

# The value of community engagement during the development of serious games for low health literate

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ATHENA SCIENCE SHOP

#### Colophon

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# List of abbreviations

#### Abbreviation

EC PartE SG WHO

#### Definition

European Commission Participation Evaluation Serious Games World Health Organisation

#### Executive summary

Due to the Covid-19 pandemic, low health literacy was once again highlighted as an understated global health problem (Paakkari & Okan, 2020). Serious games (SGs) have been found to be effective intervention tools that could address some of the issues people with low health literacy have, for instance by transferring health-related knowledge or help with adhering behavioural skills. However, people with low health literacy are often not targeted with SGs. Besides, the engagement of the target audience while playing the game is an important attribute of the effectiveness of SGs due to the use of behavioural and motivational theory in SGs designs (DeSmet et al., 2016; Shegog, 2010). The engagement of a (vulnerable) target audience specifically during the design phase is also known as "(community-based) participatory design" and can be implemented in various ways during the design process. Noteworthy, participatory design is still an uncommon approach during the development of SGs even though several studies have demonstrated the importance of participatory design in various settings. Namely due to the complexity of processing the input received from the target audience and the participants' lack of knowledge on SG content and design (Khaled et al., 2014; Maheu-Cadotte et al., 2021). The objective of this study is therefore to give recommendations on whether it is valuable to use community-based participatory design during the design phase of SGs. Hence, the corresponding research question is:

# "What is the value of community-based participatory design during the development of SGs for people with low health literacy?"

To address the research question, a qualitative research approach was employed, consisting of ten semi-structured interviews. The interviews delved into six dimensions derived from Gerard and Sosa's (2014) Participation Evaluation framework: objective, practice, interaction, barriers, representation, and impact. Participants were selected based on their experience with health-related SGs or SGs targeting individuals with low health literacy, as well as having experience with community-based participatory design for SGs. The interviews were conducted online using Microsoft Teams and audio-recorded for transcription. Thematic analysis was performed using ATLAS.ti, leading to the identification of four new themes: phases to engage the target audience, the co-creation session, impact, and barriers and pitfalls. Ethical considerations were taken into account, and a data management plan was implemented to ensure the respondents' confidentiality.

After analysis, it was evident that all respondents used the terms co-creation or co-design interchangeably to describe community-based participatory design. The target audience could be engaged in four stages: pre-design, design, evaluative, and implementation phases. Most respondents did not frequently involve the target audience in the pre-design phase, relying instead on assumptions and theoretical research. For the design phase, however, most respondents engaged the target audience, but opinions differed on whether feedback should focus on game content, design aspects, or both. Clear protocols for co-creation sessions were lacking among respondents, but they agreed on session duration, between 30 minutes and 2 hours, and the importance of adapting it to the target audience. Small group sizes were preferred, often in a focus group setting where prototypes were tested, games were played, surveys were conducted, or interviews were held. Co-creation had a positive impact on the quality and alignment of the final product, making the development process more efficient and enhancing resonance with end-users. The majority of respondents believed that co-creation also positively affected participants by transferring knowledge and fostering a sense of fulfilment. Time constraints and limited resources were the main barriers identified, while pitfalls included socially desirable feedback, other sources of noise, and the risk of inadequate representation of the target audience.

In this study three key findings were identified. Firstly, visualisation or the use of graphic

support has been found to be an important attribute of the effectiveness of the co-creation sessions. This was a recurring topic throughout all interviews and often associated with the low abstraction level of the participants of the co-creation sessions. Moreover, both literature and the findings indicated that the use of visualisation for instance increases the engagement, it leads to a better understanding of the concepts and sparks creativity. Secondly, co-creation is best done iteratively and that the intensity in which this is done influences the quality of the SG. The findings and literature showcased the differences in what manner the target audience could be engaged, but it became evident that it is best to receive feedback from the target audience frequently because one's assumptions are often not sufficient. Lastly, the positive impact co-creation. Both the findings and some literature supported that co-creation is related to the efficiency of the development process as well as the quality and alignment of the final product. Strikingly, most barriers that were stated in studies concerning SGs and co-creation were not found as barriers in this study.

