Empowering Neurodiverse Voices in Research Ethics through a Playful Card-Based Approach

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Abstract: Whenever carrying out research, all participants must know their rights, especially when those participants are perceived as being part of a vulnerable group; however, discussing ethics in investigation can be difficult. To solve this challenge, a playful approach was taken, as playfulness can make dull tasks – especially those that can cause discomfort and difficulties – more entertaining and help people approach them with an open mind. This study reports on four empirical approaches that used a playful process to raise awareness about ethical concerns when doing research with neurodiverse people. For this activity, 39 cards describing and illustrating several relevant and evidence-based ethical principles were created. Then, three case studies were developed, each based on a different focus group composed of ten neurodivergent self-advocates and one with professors and students from Brazil. Each neurodivergent group was also accompanied by three support workers from the partner associations (two of the groups were accompanied by the same individuals). In total, 56 participants engaged in a playful activity that consisted of a game of 'broken telephone' where the title of a card (representing an ethical principle) is read to one of the players who then has to whisper it to the next person in line, repeating this process until reaching the last person. The last person then says what they heard out loud, with the original message being revealed for contrast. The title of the cards was discussed by the groups to understand if it was clear and understandable or difficult and confusing. Although not all the cards were validated through the activity, 14 were flagged by neurodivergent people as "needing changes". The feedback was recorded and is presented here. This study set out to validate a set of cards in easy-to-read language that could introduce ethical concepts to participants in research projects through a playful activity. Future study will see the cards iterated upon through the feedback gathered along with the creation of a small guide on how they may be used in playful activities.

Keywords: Playfulness, Ethics, Neurodiverse People, Participatory Research, Card Games.

1. Introduction

Play is contextual and an expression of our individual and collective character (Sicart, 2017). As an indicator of well-being, play is fun (Bateson & Martin, 2013), and can be experienced outside of the game sphere, through a playful design of objects, actions, and personal experiences. Although playfulness "is the attitude of play without the activity" (Sicart, 2017, p. 21), such as a physical interaction, or a psychological, and emotional attitude toward a specific situation, playfulness can be also seen as a personality trait (Heljakka, 2023; Proyer et al., 2021). According to Proyer (2017), playfulness "allows people to frame or reframe everyday situations in a way such that they experience them as entertaining, and/or intellectually stimulating, and/or personally interesting" (p. 114), having a similar perspective, Barnett (2007) also states that playfulness is "the predisposition to frame (or reframe) a situation" (p. 955).

1.1 Playfulness in Adults

There are several approaches in the literature regarding playfulness, usually associated with children and their education, being seldom studied regarding adults (Fagundes and Menezes, 2021; Guitard et al., 2005; Jovanović, 2021; Leather et al., 2021; Shen et al., 2014), which lead to different conceptualisations or definitions of 'playfulness' (Guitard et al., 2005; Proyer and Wagner, 2015; Shen et al., 2014).

Studies have demonstrated that playfulness has had a comprehensive range of positive outcomes in adults (Proyer and Wagner, 2015) that are similar to those in children (Guitard et al., 2005). Some of these benefits are related to health and productivity indicators, job and academic performance, creativity, positive emotions, stress coping, interpersonal relationships, sense of humour and well-being (Barnett, 2007; Guitard et al., 2005; Leather et al., 2021; Pang and Proyer, 2018; Proyer et al., 2021; Shen et al., 2014).

Many studies involving game activities and mechanics (gamification) are more game-oriented and we want to dissociate from this analysis of playfulness. If we focus on product design, for instance, we see that many of the objects developed reflect the playful characteristic of the designer, a process of playful thinking, in which the form and function of the object are simply replaced by fun aesthetics. The “magic bunny” design by Alessi, is a clear example of when the “form follows fiction” (Legaard, 2020), validating that "the link of playful play to creativity and hence to innovation in humans is strong" (Bateson, 2014, p. 99). This playful play is outside the sphere of the game but within the realm of the creative process of playing with objects, processes, and ideas.

When using a playfulness approach with adults for learning purposes, we can take the case presented model of Nørgård et al. (2017) for a signature pedagogy in higher education that is constructed by three traits of teaching and learning, with a more gameful aspect: (1) the surface (game) structure, which encompasses the visible actions (e.g. game mechanics, adequate and flexible levels of challenge); (2) the deep (play) structure, relating with assumptions (e.g. collaboration, the conceptualisation of possibilities); but also with (3) the implicit (playful) structure, that corresponds to the values (e.g. accepting risk-taking and failure, internal motivation).

