically from doing so independently, indicating an enhanced sense of self-efficacy. (P4, P7).

The second category, "Learning" refers to the positive emotions associated with gaining new knowledge. Participants identified **"**Discovering Something New" as a rewarding experience, with some of them reporting that they were initially unfamiliar with both the theme and platform and found them interesting (P1). Additionally, some participants expressed satisfaction in "Overcoming a Challenge," sharing feelings of pride in their ability to navigate the platform and learn about a topic they perceived as complex (P9).

Lastly, "Contribution to a Meaningful Cause" reflects the fulfilment participants felt from supporting a cause that resonated with them in a direct or indirect way. This theme includes "Altruism," where users felt a sense of satisfaction from contributing to a platform aimed at helping others (P10); and "Personal Relevance," with participants feeling a deeper connection to the cause due to personal experiences related to health issues (P2).

3.3.2. Negative Affect Subscale

The results for the Negative Affect score are summarized in *Table 5.* The Cronbach's Alpha for the Negative Affect subscale was 0.64. While this value suggests a moderate level of internal consistency, it is lower than the ideal threshold of 0.70, which may indicate that the items within this subscale are less cohesive in their measurement of Negative Affect. In this study, the mean Negative Affect score was 6.70 (SD = 1.83), with a range from 5 to 11. This relatively low mean score - considering Watson and colleagues (1988) suggested 8 as a benchmark- suggests that participants did not experience a significative amount of negative emotions while using the MY GENE platform.

Table 5

PANAS-VRP Scored- Negative Affect Items

Participant Code	Negative Affect Items
1	7
2	5
3	7
4	8
5	11
6	7
7	6
8	6
9	5
10	5
	6.70

Following the PANAS-VPR scale, participants were not only asked to describe what generated the more negative feelings while using the platform but also what generated the less positive ones. The results of that question are summarized in *Table 6.*

Table 6

What Generated More Negative Emotions (PANAS-VPR)

Category	Subcategory	Definition	Quotes
Technical Problems	Navigation Difficulties	Difficulties using platform's features.	"The map sometimes misled me. It seemed like I could click on certain things, but then I couldn't (…)" (P2)
	Slow Performance	Slow website performance, with longer waiting	"I don´t know if my internet was slow, but the platform took a long time to

		periods than expected	process (…) made me impatient." (P6)
Emotional Factors	Sadness	Emotional discomfort related to the sensitive content presented in the platform.	"I felt sad (…) thinking about the genetic risk and how difficult it must be to live with that concern." (P4) “(….) I felt sorry for the families going through this." (P3)
	Boredom	Feelings of boredom regarding the platform's content.	"I felt a bit bored overall." (P9) "I found the site somewhat monotonous (…)." (P5)
	Frustration	Feelings of frustration and confusion related to the topic itself or to the platform.	"I felt frustrated because I didn’t understand much about the topic, (…) the names were too scientific." (P10)

When the participants were asked about what brought up more negative emotions, two categories where identified: “Technical Problems” and “Emotional Factors”.

The category "Technical Problems" captures how the platform's technical challenges affected participants' overall experience. Some participants reported "Navigation Difficulties", specifically pointing out that certain features were misleading, such as the platform's map, which confused users regarding its intended function (P2). Additionally, "Slow Performance" of the platform (P6) was noted as another significant issue, which bothered the users due to the periods of waiting for loading, that exceeded expectation.

The second category, "Emotional Factors," reflects the range of “negative emotions” experienced by participants while using the platform. Some participants expressed "Sadness" when engaging with the sensitive topics presented, especially when thinking about the implications for families (P3, P4). Others reported feeling "Boredom", stating that the platform did not meet their expectations for engagement and interactivity (P5, P9). Finally, "Frustration" was highlighted by users who struggled with their lack of knowledge on the topic and had difficulty understanding specific terms (P10).

3.3.3. Correlation between Positive and Negative Affect Scales

To determine whether the Positive and Negative Affect Scales were correlated, a Pearson correlation analysis was conducted. The results showed a correlation coefficient of $r = 0.142$ with $p = 0.70$ ($p > 0.05$), indicating a very weak positive correlation that was not statistically significant. This result suggests that there is no meaningful relationship between the two scales.

3.4. SUS and PANAS-VPR

3.4.1. Correlation Analysis (Subscales)

To investigate the correlation between Positive Affect and SUS score, a Pearson correlation analysis was conducted, resulting in $r = -0.08$, with $p = 0.822$ ($p > 0.05$). This result suggests that there is no meaningful relation between the PA scale and SUS scores.

In contrast, the correlation between Negative Affect and SUS scores was found to be significant, with a Pearson correlation coefficient of $r = -0.64$ and $p = 0.047$ ($p < 0.05$). This indicates a moderate negative correlation, suggesting a meaningful relationship between the Negative Affect scale and SUS scores.