To conclude, this study aimed to answer whether it is valuable to engage the community during the design phase of SGs targeted for low health literate. The findings showed that engagement of the target audience during the design of SGs is beneficial in terms of the quality and alignment of the SG. Besides, visualisation seems to be an important attribute of the impact of the co-creation sessions. Due to the heterogeneity of the respondents, in terms of their profession and target audience of their SGs, these findings might be generalizable. It must be noted that the viewpoints of low health literate were not explored throughout this study and saturation of the data collection was nearly reached. Many findings were also in line with literature regarding participatory design and co-creation but not always with studies in the context of SGs. However, the identified practices, impact and barriers do add to the rising body of studies concerning co-creation for SGs and specifically for marginalised groups.

This study derived four recommendations applicable to future SG projects and studies. Firstly, engage the target audience iteratively, starting from the pre-design phase, to ensure alignment with their needs and capabilities. Secondly, facilitate different levels of engagement to accommodate time constraints and reduce the number of absentees., allowing the target audience to choose their involvement intensity based on the objectives of the SG designers. Developing a warm bond with the target audience is also crucial. Thirdly, establish clear objectives and tailored protocols for each co-creation session, considering the capabilities of the target audience and adjusting them based on the development phase. Lastly, further research should validate the findings and explore the perspectives of low health literate individuals through semi-structured interviews and participatory observation of co-creation sessions during the SG development process.

#### 1. Introduction

Over the past decade, worldwide, there have been many calls for action regarding health literacy among the population. Health literacy can be described as: to what extent an individual can obtain, comprehend, and apply health information, to make suitable health decisions. In Europe, approximately between a third to half of the population has low health literacy, making it a significant problem (Baccolini et al., 2021; Quaglio et al., 2016). People with low health literacy experience difficulty with health-related knowledge and comprehension skills (Berkman et al., 2011). As a result, low health literacy has been associated with lower use of health services and poorer health outcomes. For instance, it has been linked to lower adherence of preventive measures, increased hospitalisation, poorer ability to take medications correctly, and interpret health information (Baccolini et al., 2021; Berkman et al., 2011). Low health literacy is most prevalent among the elderly, people with low educational attainment, low literacy, and low socio-economic status, as well as vulnerable groups such as people with intellectual disabilities. Subsequently, it also reinforces existing inequalities in society (Quaglio et al., 2016; Baccolini et al., 2021).

The Covid-19 pandemic once again highlighted the importance of health literacy and that it is still an understated global health problem (Paakkari & Okan, 2020). Studies state that health literacy is not only a determinant of global health but also has an influence on the spread and prevention of communicable and non-communicable diseases. In addition, it is an attribute of the preparedness of individuals for solving problems related to these diseases (Spring, 2020; Abdel-Latif, 2020; Paakkari & Okan, 2020). Noteworthy, Covid-19 had an even worse and more frequent impact on people with low health literacy (Bin Naeem & Kamel Boulos, 2021). This was mainly due to the troubles they experienced with understanding and adhering to the preventive measures because the language used was either too difficult, there was an overload of information, or they did not know how to apply it in practice. The accessibility of information also played a role because the formats were, for instance, not accustomed to their needs or they could not distinguish misinformation from real information (Bin Naeem & Kamel Boulos, 2021; Embregts et al., 2020).

There have been several studies on intervention methods regarding health literacy but one that has risen in popularity over recent years are SGs. SGs deems an effective intervention for people with low health literacy, especially for young people with low education or mild disabilities (Torres-Toukoumidis et al., 2022; Haruna et al., 2021). SGs have been around for decades and have become more trending in the current digitalization era. They could be described as entertainment tools with a primary focus on delivering a specific purpose, where new knowledge and skills will be acquired while playing the game (Zhonggen, 2019). The purposes of SGs often differ from being educational, training, changing behaviours, or attitudes (Hammady & Arnab, 2022). They are therefore used as a tool in various fields such as education, healthcare, government, and industry. The development of SGs depends on several factors such as the game genre, teaching topic, and target audience (Silva, 2019). Noteworthy, the main goal of all SGs is that the knowledge acquired by the users via the game is also portrayed in real life outcomes (Whyte et al., 2014). Even though SGs aim to achieve the objective they are designed for, the games remain to follow the general game structure to be interactive and amusing at the same time (Hammady & Arnab, 2022). However, the entertainment elements in place are specifically designed with underlying theories to facilitate, promote, and sustain the learning process. Whereas the engagement elements of regular games are primarily designed to foster better game play and entertain their players (Whyte et al., 2014). This difference has led to SGs creating a motivational learning environment, while promoting the participation of the target audience (Calik et al., 2022; Giessen, 2015; Silva, 2019).