The last structure was constructed based on the theoretical lens of the magic circle that relates to playful learning (Nørgård et al., 2017). Simply put, the magic circle of play refers to the space where play happens, being outside reality and featuring its own rules (Huizinga, 1971). When applying the concept in the learning process, Whitton (2018) mentions that it is important to consider that the play space happens outside the real world constructed by the players and that it is safe, where the rules of the real world don’t necessarily apply - although they cannot be entirely forgotten as power relations and tensions are present. In this sense, Whitton (2018) identifies three pedagogical advantages for using playful learning approaches: “the positive construction of failure; support for learners to immerse themselves in the spirit of play; and the development of intrinsic motivation to engage with learning activities” (p. 3).

Playful activities help to create a safe space, but such does not happen immediately, players need time to construct it and develop trust and relationships with the rest of the players and teachers (Whitton, 2018).

Having these aspects in consideration, our main aim was to validate the ethics cards developed with neurodiverse people (PwID and autistic people) while at the same time raising awareness among them about ethical considerations that must be taken into account when participating in research.

Considering that the validation process and learning about ethics can cause emotions of boredom, we decided to take a playful (learning) approach to the activity by using the ‘Broken Telephone’ game mechanics to present the developed ethics cards. These cards are an easy-to-read version of the guidelines developed by Casimiro et al. (2023) surrounding the inclusion of PwID in research processes.

2. Methodology

2.1 Cards Development

The cards’ objective is to offer simple definitions of ethical concerns that should be acknowledged when conducting research with or about PwID. Their main goal is to be informative to this specific group about their rights and duties when participating in research, considering that many PwID have been research subjects many times throughout their lives while also being particularly uninformed about how this process is conducted compared to people without intellectual disability (McDonald et al., 2018). As a secondary objective, the cards have been designed to be easily manageable by facilitators who are not necessarily experts in the subject but want to conduct more inclusive research. This way, with minimal interaction with the cards, they can more easily understand their content and how to use them in a way that promotes the rights of PwID.

Initially, it was determined that the cards needed to include the following information: card title, explanation of the title, card code, ColorAdd code, card classification, illustrative image, QR code, financing agency’s logo, and the project reference. Some prototypes were made, until arriving at a layout for the card's front and back (Figure 1).

Figure 1: Beta version of a card's front and back layouts (The main title of the card in Portuguese language is "The final decision is always mine").

2.2 Participants

2.2.1 Study 1 - Portugal

In Portugal, the study was conducted in two different locations: APPACDM and CECD. In APPACDM, two groups of neurodivergent people participated. These consisted of nine (*n* = 9) and eight (*n* = 8) participants, respectively, and both were accompanied by the same three (*n* = 3) support workers (SW). In CECD, nine participants and three SW participated (*n* = 12). In total, the study in Portugal consisted of three sessions and a sample of 32 people (*N* = 32).

All neurodivergent participants were adults ranging from 19 to 54 years old (*M* = 29,23; *SD* = 8,69), of which seven were female (26,92%) and 19 were male (73,08%). Although SW participated in the activities, they were not the focus of this study, with data collection focusing on the neurodivergent participants.

2.2.2 Study 2 - Brazil

This study happened during two sessions, hosted by two Higher Education Institutions (HEI) in Rio de Janeiro, Brazil: first, at the Research Group of Identity and Teachers' Knowledge (GPIDOC), of the Higher Institute of Education of Rio de Janeiro (ISERJ) - free translation; and second, at the "Laboratory of Inclusion and Symbolic Mediation, development and learning" (LIMDA), from the Postgraduate Program in Education (PPGE) of the Federal University of Rio de Janeiro (UFRJ) - free translation.

The first was attended by 24 participants: 22 students in varying stages of their undergraduate degrees and two professors, all from the host institution (ISERJ). The second session was attended by one undergraduate student, one graduate student and one teacher from the host institution (UFRJ), and nine attendants from outside institutions, seven of which are postgraduate researchers, one professor and one industry expert, as demonstrated in Table 1.