3.4.2. Correlation Analysis (Individual Items)

To examine the relation between individual PANAS-VPR items and System Usability Scale (SUS) scores, a Pearson correlation analysis was conducted. The results are visible in Table 7.

Table 7

SUS and PANAS-VPR Correlation

PANAS-VRP Item	r value	p value
PANAS_Atormentado (Distressed)	-0.46	0.18
PANAS_Determinado (Determined)	0.33	0.35
PANAS_Culpado (Guilty)	Not possible to compute	
PANAS_Assustado (Frightened)	−0.11	0.76
PANAS_Ativo (Active)	0.03	0.94
PANAS_Inspirado (Inspired)	−0.33	0.35
PANAS_Amedrontado (Apprehensive)	−0.50	0.14
PANAS_Entusiasmado (Enthusiastic)	−0.16	0.65
PANAS_Nervoso (Nervous)	−0.64	0.05
PANAS_Interessado (Interested)	−0.05	0.89

The analysis revealed that the “Nervous” item was the only one exhibiting a statistically significant correlation with SUS scores, showing a moderate negative correlation (r= −0.64, p=0.05). These results indicate that participants who reported feeling more nervous tended to rate the platform’s usability lower, although it is important to note that this correlation does not necessarily imply causation. None of the other PANAS items showed significant correlations with SUS scores.

It is also important to note that the item Guilty could not be included in the correlation analysis due to a lack of variability in responses, as all participants uniformly rated this item as "1", prevented any meaningful statistical analysis.

3.5. Suggestions for Platform Improvement

The thematic analysis of participants' feedback regarding MY GENE resulted in two main categories for improvement: " Ease of Navigation” and “ Incorporate More Content”, each containing several subcategories that reflected distinct user suggestions. These results are summarized in *Table 8.*

Table 8

Suggestions for Platform Improvement

Category	Subcategory	Definition	Quotes
Ease of Navigation	Improving Search Features	Make the information easier to find	“ (…) it should be easier to find things, like having a search bar." (P1)
	Faster Map and City Navigation	Making the map and city navigation more intuitive and direct	"I would simplify the navigation (…) on the house map you could just click and go to places (…)” (P5); “(…) dragging the map takes too much time." (P7)
	Progress Tracking	Incorporate a feature that allows users to know how much of the platform they have already explored	“(…) have a progress bar to know how much of the platform we’ve already seen." (P10)
	Version Options	Include the option of selecting a simple or an advanced version of the platform based	“(..) it would be nice to have a simpler version and another one for those who already

		on the user’s level of knowledge.	know more about the topic." (P3)
Incorporate More Content	Increase Interactivity	Add more interactive elements to the map	"(..) add more interactive elements, not just tasks or information." (P4); “The platform should have more buildings to interact with, they are in the map anyway (…)” (P9)
	Variety of Material	Add different material types to the platform to engage more people effectively	“ (…) could be just things like materials to print, games, especially for younger children." (P2)
	Music	Add background music to improve the atmosphere	“ (…) the option of background music to make the environment a bit less serious and more confortable." (P9)

The “Ease of Navigation” category highlighted participants' desire for a smoother and more intuitive navigation on the MY GENE platform. One significant subcategory was “Improving Search Features” where participants expressed a need for easier access to information and map navigation, with one participant stating, "(…) it should be easier to find things, like having a search bar " (P1). Another important subcategory was “Faster Map and City Navigation”, with participants suggesting that navigation should be more intuitive and less time-consuming. One participant mentioned, "I would simplify the navigation (…) on the house map you could just click and go to places" (P5), while another expressed frustration with the current method, stating, "(…) dragging the map takes too much time" (P7). Additionally, participants indicated a need for “Progress Tracking”, suggesting the implementation of a progress bar to know how much of the platform they’ve already seen" (P10) and recommended the addition of “Version Options”, where different versions of the platform could be available for the user to select according to level of their knowledge on the topic (P3).

The second category, “Incorporate More Content”, emphasized the importance of making the platform more interactive and personalized. One subcategory under this theme was “Increase Interactivity”, where participants expressed a desire for more engaging elements within the platform. For example, one participant suggested taking advantage of the existing buildings on the map by making them interactive (P9). Participants also highlighted the need for a “Variety of Material”, suggesting that different types of content, such as games and materials to print, could be included to engage diverse users, particularly children (P2). Lastly, participants mentioned the addition of “Music,” with one expressing a preference for background music to create a more relaxed atmosphere (P9), making the platform usage more pleasing.

3.6. Barriers to Youth Engagement in Research

When analysing the principal barriers that prevent youth engagement in scientific research, the thematic analysis revealed two categories: “Logistical Challenges” and “Lack of Information”. *Table 9* displays the different themes identified.