The engagement of the target audience is an important attribute of the effectiveness of SGs due to the use of behavioural and motivational theory in SGs designs (DeSmet et al., 2016; Shegog, 2010). This engagement of the target audience during the design phase is also known as "participatory design" and can be implemented in various ways during the design process. For instance, the study of DeSmet et al. (2016) showed that user testing is crucial for the design of serious gaming just as professional, user, and stakeholder expertise. Correspondingly, this is also the form of participatory design that is used most often in the context of SGs. In addition, it can also be done in the form of co-creation, where for instance the input of the end-users is used to guide the design of the game. Participatory design aimed for specific groups is also referred to as community-based participatory

design because it is about engaging those who are affected by a particular problem in the process of solving or mitigating that problem McClosky et al. (2011). Implementing community-based participatory design in the development of health interventions has shown to result in interventions that empower the community and diminish stigma (Leorin et al., 2019).

Even though many studies have demonstrated the importance of participatory design in various settings, it is still not a common approach for the design process of SGs (Khaled et al., 2014; Maheu-Cadotte et al., 2021). The reason why it is not widespread (yet), is largely due to the complexity of translating the objective into the game whilst subsequently listening to the feedback of the end-users. This often makes it a difficult and time-consuming process. Moreover, people with low health literacy are in general often not targeted for health-related serious games, despite the shown effectiveness of SGs on improving health literacy in the context of well-being, mental health, sexual health, and promoting a healthy lifestyle (Torres-Toukoumidis et al., 2022; Haruna et al., 2021)Hence, the research objective of this study is to give recommendations on whether it is valuable to implement community-based participatory design during the development of SGs for people with low health literacy. This will be done by conducting interviews with people that have experience with community-based participatory design for health-related SGs or SGs targeted for people with health concerns. Ultimately, it is expected that the results of this study will highlight whether community engagement should be implemented in the design process of SGs in general and specifically for marginalised groups. Moreover, the findings of this study could also give guidance on how the participatory design should be implemented during the design phase. This study aims to answer the following question:

What is the value of community-based participatory design during the development of SGs for people with low health literacy?

#### 2. Contextual background

Health literacy and SGs are both concepts that have gained more attention over the past decade. Globally, health literacy has been acknowledged as a determinant of (public) health and socioeconomic differences in health outcomes. Noteworthy, there is still a lack of knowledge on the development and health outcomes of health literacy inventions in Europe because most studies regarding health literacy have been concerning countries outside of Europe (Visscher et al., 2018). The Netherlands, on the other hand, has a higher rate of game industry companies that focus on developing SGs compared to other countries (*The Netherlands: Europe's playground*, 2018). The context provided below will therefore focus on the policies, implementations, and actors that are relevant within the realm of health literacy and SGs in the Netherlands to get a better understanding of the context of this study.

#### 2.1 Health literacy agenda

Due to the rising recognition of the health outcomes caused by health literacy, over the years several strategy and policy proposals have been made in Europe to battle the health literacy challenge. In 2007, the European Commission (EC) included health literacy as a priority in the EC white paper, which contains public health related policy proposals. The white paper 'Together for health: a strategic approach for the EU 2008-2013' mentioned that health policy must include the abilities needed for health, such as health literacy, as well as the participation of residents in decision-making (Quaglio et al., 2016; Baccolini et al., 2021).