Table 1: Specification of participants in Study 2

Title		Undergraduate	Graduate	Postgraduate	Professors
ISERJ	Host In.	22	–	–	2
	Outside In.	–	–	–	–
UFRJ	Host In.	1	–	1	1

Title		Undergraduate	Graduate	Postgraduate	Professors
	Outside In.	–	1	7	1
Total		23	1	8	4

3. Procedure

3.1 Study 1 - Portugal

For each of the three sessions (two at APPACDM and one at CECD), neurodivergent people, along with the accompanying SW, gathered in the same room to be part of the activities. For the introduction, each moderator introduced themselves to the participants, with one of them explaining the research project's goals and the participants' roles as valuable contributors to the research. Once this introduction was finished, an icebreaker activity was conducted to incentivise interaction between moderators and neurodivergent people - also fostering interaction between themselves. After this activity, the moderating team introduced the ethics cards, explaining their general purpose and the activities that would be conducted with them. These activities were made to generate opportunities for participants to engage with the contents of the cards in a more playful context, making them more accessible and less daunting. The two activities were:

- **Broken Telephone Game:** A card was given to one of the participants who then had to whisper its title to the person sitting next to them. Once this was done, each participant had to whisper it to the next person in line, continuing in succession until reaching the last person in the group who would then have to say the supposed title of the card out loud. If any participant expressed difficulty in communicating their message, one of the moderators would provide support. After hearing the final result, the actual title of the card was revealed, with the participants and the moderators discussing its meaning.
- **Debating the Cards:** The participants received cards and read them to the rest of the group. Then, moderators encouraged the participants to debate the meaning of the card and attempt to come up with examples of how the guideline could be applied. The goal was for participants to discuss - and for the moderators to assess - how clear the meaning of the card was and how they thought it could be improved.

Throughout the sessions, the activities were adapted to tackle participants' needs and behaviour – such as speech impediments, illiteracy, etc. After conducting the activities, participants were asked what they enjoyed about them and what they thought could be improved - drawing attention back to the cards to see if there was any additional feedback the participants might want to give.

3.1.1 Revision of the Cards

Based on the feedback received during the three initial sessions, some of the titles and descriptions of the cards were edited to be more straightforward, switching some words to more common and simpler synonyms. It was also noted that some more complex words, such as "adaptations", were easier to understand than the research team expected. It was later discussed with the SW from APPACDM that this word, although a little bit more complex than their usual lexicon, was part of their day-to-day lives, especially during discussions about Individualised Education Plans.

This demonstrates that, while it is important to avoid needlessly complicated and uncommon words, we must also recognize that new and more specific words can and should be introduced to neurodiverse people, given the appropriate context, because they can make them better informed. In this specific scenario, the alternative word "change" does not carry the same subjective meaning of "adaptation", and, therefore, would result in them not being as informed as they should be.

Moreover, it was also noted that the participants chose cards mostly based on the colour of their favourite football team, which deviated from the intended purpose of the colour-coding of the cards and led the team to question how the colours were impacting the participants' contact with the varied types of concepts being introduced.

Lastly, we also observed that the explanation of the title on the front of the card sometimes led to confusion: literate participants were unsure whether to just read the title of the card or to also read the text. Upon review,

we also came to realise that the text offered an unnecessary cognitive load to all the steps of the activity and that by moving it to the verse of the card it would still be accessed when participants or facilitators chose to do so.

Considering the previous reasonings, the cards' content was re-evaluated with the intent of minimising cognitive load (removing elements that did not help conduct the activities at hand) and more explicitly separating the contents for participants to interact with (in the front) from the contents meant for facilitators to consult upon (in the back), as demonstrated in Figure 3.

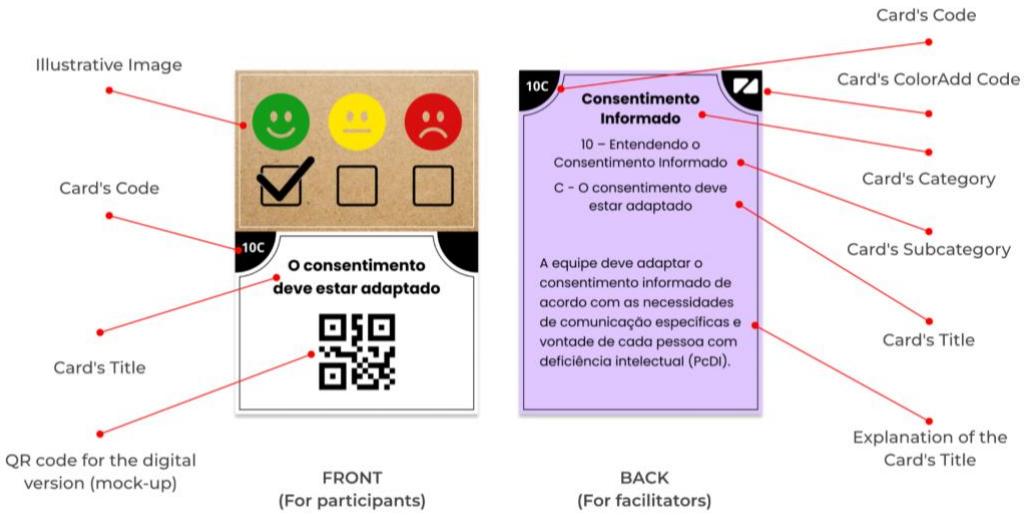

Figure 2: Example of a Card's front and back, with pointers to what's included in it.