Table 9

Barriers to Youth Engagement in Research

Category	Subcategory	Definition	Quotes
Logistical Challenges	Lack of Availability	Participants find it difficult to allocate time due to their busy schedules with school and extracurricular activities.	"I don’t have time because of dance practice (…)” (P1)

	Difficulty in Transportation	Participants face logistical challenges, particularly in attending without help.	"(…) difficulty getting around without my parents." (P9)
	Parental Consent	Participants require parental approval to participate in activities.	"My parents might not sign it." (P4)
Lack of Information	Lack of Knowledge About Previous Requirements	Uncertainty about what to do in research moments leads to feelings of being lost or unprepared.	"If I don't know exactly what I'm going to do, I feel really nervous." (P2)
	Lack of Awareness about Opportunities	Participants are not aware of available opportunities or where to find information.	"I don't know where to check for studies." (P3)

"Logistical Challenges" comprises three different subcategories: "Lack of Availability"; "Difficulty in Transportation"; and "Parental Consent". Participants frequently indicated that their busy schedules, filled with school responsibilities and extracurricular commitments, made it difficult to allocate time for additional activities (P1). "Difficulty in Transportation" also emerged as a significant logistical barrier, especially for those who rely on parental support for transportation (P9). This reliance on parental involvement extended beyond transportation, as some participants also noted the necessity of "Parental Consent" to engage in activities, which could be an obstacle (P4).

The second category, "Lack of Information", encompassed challenges related to a lack of awareness about available research opportunities and their conditions. Participants expressed that insufficient clarity regarding the expectations of the studies could leave them feeling unmotivated to engage in future research, with some reporting that this uncertainty leads to nervousness: "If I don't know exactly what I'm going to do, I feel really nervous" (P2). Additionally, participants noted a lack of awareness about available study opportunities and where to find relevant information, stating that even if they are curious and interested in participating, they do not know how to access the necessary details to engage (P3).

3.7. Motivations to Youth Engagement in Research

When analyzing the main factors that motivate youth participation in scientific research, the thematic analysis revealed three primary categories: “ External Incentives and Motivations”, “Contributing to a Better Academic Future” and “Having Alternatives Concerning Transportation”. Each of these categories and their respective subcategories is presented below in *Table 10.*

Table 10

Motivations to Youth Engagement in Research

Category	Subcategory	Definition	Quotes
External Incentives and Motivations	Financial Rewards	Desire for monetary compensation for participation.	"A monetary incentive would be great. " (P4)
	Tangible Rewards and Prizes	Interest in receiving tangible rewards for participation..	"Knowing that there would be rewards for participating, would motivate me like a prize or voucher." (P2)
Contributing to a Better Academic Future	Career Exploration	Desire for activities that provide insights into future career options.	"(…) about an interesting topic that helps me understand what I want to do in the future." (P6)
	Certificates and Recognition	Appeal of earning certificates or recognition for academic purpose	"Having a useful certificate for my CV (…)." (P8)

Having Alternatives Concerning Transportation	Online Participation	Preference for activities that are easily accessible online.	"(…) should be something online that is easier to access." (P9)
	Participation During School Time	Preference for activities that do not require transportation since they could be held in school	“I would really like to be more engaged if I had the change, for instance an open day at school where we could the research there!” (P5)

The first category, "External Incentives and Motivations," reflects the participants' desire for tangible or financial rewards as a key motivating factor. Some participants indicated that "Financial Rewards" would encourage their participation (P4), while others indicated an interest in receiving non-monetary rewards, such as vouchers or prizes (P2), which falls under the subcategory of "Tangible Rewards and Prizes".

The second category, "Contributing to a Better Academic Future," emphasized how research opportunities can influence participants' future aspirations. Within the subcategory of "Career Exploration," participants expressed a desire for research topics that align with their academic interests and help them explore potential career paths. One participant remarked on the importance of engaging with research that could provide insights into their future profession, stating their motivation would be higher if the study was, *"(...) about an interesting topic that helps me understand what I want to do in the future"* (P6). Similarly, the subcategory of "Certificates and Recognition" reflects participants' interest in earning academic recognition through research participation. One participant specifically highlighted the appeal of receiving a certificate that could be added to their resume, saying, *"Having a useful certificate for my CV (...)"* (P8).

Lastly, the third category, "Having Alternatives Concerning Transportation," focused on practical aspects of the research regarding its format and location that could make participation more accessible. Under the subcategory of "Online Participation," participants expressed that online studies would be more convenient, as they would eliminate the need for transportation and make it easier to engage (P9). In a similar flow of ideas, the subcategory "Participation

During School Time" highlighted the preference for research activities that could be integrated into the school day, reducing the need for external transportation. One participant suggested holding research sessions at school, proposing an open day focused solely on research where students could participate in different studies on-site (P5).

4. Discussion

This study aimed to evaluate the usability and emotional impact of the MY GENE platform from the perspective of young users, while also gathering feedback to improve the platform and identifying barriers and motivations for youth engagement in research. The discussion below addresses each of these objectives, relating the findings to the broader context of research, highlighting strengths and limitations, and considering implications for future research and practice.