Then, in 2012, the importance of health literacy was also covered in the 2020 Health strategy of the World Health Organization (WHO) office for Europe. This strategy mentioned the benefits of improved health literacy for European citizens as well as the benefits of basing health promotion programmes on engaging and empowering the citizens (Quaglio et al., 2016; Baccolini et al., 2021). In 2013, the health ministers of the European Union agreed on the 'Vilnius Declaration for sustainable health systems for inclusive growth in Europe'. This declaration urges immediate improvement of the investment in disease prevention and health promotion programmes by European governments, in which health literacy is mentioned as a means in which must be invested (Quaglio et al., 2016). More recently the WHO has covered health literacy in the 2030 Agenda for Sustainable Development, in which health literacy is mentioned as one of the crucial health promotion pillars.

Despite these international proposals, not many European countries have actually implemented health literacy in their national policies. In 2015, only six European countries had formed health objectives concerning health literacy. Noteworthy, the Netherlands was not one of those six countries (*Health literacy on the European agenda* | *RIVM*, 2015). In 2022, the Ministry of Health, Wellbeing, and sports wrote a letter to the parliament named: 'Vision and agenda quality of care: access to good care for everybody'. This letter explained the importance of health literacy by naming possible health effects and mentioned ways to move forward. One of the proposals was to shift more towards engaging citizens in the decision-making process of their care. However, it was not explicitly mentioned with what means this should be done which, as previously mentioned, showcased that low health literacy is still an understated issue .

#### 2.2 Relevant serious games

SGs can be used in several fields and differ in target audience but SGs targeted for people with low health literacy are still infrequent. One thing that all SGs have in common is their combination of (primarily) educational objectives and playful elements. To illustrate, three SGs targeted for a subgroup of low health literate will be discussed, two of which are concerning non-health related objectives.

Firstly, the study of Flogie et al. (2018) developed a digital SG to improve the

personal development and cognitive skills of children with learning difficulties. The study demonstrated that the game had strengthened their skills, which had a positive impact on their social capabilities (Flogie et al., 2018). They also highlighted that literature on SGs often only concern the mainstream population and thus neglect the potential benefits such interventions could have on marginalised groups. However, it is noted that tailoring of such interventions is needed to accommodate the needs of these groups.

Secondly, 'Mediajungle' is a Dutch SG aimed for people with mild intellectual disabilities and with the intent to teach them greater media awareness and informed media usage (*Mediajungle*, z.d.). This game is a combination of a board game and a digital application. The end-users were involved during the development of the game and their involvement has resulted in an inclusive game that is easily understood and enjoyed by the end-users (*Mediajungle*, z.d.). Noteworthy, Mediajungle has not mentioned how, when or in what manner the end-users were involved during the design phase.

Lastly, 'You&I' is a Dutch digital SG to enhance the well-being of adults with mild intellectual disabilities (Derks et al., 2021). Co-creation with three representatives was used to develop the game and ensure that the needs of the end-users were translated into the game. The input of the participants was perceived as valuable. Nonetheless, concerns were raised that the small sample of representatives would not be a fair representation of the whole community. In addition, the effectiveness of the game has not yet been examined (Derks et al., 2021).

#### 2.3 Actors

#### 2.3.1 Low health literate: Low educational attainment and mild intellectual disabilities

In the Netherlands, approximately a quarter of the population has low health literacy (Willems et al., 2022). An important sign of low health literacy is low educational attainment, namely people that only attained primary education till the first level of secondary vocational training or attained at least 10 years of education outside the Netherlands (Pharos, 2022). Low health literacy is also prevalent among people with mild intellectual disabilities; in 2018 it was estimated that nearly 6,4 percent of the Dutch population has a mild intellectual disability (Woittiez et al., 2019).

Both lower education and mild intellectual disabilities can often not be noticed from one's appearance. Their needs and concerns are therefore often overlooked, misunderstood, not recognized or not rightfully addressed by others such as their medical professionals (Pharos, 2022). These instances could lead to unpleasant experiences such as lack of confidence and shame for the low health literate. Moreover, they also tend to experience difficulty with reading and understanding generalised information daily. Noteworthy, the study of Meppelink et al. (2015) demonstrated that regular health information messages are less understandable for people with low literacy, whereas messages made intentionally for people with low literacy can just as easily be understood by people with adequate literacy without negative consequences. It is helpful for those experiencing low health literacy when information is made more accessible by being written in a simple and concise language, with additional images as supportive tools (van Ginkel & Adema, 2019).