3.2 Study 2 - Brazil

After the initial testing of the Ethics Cards with their target audience, we conducted further validations of the cards, this time among peers, during two sessions in two different host institutions: ISERJ and UFRJ. These institutions were selected due to being HEI with dedicated Departments, Postgraduate Programs and Study Groups involved in the research of education, having a particular focus on inclusivity and diversity. Both sessions consisted of the following schedule:

- 30-minute presentation of the GameIN Project, detailing the process behind the development of the Ethics Cards.
- 45–60-minute activity, during which participants formed groups of 4–6 participants, received a corresponding part of the Ethics Cards and needed to select one of them to be used as a guideline to adapt a project, service or activity of their choice, for it to be more inclusive towards PwID.
- 15–30-minute feedback session, during which all participants could ask questions and provide opinions to further develop the cards.

Each group was asked to write a proposal for their project adaptation, addressing which card they selected (and why), what project they selected, and the adaptations they proposed. All groups then presented their projects to the other groups, who then had the opportunity to offer feedback and commentary.

4. Results

4.1 Study 1 - Portugal

4.1.1 APPACDM (Session A)

As the broken phone activity was being presented at the start of the session, one of the participants informed the moderators that they were hard of hearing, giving them the opportunity to adapt the game to their needs. For this, the support workers sat next to two specific participants to facilitate their participation. This layout remained for the rest of the session.

One of the moderators only participated at the start of each round, either reading the card to the first participant or showing it to them so they could say it to the next participant in line. The participants seemed to be enjoying

themselves throughout the activity, interacting with each other and being amused by how different - and 'broken' - the final message was. The moderators believe there is the possibility that some participants were purposefully changing the message to a more humorous one; however, this was not seen as a complete negative as it contributed to the participants' enjoyment of the activity. Regarding the message of the cards, some participants had difficulty understanding the full meaning of the guidelines described in them and gave suggestions on what words to use to make them easier to understand.

During the feedback activity, four specific participants gave most of the comments. Nonetheless, other participants would also make statements that demonstrated that they understood the meaning of the message. When asked what was their favourite part of the session, most participants named the broken telephone activity.

4.1.2 APPACDM (Session B)

This session was affected by the participants being seemingly tired from the offset of the session, with one eventually asking to leave the session to rest and another falling asleep during the session itself, but that had chosen to stay. It is possible that this affected their performance during the activity, even though they stated that they enjoyed it. Same as the previous session, the SW were asked to sit beside the neurodivergent participants who might need more support to participate - one of these was a participant who informed a moderator that they were illiterate.

The participants seemed to have enjoyed the broken phone activity. When discussing the meaning of the cards, one participant, in particular, monopolised the discussion, also discussing them with the moderators and the SW; a significant part of the other participants specifically waited for moderators to ask them directly what they thought of the cards. The more active participant even offered themselves to explain the cards to the other participants, since most were having trouble understanding their meaning.

During the feedback activity, the participants would mostly state that they had no trouble understanding the cards while discussing them, though some would still only comment if explicitly asked to do so. Participants were equally split between which of the activities they enjoyed the most and if they would rather have played in smaller groups.

4.1.3 CECD

The SW were once again placed next to the participants who would have more difficulty in the activities - such as one illiterate participant. When the broken telephone activity was introduced they laughed together at the idea of what could be the final broken message.

As they played, they seemed to be in a good mood, entertaining each other by making exaggerated expressions when the message was passed onto them. Some of the neurodivergent participants also discussed the themes of the cards between themselves, at times discussing them with the moderators and the SW. The moderators, through their observations, suspect that some of them may have purposely changed the message to generate more humorous results, resulting in general laughter by the participants once they heard the final message; it was not possible to confirm this suspicion.

After some rounds, the participants were split into two groups playing the same broken phone activity. This appears to have also worked well, as participants had to wait less time for the message to reach them and some of them also enjoyed the added element of 'competition' as both groups tried to preserve the original message the most. Once the activity was completed, the moderators asked which of the versions they preferred the most, to which they generally answered the one where they all played together. Throughout the activity, on both variations, some of the neurodivergent participants would at times compliment each other for being able to pass the message to the next person in line.