4.1. Interpretation of Results

Usability Evaluation

The usability evaluation of the MY GENE platform, based on both the UX tasks and System Usability Scale (SUS) scores, provides encouraging results while also highlighting areas for improvement. Although the success rates of the UX tasks exceeded commonly accepted usability benchmarks (Brooke, 1996), variations in task performance, particularly in Task 4 (with an 80% success rate, the lowest of the four tasks), suggests that certain areas of the platform may be overly complex or confusing for young users. A deeper analysis of Task 4 could identify specific design elements contributing to this difficulty, such as unclear navigation paths or unintuitive features. Addressing these complexities could further enhance the overall user experience and reduce potential usability problems.

The final SUS score of 74 is coherent with this high solid level of usability reflected by UX evaluation tasks, while confirming there is still potential for improvement. According to Kortum and Miller (2008), a score of 74 would be rated as "good" but not "excellent," suggesting the platform is functional and well-received but could benefit from further refinement. In comparison, scores above 80 are typically considered indicative of "excellent" usability (Sauro, 2011). These findings are consistent with other studies, where e-health platforms designed for younger audiences showed moderate success but required further optimization to improve user engagement (Ervasti et al., 2019; Lostelius et al., 2023).

Research on young users' interactions with e-health platforms shows similar patterns. Studies indicate that younger, tech-savvy users tend to have higher expectations for seamless, intuitive designs (Newton et al., 2021). However, these users are also more sensitive to minor usability issues, which can significantly affect their continued engagement with digital health tools (Norman & Verganti, 2014). This sensitivity to usability challenges has been linked to decreased engagement, as observed in other e-health platforms targeting youth audiences (Arthurs et al., 2022). Therefore, while the MY GENE platform demonstrates good usability, ongoing refinement based on user feedback is crucial to meet the elevated standards of younger users. This is particularly important given the platform’s original goal to engage parents and children both independently and together- ensuring that youth remain actively involved is crucial for the platform's effectiveness as a collaborative tool for families.

Emotional Impact

Despite predominantly positive emotional experiences reported by participants, the presence of negative emotions remains considerable, with a mean Negative Affect score of 6.70. This duality indicates that while the MY GENE platform engages users on a positive level, it also introduces challenges that may threaten overall experience.

Participants often cited technical problems as significant sources of negative affect, particularly in relation to navigation difficulties and slow platform performance. These findings resonate with existing literature indicating that usability challenges can significantly impact user satisfaction and engagement, especially among younger users (Newton et al., 2021). When technical issues arise, they can evoke feelings of frustration and impatience, potentially overshadowing the positive experiences associated with task completion and learning.

Furthermore, emotional reactions linked to sensitive content, such as feelings of sadness when dealing with topics related to genetic risks, suggest a more complex emotional landscape. This is consistent with findings from research indicating that users, particularly younger ones, can feel overwhelmed when exposed to emotionally charged information about their health (Werner-Lin et al., 2018). For platforms like MY GENE, it is essential to integrate features that offer emotional support, such as contextual guides or preparatory content that helps users better handle sensitive information. While some of these features, such as the "wellbeing SPA," are intended to address these concerns, further refinement may be necessary to ensure their effectiveness.

Interestingly, there was no correlation between the Positive Affect scale and the System Usability Scale (SUS), suggesting that positive emotions do not necessarily translate into higher usability ratings. This is in line with prior research, which illustrates that emotional experiences are complex, and positive feelings alone do not guarantee favourable usability evaluations (Lewis, 2014). In contrast, the analysis revealed a moderate negative correlation between the Negative Affect scale and SUS scores, indicating that users who experienced more negative emotions rated the platform's usability lower. This underscores the importance of addressing negative emotions, as they can heavily influence users' perceptions of a platform’s usability (Zhou et al., 2021).

Further analysis of individual items on the PANAS scale revealed that the only statistically significant correlation with SUS scores was for the item Nervous, which showed a moderate negative correlation. In order words, participants who reported feeling more nervous were more likely to rate the platform's usability lower. This is consistent with prior research, which suggests that anxiety and nervousness can diminish user engagement and satisfaction (Newton et al., 2021). However, none of the other emotional states measured by PANAS exhibited significant correlations with SUS scores, indicating that certain emotions may exert a more pronounced influence on usability perceptions than others.

Suggestions for Platform Improvement

Participants' feedback highlighted key recommendations for enhancing the MY GENE platform, focusing on both navigation and content. Suggestions such as implementing a search feature and progress tracking bar can significantly improve user experience by making information more accessible and engaging to users. Additionally, increasing interactivity and diversifying content—such as incorporating games and printable resources—addresses varying learning styles and preferences, fostering greater user satisfaction and tailoring resources to different populations. For example, adding printable drawings could make MY GENE inclusive for children, a population not originally considered in the platform's design.