However, this does not always solve their issues with using the gained knowledge in practice. SGs are therefore an adequate intervention tool because it creates an autonomous safe learning environment for the low health literate, where they do not feel easily judged by third parties (Hardiyanti & Azizah, 2019). Moreover, SGs combine visual, oral, and written elements to facilitate an accommodated learning experience. Nonetheless, it cannot be assumed that a SG designed for them by people that are health literate will automatically be adequate to address their needs and rightfully

represent them. Especially, considering the history of them being overlooked or misunderstood by others. Applying community-based participatory design models to SGs development could be a solution to ensure an intervention that is aligned with their abilities and is appealing to them. Since, it gives the low health literate a chance to represent themself and voice their concerns by engaging them during the design phase.

#### 2.3.2 Game developer

In the context of SGs, the game developer and their corresponding executive party are the most influential and responsible for the design and impact of the game. They need to determine the learning objectives beforehand and then also correctly translate these into the SGs. However, the actual effectiveness of SGs depends on the impact on the target audience and how they perceive the game. Strikingly, it is difficult for the developers to extensively include the target audience during the design and implementation phase of SGs because the main focus of the developers is to form the educational elements. Whereas the end-users focus mainly on the gameplay, entertainment elements, and overall ambiance of the game. As a result, the target audience is often not involved during the design phase because it could be a difficult and time-consuming process.

#### 2.3.3 Health literate non-governmental organisations

In the realm of health literacy, NGOs dedicated to health literacy play an important role because they advocate for the needs and experienced challenges of people with low health literacy. There are several health literacy related NGOs in the Netherlands, such as Pharos, Nivel, and the foundation for the illiterate. They also aim to spread awareness on health literacy, its health outcomes, and ways to offer help by arranging training courses to professionals, making meaningful content, and conducting research. For example, Pharos offers a free checklist with guidelines made to help professionals judge the accessibility of their information content for people with low health literacy (Pharos, 2022a). These NGOs gain their expertise by collaborating with professionals, health literate themselves, and other representatives.

#### 2.3.4 Remaining actors

Less influential stakeholders in health literacy and SGs include government and policy makers, who could benefit from SGs addressing health literacy but currently lack specific policies for SG development. Health care providers and representatives of low health literacy possess expertise in the needs and concerns of individuals with low health literacy, making their involvement during the design phase of SGs valuable. Educators in schools for lower education also offer meaningful insights, as they have daily contact with individuals who may have low health literacy, and their experience in making information accessible and understandable aligns with the needs of this target audience.

## 3. Theoretical background

This research aims to evaluate the value of community-based participatory design during the development of SGs. The conceptual analysis has identified community-based participatory design as the primary concept. This concept will be defined and subsequently applied to the context applicable of this study. In addition, theories regarding the value evaluation of community-based participatory design will be assessed to lead to the conceptual framework.

#### 3.1 Defining community-based participatory design

The concept community-based participatory design is a combination of the concepts: community, engagement, and participatory design, and it will be used in this study to narrow down the scope of both concepts. First, the concept of community engagement is broad, context dependent and does not have one clear definition. It could be described as the participation of a community in the decision-making regarding their community or as engaging those who are affected by a particular problem in the process of mitigating that problem (McCabe et al., 2006; McClosky et al., 2011). Next, participatory design is a broad design approach and is often described as a model that aims to achieve empowerment and mutual learning by collaborating with representatives of a community to design adequate solutions (Drain & Sanders, 2019; Bossen et al., 2016). However, the concept of community-based participatory design is still broad but more concise than both concepts separately. In particular, community-based participatory design focuses on marginalised or low-resource communities instead of general communities (Racadio et al., 2014). It is therefore more suitable for the context of low health literate because they as well are a marginalised population. Community-based participatory design could be referred to as the participation and empowerment of a marginalised community during the exploratory and implementation stages of a project (Racadio et al., 2014). This definition will also be used throughout this paper when referring to community-based participatory design or community engagement.