During the feedback activity, some neurodivergent participants engaged in a discussion regarding how sometimes they are not treated as expressed in the cards. Others were reluctant to state that they did not fully understand the cards, but after being motivated by the moderators they would eventually express themselves. Once one of the moderators asked the neurodivergent participants to describe how they would explain the card to one of their friends, they began to open up more and talk to each other. Participants appeared to enjoy both activities.

4.2 Study 2 - Brazil

4.2.1 ISERJ and UFRJ

Both sessions consisted of a mixture of students and teachers from the host institution; however, at UFRJ, there were some outside participants, as well as a higher concentration of postgraduate participants.

These sessions intended to test whether the cards, as they were, acted as viable tools to be used by facilitators who wanted to conduct research activities in partnership with PwID. To assess if they achieved this goal, all participants were asked to respond to two questions: whether they learned something new about conducting research in partnership with PwID - of which most did (n = 35) and one did not (n = 1) -, and if they perceived the Ethics Cards as effective tools to facilitate activities in partnership with PwID - of which 28 said yes and eight said no.

5. Results and Discussion

Overall, in study one it was possible to see that the playful approach worked in terms of turning a task that could otherwise be boring into a more playful one. The participants, throughout the session, were engaged and liked the idea of the 'Broken Phone Game'. By implementing this strategy both groups of intervenients (research team and participants) could get to know and be familiar with each other. For instance, it was possible to note that there were several types of players: ones that liked to add a fun element to the game by inventing a new phrase and ones that liked to follow the rules.

Altogether, the participants from study one had a good time, were participative, gave their opinions and enjoyed the session. It was also noted that they preferred the game (the traditional version, not the competitive one) rather than just debating the cards.

Regarding the validation of the cards, based on the feedback received, it was concluded that the cards needed to be redesigned. Needing to be simpler on the front (for neurodivergent people) and save the more complete information for the back (for facilitators).

In this sense, the front will only have the illustrative image, the card's code and title, and the QR code (having eliminated the ColorAdd code and the explanation, and added the QR code). Additionally, it was also recommended to leave the background colour on the front of the card white, to help with readability. The back will have the card's code and ColorAdd code, the category, subcategory and title of the card, as well as its respective explanation (having eliminated the QR code, funding agency's logo and the project reference, and added the explanation of the card).

As for study 2, the validation of the cards among peers - professors and students - from Brazil, seemed to show that the cards taught them something new about doing research with PwID and that the cards were perceived as being an effective tool to help facilitate activities with PwID.

By validating with two different groups (neurodivergent people and peers) it was possible to understand if the cards could be useful for both, identifying their positive and negative aspects and their perceived effectiveness in the field.

6. Limitations and Future Directions

As learners need time to create space and to develop trust with the teachers, it is possible that because this session was made so early on in the project, the participants still needed to build a safe space or trust with the researchers. Additionally, due to their experiences with stigma, PwID typically avoid negative criticism (Esdale et al., 2015). Therefore, we noticed that the participants frequently responded, for example, 'No, everything is fine' when asked if they would change anything, although we noticed that they had some difficulties. Moreover, some only gave their opinion when directly asked so, in future studies, it should be considered how researchers might operationalise when such happens.

Considering this, we believe that the relationship established with the participants at a later stage of the project would produce different results.

Also, due to limitations of time, it was not possible to validate all 39 cards. Therefore, in the future, when all the cards are re-designed based on the feedback received, a new validation process is needed in which all cards must be included.

This activity aimed to validate the cards and assess how they could be more accessible for neurodivergent

people, not to assess if the approach implemented facilitated the learning process or if participants learned what was written in the cards. As such, future work could focus on the implementation of the cards with neurodiverse people, through the use of the 'Broken Phone Game' - or any other playful learning approach - and assess if it helped the learning process of this theme.

Lastly, it could also be helpful to translate and validate in other languages for a broader application and to understand how students perceive ethics and ethical research with PwID.

Acknowledgements

This study was funded by national funds through the FCT - Foundation for Science and Technology, I.P., under project GameIN (2022.07939.PTDC) – available at https://doi.org/10.54499/2022.07939.PTDC.

This study was also partially financed by the Coordenação de Aperfeiçoamento de Pessoal de Nível Superior – Brasil (CAPES) – Finance Code 001, and by FAPERJ – Fundação Carlos Chagas Filho de Amparo à Pesquisa do Estado do Rio de Janeiro, Processo *SEI E-26/201.579/2023*.

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