It is important to recognize that these insights are unique to younger participants and were not identified by adult users. This distinction underscores the vital importance of involving young users in the design process, as their perspectives and needs can differ significantly from those of adults. A recent scoping review conducted by Malloy and colleagues (2023) on co-designing digital health interventions with youth emphasizes the value of these insights in digital contexts. It is essential to consider that today’s youth is the most technologically savvy generation, having grown up immersed in technology, which enables them to offer enriching contributions to enhance not only their own experiences but also those of other users. Furthermore, Malloy et al. stress the underrepresentation of this younger demographic group and the uniqueness of their perspectives, aligning with this study's aim to promote greater youth participation in future research.

Barriers and Motivations to Youth Engagement in Research

Contrary to the prevalent belief that young people lack interest in research and civic engagement, the results of this study reveal a desire among youth to participate in scientific studies. The analysis of barriers to youth engagement identified logistical challenges—such as busy schedules, transportation issues, and the necessity for parental consent—as the primary obstacles preventing young individuals from fully participating in research activities. Literature supports these findings, indicating that external factors, rather than a lack of interest, often deter youth from engaging in research (Wagner et al., 2019). The logistical challenges highlighted in this study reflect the realities of young people's lives, where academic responsibilities and extracurricular commitments compete for their time. Participants expressed that their busy schedules made it difficult to allocate time for research activities; however, none indicated a lack of willingness to take part in future studies, underscoring practical limitations.

Despite these challenges, young people exhibit both altruistic motivations and external motivators that drive their interest in research. Participants expressed a desire to contribute to scientific knowledge and make a positive impact, indicating that altruism plays a crucial role in their motivation to engage. At the same time, external incentives—such as financial rewards, certificates, and tangible prizes—can significantly enhance participation. A study by Bennett and colleagues (2018) supports the idea that extrinsic rewards can motivate adolescents, particularly when these rewards are tied to meaningful experiences. By recognizing these barriers and motivations, researchers can work to create more inclusive environments that facilitate youth involvement.

4.2. Limitations of the Study

Despite its valuable contributions, this study faces limitations that require caution when interpreting the data. First, the sample size of only 10 participants limits the generalizability of the findings. While small samples are common in user experience (UX) studies (Nielsen, 1999), the diversity of analysis requires careful interpretation. Additionally, self-selection bias may have also influenced participant composition; those comfortable discussing genetic risk may differ systematically from non-participants (Zheng et al., 2023). Moreover, ethical considerations excluded individuals with genetic syndromes, which may limit the representativeness of feedback and leave gaps in understanding the specific needs of this targeted group. Future studies in similar contexts should aim to include these affected individuals within an ethical research framework to better assess and address their unique needs.

Although the mixed-methods approach was thorough and followed a solid design, reliance on self-reported data poses significant challenges. Participants may exhibit social desirability bias, skewing their responses (Nederhof, 1985), which raises questions about the accuracy of reported experiences, barriers, and motivations. The subjective nature of user experience complicates broad conclusions, as individual pre-existing differences can significantly impact perceptions in subjective circumstances (Purdy, 2021). This variability is particularly relevant in a sensitive scenario such as genetic risk, where experiences highly differ based on personal, cultural, and social factors (Werner-Lin et al., 2018). Finally, despite efforts to remain objective, it is also important to highlight potential researcher bias, which may, unintentionally influence various aspects of the study, including the design and the data analysis itself (Hammersley, 2015).

Although these limitations do not compromise the significance of the study, they call for cautious interpretation of the findings and highlight improvement areas. Rather than serving as prescriptive rules, these considerations offer a reflection on current limitations, which can inform the development of more effective practices in the future.

4.3. Implications for Future Research and Practice

The findings from this study on the usability and emotional impact of the MY GENE platform emphasize a critical, yet underexplored, intersection of psychology, cancer risk communication, and user experience (UX) design. This research demonstrates the potential of UX principles to positively impact psychological well-being, broadening their applicability across various contexts. Despite its limitations, this study lays a pioneering foundation that challenges conventional approaches in psychology, underscoring the importance of interdisciplinary collaboration.

The insights gathered offer valuable opportunities to enhance the MY GENE platform by incorporating user feedback to refine its content and features. Future efforts should focus on identifying specific usability or emotional barriers that may hinder the overall experience, enabling more targeted improvements. Additionally, research in similar contexts could also benefit from applying alternative methods, such as focus groups, to deepen understanding of how young users engage with these platforms and address uncertainties remaining after this study.

Since engaging young users throughout the design process has proven to be beneficial, future research should prioritize participatory design approaches involving this population. Actively involving youth in all stages—not just in post-feedback phases—can lead to even more relevant and innovative solutions. Considering the importance of fostering youth involvement, the barriers to engagement identified in this study represent a critical area for further exploration. Acknowledging these challenges is just the first step; addressing them will require innovative strategies. These efforts could benefit from initiatives such as partnerships with educational institutions and the promotion of online studies to increase accessibility. Integrating research participation into school curricula is another promising path, alongside offering incentives, such as vouchers or certificates, which are cost-effective and were identified as a motivation for participation.