#### 3.1.1 Community-based participatory design applied to serious games

As far as SGs, community-based participatory design could be implemented during the whole design phase but usually it only happens at certain steps during the design phase. The most common approach is in the form of end-user testing, where a sample of the community pre-tests the SG before launching it to the public. By doing this the participants could still provide feedback and their concerns in regard to the SGs, which the developers could then use to incorporate this feedback to adapt the game to become more effective. However, the study of Dekker and Williams (2017) argued that this approach could actually not be categorised as participatory design because the end-users are only engaged at the testing stage instead of earlier during the actual design phase. A similar approach which is a form of participatory design is using the end-users as informants. In this situation the end-users can provide their input and feedback at certain stages during the design phase, these stages depend on the preferences of the designers. For instance, as informants the end-users could be asked to provide feedback on the draft game elements. Moreover, experts could also be used as informants. Another approach is co-creation whereby the participants are involved as partners during the whole design phase or can influence the design process only at certain stages. Noteworthy, several studies found that the informant approach is more often implemented then the co-creation approach (Dekker and Williams, 2017; DeSmet et al., 2016).

#### 3.1.2 Effects of implementing community-based participatory design

The implementation of community-based participatory design has shown to be beneficial in

various contexts. For instance, the study of Shore (2006) stated that community engagement could improve health outcomes and lead to lasting collaborations by building trust and facilitating communication. In line, the study of Harrington et al. (2019) noted that it could stimulate advocacy and strengthen community ties, which is especially important due to the marginalised nature of these communities. However, particularly for SGs, the implementation is more complex than in other settings. Due to the main focus of the designers on translating the objective into the SG, it is more complex to engage the end-users during the whole design phase because they lack knowledge on this domain. This is also the most common reason to not implement participatory design during the development of SGs. Additionally, when implemented, studies found that the preference is given to the informant approach instead of the co-creation approach (Dekker and Williams, 2017; DeSmet et al., 2016). Despite the complexity, applying participatory design to SGs could contribute to the effectiveness as well as provide value to the end-users by improving their knowledge on the subject and empowering them (Khaled & Vasalou, 2014). To illustrate, the study of Neuhauser (2017) stated that participatory design applied to health literacy interventions is related to positive health outcomes and a decrease of health inequalities.

#### 3.2 Theories on value evaluation of community engagement

The term value derives from the Latin word 'valere', depending on the context meaning 'worth', 'price' or 'usefulness'. The value of something can be evaluated based on theories or frameworks. Most frameworks give their own definition of value in line with that context. Three frameworks were identified that could be applicable to use in the context of community engagement and SGs, which will be discussed below.

#### 3.2.1 The three values of participatory design

Three different values applicable to participatory design were stated in the study of Ali & Liem (2015), namely user or experience, monetary, and societal value. User or experience value concerns the designers' ability to incorporate user interests into the product, thereby enhancing user loyalty and improving their experience. Monetary value refers to the potential for organisations to profit from implementing participatory design, particularly through the creation of innovative products. Societal value encompasses the impact of participatory design on society, including product sustainability and improved collaboration among stakeholders. Despite their distinctiveness, the meanings of these values are vague, posing challenges for implementation in this study. Additionally, in the context of this study, monetary value is less relevant, as previous research on participatory design in SGs mainly mentioned that the difficulties were surrounding the translation of the interests and the gained benefits. Therefore, to align with the context of SGs, greater emphasis should have been placed on societal value and user or experience value.

#### 3.2.3 Program theory

Program theory is a causal framework that aims to evaluate the process of a project, instead of dividing it into three separate values. The study of Hansen et al. (2019) applied program theory to evaluate participatory design. This theory consists of three themes: input, process, and effects. Input encompasses the necessary resources throughout the project. Process focuses on measures taken by the participants, divided into mechanisms (underlying factors) and activity (methods employed, e.g., workshops). Effects are categorised as output, outcome, and impact, representing short-term effects, long-term effects, and developed products. While program theory addresses implementation questions, its causal structure prioritises outcomes and means. However, it lacks consideration of

influencing factors during participatory design. Implementing this theory as a framework in this study may overlook emerging barriers or concerns not explicitly covered by the three themes.

#### 3.2.3 Tool-to-think-with framework

A "tool-to-think-with" is a conceptual framework to evaluate participatory design proposed by Frauenberger et al. (2015). This approach composes four lenses with supportive questions, namely epistemology, outcomes, stakeholders and values. The epistemology lens focuses on the knowledge formed during the process, questioning its types, trustworthiness, sharing methods, and transferability. The values lens explores participants' priorities and their influence on the design process. The stakeholder lens examines the identities and benefits of involved stakeholders. The outcomes lens considers sustainability, ownership, and diverse interpretations of the outcomes. This framework is considered a holistic approach for analysing participatory design (Malinverni et al., 2016; Drain et al., 2018). However, it may be less suitable for community-based participatory design due to its inadequate consideration of community vulnerability and the potential pitfalls of overlooking or misrepresenting the community. Nevertheless, compared to previous theories, this framework delves deeper into the interests and outcomes of participatory design.

To conclude, the current literature provides a variety of frameworks to evaluate participatory design, however the themes differ per framework and the evaluated value therefore also differs. Three theories to evaluate community engagement, in particular, were explained, and discussed whether they were applicable to the context of this study. The following section will touch upon a conceptual framework that will further specify the meaning of community engagement in the context of SGs and will give a uniform overview on how to evaluate the value of community engagement. This framework is named Participation Evolution and builds upon the strengths of the three mentioned theories (Gerard and Sosa, 2014).

#### 4. Conceptual framework

Due to the variety in theories and frameworks regarding the evaluation of community engagement, the study of Gerard and Sosa (2014) proposed a comprehensive and concise framework, named Participation Evaluation (PartE), to evaluate participatory design. The intent of their framework is to serve as a uniform reference frame, to evaluate participatory design openly and in-depth. In addition, it could also display the reasoning behind similarities and differences between participatory design implementations. PartE has also been referred to as a holistic approach, like the 'tool-to-think-with' framework (Drain et al., 2018). This framework will therefore be applied in this study to guide the evaluation of the value of community engagement of low health literate in the design phase of SGs. Especially, due to the generalisability of this framework is based on general participatory design. This framework consists of six distinctive dimensions, which can be specified with a variety of corresponding attributes. The themes are objective, practice, interaction, barriers, representation, and impact, see Figure 1 (Gerard & Sosa, 2014). Noteworthy, the themes are not bound by their attributes because the named attributes only highlight possible features of each theme. Each theme will be touched upon and subsequently illustrated in the context of this study in the following sections.

Dimensions	Objective	Practice	Interaction	Barriers	Representation	Impact
Attributes	a) Material Things	a) Well-known	a) Contribution of	a) Economic	a) Direct,	a) Short-term,
	b) Organisation,	Formats	resources &	b) Environmental	Autonomous	Small scale
	Rules,	<li>b) Emergent</li>	information	c) Political	<li>b) Indirect,</li>	<li>b) Long-term,</li>
	Information	Practices	<li>b) Exchange &amp;</li>	d) Social	Delegated	Large scale
	<li>c) Mind-sets,</li>	c) Novel,	Awareness of	<ul> <li>e) Individual</li> </ul>	<li>c) Appropriated,</li>	<li>c) Indirect,</li>
	Paradigms	Unpredictable	Contributions		Self-appointed	Unintended
		Approaches	<li>c) Collaborative</li>			
			Contributions			

Figure 1: The PartE framework by Gerard and Sosa (2014).