Ultimately, this study underscores the pioneering role that UX design and psychology can play together in shaping the future of digital health interventions. By embracing user-centered approaches in both research and practice, and by prioritizing the involvement of young people, there is immense potential not only to improve user experiences but also to empower a new generation to actively contribute to scientific and health-related discussions. In an era where youth voices are often overlooked, this research advocates for meaningful, inclusive change: and for that change to resonate in the future, it must begin now.

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Appendices

Appendix A

Informed Consent (For Participants and Legal Guardians)

CONSENTIMENTO INFORMADO PARA INVESTIGAÇÃO CIENTÍFICA

Introdução e contexto: O presente estudo surge na sequência do projeto "PLAY-THE-ODDS", financiado pela Fundação para a Ciência e a Tecnologia (FCT) (EXPL/PSI-GER/1270/2021) e promovido pelo Centro de Psicologia da Universidade do Porto (CPUP), na Faculdade de Psicologia e Ciências da Educação da Universidade do Porto (FPCEUP). No âmbito desse projeto, foi desenvolvido o protótipo de uma plataforma digital – designada "MY GENE" - para ser utilizada por famílias com risco genético de cancro, de forma a facilitar a comunicação sobre esta condição. Este estudo enquadra-se num desenvolvimento posterior desse projeto, estando a ser desenvolvido no âmbito da dissertação final de Mestrado em Psicologia Clínica e da Saúde da estudante Beatriz Alves, aluna da Faculdade de Psicologia e Ciências da Educação da Universidade do Porto (FPCEUP).

Objetivos do estudo: Este estudo tem como principal objetivo compreender a perceção dos jovens relativamente à utilidade da plataforma digital "MY GENE", visto que, até à data, esta foi apenas testada por adultos, não sendo ainda clara qual a sua utilidade do ponto de vista dos mais jovens.

Procedimentos: A participação irá decorrer online - através de um link *Google Meet*. O estudo irá decorrer na tarde de dia 26 de julho de 2024, tendo a duração máxima estimada de 1 hora. Este estudo envolve a resposta a questões sobre o que cada participante pensa acerca da funcionalidade da plataforma, o que o faz sentir e que sugestões de melhoria tem para a mesma. A plataforma "MY GENE" é de cariz informativo e consiste no protótipo de uma cidade digital, onde é possível aprender através da interação. A participação neste estudo só se confirma após devolução do presente documente à estudante responsável, assinado pela mesma, pelo participante e pelo/a seu/sua responsável legal.

Elegibilidade: Poderá participar neste estudo qualquer jovem que possua entre 13 e 17 anos de idade e que não pertença a uma família com risco de cancro hereditário. Esta característica foi definida como critério de inclusão por questões éticas, de forma a evitar qualquer desconforto adicional por parte dos participantes.

Riscos e benefícios: Não se prevê qualquer tipo de risco associado à participação neste estudo. De qualquer modo, cada participante poderá terminar a sua participação a qualquer momento e sem consequências, se assim o desejar. Este estudo não beneficia o participante diretamente, mas esperamos que os resultados permitam melhorar a plataforma "MY GENE" e contribuir, assim, para uma melhor qualidade de vida para famílias com risco genético de cancro.

Confidencialidade e proteção de dados: Os dados recolhidos acerca da plataforma poderão ser utilizados para melhoria da mesma, mantendo sempre a confidencialidade dos mesmos. Quanto a informações de contacto, serão recolhidos endereços de email para o envio de informações relativamente ao estudo e do *link* para participação no mesmo. Estes contactos serão eliminados imediatamente após o fim do estudo, a não ser que os participantes/responsáveis legais manifestem a vontade de ser contactados por email, após a conclusão do estudo, para obter acesso aos resultados.

Finalidade do tratamento de dados e disseminação dos resultados: Os dados recolhidos serão utilizados exclusivamente para fins de investigação, no âmbito da dissertação de Mestrado supramencionada. O trabalho de dissertação poderá ser utilizado em revistas científicas, conferências, ou outras atividades de fins académicos. Os resultados poderão ainda ser divulgados no website do projeto (https://www.up.pt/playtheodds/index.html). Os dados poderão ser partilhados com outros investigadores no âmbito da Ciência Aberta, não permitindo a identificação dos participantes.

Contactos: Para a apresentação de questões relativas à participação neste estudo, poderá contactar a estudante responsável pelo mesmo, Beatriz Alves, através do seu email up201906063@fpce.up.pt ou a orientadora responsável. Esta investigação decorre sob orientação da Professora Doutora Célia Sales (celiasales@fpce.up.pt) e co-orientação da Professora Doutora Sónia Sousa.

Declaro que li as informações do consentimento informado para investigação científica e estou consciente do que esperar quanto à participação no estudo. Tive a oportunidade de esclarecer qualquer dúvida que me surgisse e aceito voluntariamente participar neste estudo.

______________________________	______________________________
Nome do participante	**Assinatura do participante**

___/___/___
Data

Enquanto representante legal do/a menor, declaro que li as informações do consentimento informado para investigação científica e estou consciente do que esperar quanto à participação no estudo. Tive a oportunidade de esclarecer qualquer dúvida que me surgisse e autorizo voluntariamente que o/a menor em questão participe neste estudo.

______________________________	______________________________
Nome do representante legal do participante	**Assinatura do representante legal do participante**
______________________________	___/___/___
Grau de relação com o participante	**Data**

Declaro que os aspetos mais importantes deste estudo foram explicados ao participante e ao seu representante, antes de solicitar a sua assinatura.

______________________________	______________________________
Nome da Estudante Responsável	**Assinatura da Estudante Responsável**

Appendix B

Questionnaire Utilized to Data Collection

Questionário MY GENE (Realizado na plataforma Loop 11)

Organizado de acordo com a ordem em que cada parte aparecia, sequencialmente no ecrã da Loop 11

Obrigada por aceitares participar neste estudo! Queremos saber a tua opinião sobre a plataforma "MY GENE". Vamos pedir que tentes realizar algumas tarefas e que nos dês o teu *feedback* sobre a tua experiência. Realiza este estudo **sozinho/a,** num **ambiente calmo**, num **computador**. Será feita uma *gravação de ecrã* durante a tua participação.

Não há tempo limite de resposta e todas as respostas e resultados são válidos! Por favor, sê o mais **sincero/a e detalhado/a possível** em cada resposta. Obrigada!

(Parte 1)

1) Por favor, indica a tua idade: ___
2) Por favor, indica o teu género: (Feminino | Masculino | Outro | Prefiro Não Responder)

(Parte 2)

3) Explora o mapa para descobrir como chegar à cidade
4) Encontra o hospital
5) Encontra a biblioteca
6) Encontra informação sobre teste genético na biblioteca

(Parte 3)

Por favor classifica cada uma das seguintes afirmações, numa escala de 1 a 5, em que 1 significa "discordo fortemente" e 5 significa "concordo fortemente":

7) Acho que gostaria de utilizar esta plataforma com frequência.
8) Considerei a plataforma mais complexa do que o necessário.
9) Achei a plataforma fácil de utilizar.
10) Acho que necessitaria de ajuda de um técnico para conseguir utilizar esta plataforma.
11) Considerei que as várias funcionalidades da plataforma estavam bem integradas.
12) Achei que a plataforma tinha muitas inconsistências.
13) Suponho que a maioria das pessoas aprenderia a utilizar esta plataforma.
14) Considerei a plataforma muito complicada de utilizar.

15) Senti-me muito confiante a utilizar esta plataforma.
16) Tive de aprender muito antes de conseguir lidar com esta plataforma.
17) Se pudesses fazer alterações à plataforma para a melhorar, o que mudarias e porquê?´

Adaptado de "*Martins, A. I., Rosa, A. F., Queirós, A., Silva, A., & Rocha, N. P. (2015). European Portuguese validation of the system usability scale (SUS). Procedia computer science, 67, 293-300.*

(Parte 4)

Nesta página irás encontrar uma lista com diferentes sentimentos e emoções. Lê cada item e indica em que medida sentiste cada um desses sentimentos/emoções durante a utilização da plataforma MY GENE, sendo 1 "Nada ou muito ligeiramente"; 2 "Um pouco"; 3 "Moderadamente"; 4 "Bastante"; 5 "Extremamente".

18) Interessado/a
19) Nervoso/a
20) Entusiasmado/a
21) Amedrontado/a
22) Inspirado/a
23) Ativo/a
24) Assustado/a
25) Culpado/a
26) Determinado/a
27) Atormentado/a

Adaptado de: "*Galinha, I. C., Pereira, C. R., & Esteves, F. (2014). Versão reduzida da escala portuguesa de afeto positivo e negativo-PANAS-VRP: Análise fatorial confirmatória e invariância temporal. Psicologia, 28(1), 53-65."*

28) Por favor, indica o que trouxe ao de cima mais sentimentos/emoções positivas ao utilizar a plataforma e porquê.

29) Por favor, indica o que trouxe ao de cima mais sentimentos/emoções negativas ao utilizar a plataforma e porquê.

(Parte 5)

30) Indica quais poderiam ser os obstáculos para que voltasses a participar num estudo de investigação científica, mesmo que diferente deste.

31) Indica quais seriam as tuas principais motivações para voltar a participar num estudo de investigação científica, mesmo que diferente deste.

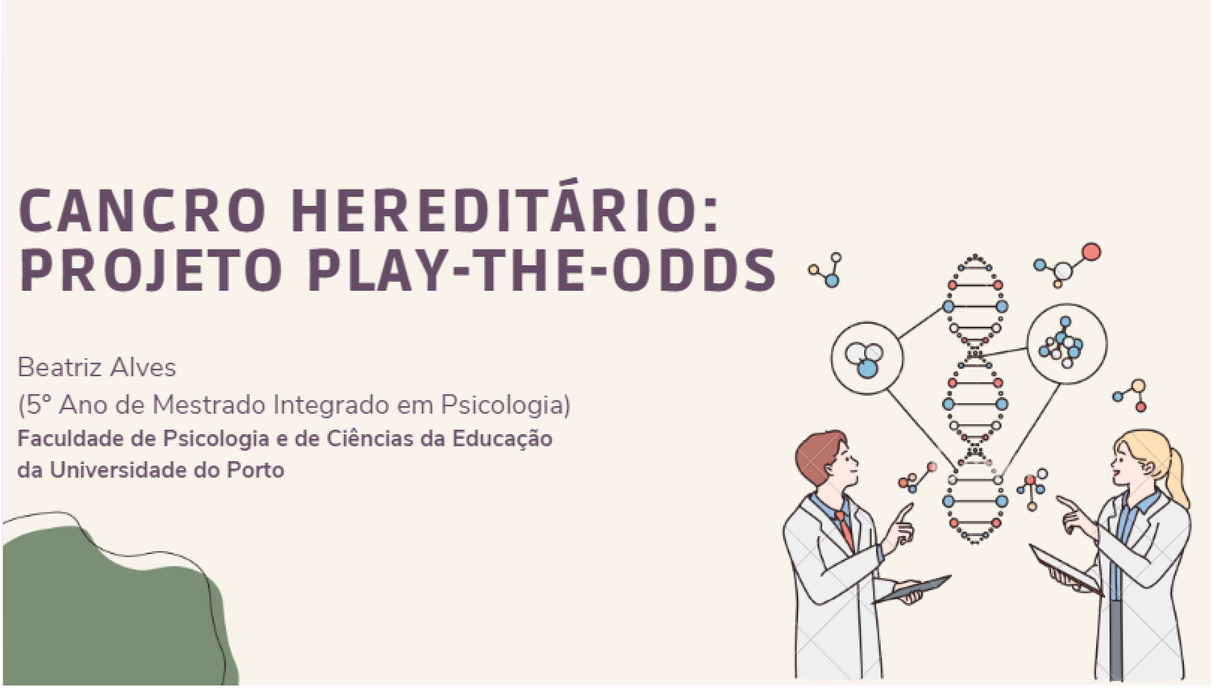
Muito obrigada pela tua participação!

😊

Appendix C

Slide Presentation Before Questionnaire Completion

BEM-VINDOS/AS!



CANCRO HEREDITÁRIO:
PROJETO PLAY-THE-ODDS

Beatriz Alves
(5° Ano de Mestrado Integrado em Psicologia)
Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto

Quem sou eu?

- Licenciada em Psicologia;
- Finalista de Mestrado em Psicologia Clínica e da Saúde;
- Especialização em Intervenção Psicológica em Saúde;
- Estagiária na Cooperativa de Solidariedade Social Sol Maior;
- Parte da equipa PLAY-THE-ODDS.

Beatriz

Tenho uma grande paixão pelo associativismo e pelo trabalho com jovens!

O QUE É "CANCRO HEREDITÁRIO"?

O cancro hereditário é um tipo de cancro causado por mutações genéticas que são transmitidas de pais para filhos. Essas mutações aumentam o risco de desenvolver certos tipos de cancro, mas não indicam com certeza se a pessoa virá ou não a desenvolver a doença.

IMPLICAÇÕES PRÁTICAS

- Sentimentos de incerteza e medo;
- Sentimentos de culpa e desorientação;
- Dificuldades de comunicação e falta de informação;
- Dúvida sobre como introduzir o tema (teste apenas depois dos 18 anos).

AJUDAR A COMUNICAR

O projeto PLAY-THE-ODDS nasceu para ajudar a criar uma ferramenta que facilitasse a comunicação entre pais e filhos sobre o risco genético de cancro. Vários profissionais de diferentes áreas trabalharam para construir um site onde fosse possível encontrar informação e recursos interativos para ajudar as famílias a conversar.

PORQUÊ JOVENS?

O protótipo desta plataforma foi já testado por adultos, mas não por jovens. Mas, se queremos fazer algo adaptado a famílias, não basta saber a opinião dos pais: precisamos da opinião dos filhos! É aqui que entram os participantes jovens, para ajudar a tornar esta plataforma na melhor possível.

DÚVIDAS?

OBRIGADA!

O VOSSO CONTRIBUTO É MUITO IMPORTANTE

FACULDADE DE **PSICOLOGIA E DE CIÊNCIAS DA EDUCAÇÃO**