The dimension of *objective* refers to the overarching aim that wants to be achieved by implementing participatory design in a project. Based on the corresponding attributes these objectives could differ between developing material things or altering organisations, information pathways or perspectives (Drain et al., 2018). This theme is therefore slightly similar to the 'input' theme of the previously mentioned program theory, however compared to the program theory the focus here is less on the needed means but more on the intent behind them (Hansen et al., 2019). Since the attributes are not mutually exclusive, the overarching aim of community engagement in SGs could combine all or some of the mentioned attributes. This is because the end-goal of community-based participatory design in most SGs is to achieve a tangible end product. The objective could also include changing behaviour, which aligns with altering organisations or pathways, as well as changing social perceptions, which relates to altering perspectives. Given the educational nature of SGs and their involvement with a specific community, the objective dimension is likely to encompass a combination of these different attributes.

The second theme *practice* relates to instruments and methods that are used during the participatory design (Drain et al., 2018). This dimension is similar to the input theme of the program theory and then specifically the subcategory of activity because both themes refer to the materials and approaches used during the participatory design (Hansen et al., 2019). Three corresponding attributes were listed for this theme, namely well-known formats, emergent practices and novel or unpredictable approaches (Drain et al., 2018). In the context of SGs, the methods and instruments will be dependent on the objective of the game and the chosen community. For instance, for people with mild intellectual disabilities a combination or adaptation of well-known formats, such as visualisation games, could be used to interact with them in an understandable way. Also, different approaches and a combination of the attributes could be used, dependent on the way that community engagement would be implemented during the design phase,

Thirdly, the dimension *interaction* refers to the nature of contributions and how the information flows between the participants of the participatory design and has three attributes. This is similar to the epistemology lens of a tool-to-think-with (Frauenberger et al., 2015). The first is contribution of resources and information, this mode consists mostly of a one-way interaction where only one party chooses and spreads the tools and information among the other participants. The second attribute is exchange and awareness of contributions, this mode builds upon complementing each other because each participant shares their knowledge. As a result, the participants become aware of each other's strengths and limitations, and it fosters collaboration between the participants. The last attribute is collaborative contributions and builds upon the previous attribute, only this time there is also mutual learning and a deep understanding between the participants.

The theme *barriers* relate to limitations and challenges that occur during participatory design. These could be economic, environmental, political, social and/or individual. These barriers could have an impact on fulfilling the objective and implementation of the practice. For this study, the barriers are especially an important aspect because if the barriers outweigh the benefits of engaging the community during the design phase it would negatively impact the value.

Next, the dimension *representation* concerns the inclusion of the participants in the decision-making. Three different attributes comprise how the participants can be involved. The first is appropriated or self-appointed and in the context of this study it would mean that a representative of the community appoints themself to become the voice of the whole community. The second attribute is entrusted or delegated and slightly differs because in this case the community appoints a person they deem as trustworthy to become their spokesperson. The third attribute is direct autonomous and in this case the people of the community represent themselves. This dimension is especially important in the context of community during the design phase. In addition, it touches upon the extent to which the participants are truly and fairly represented in participatory design.

Lastly, the theme *impact* relates to the short-term, long-term and indirect or unintended outcomes of participatory design. This last theme therefore corresponds with the effect theme of the program theory, the outcomes lens of a tool-to-think-with as well as the societal and user/experience value of the three values (Ali & Liem, 2015; Hansen et al., 2019; Frauenberger et al., 2015). Most studies concerning community engagement in SGs solely focused on the impact the implementation had on the effectiveness of SGs.

The six dimensions presented in the study of Gerard and Sosa (2014) facilitate a systematic way to evaluate community-based participatory design. This framework has been acknowledged as an adequate evaluation framework by several studies (Bossen et al., 2016; Drain & Sanders, 2019; A. J. Drain et al., 2021). The overall value is assessed through the themes in combination with their attributes because they help to reveal the different perspectives and experiences of the participants and other involved actors. In addition, the findings of each theme can be further specified and analysed with additional literature. Thus, the six dimensions will guide the evaluation of the value of engaging people with low health literacy during the design phase of SGs.

#### 4.1 Sub-questions

Based on the PartE framework by Gerard and Sosa (2014) and theoretical background, the following sub-questions were derived:

- To what extent is community-based participatory design currently implemented for SGs?
- What is the objective of implementing community-based participatory design for SGs?
- ♦ What is the set-up of community-based participatory design for SGs?
- What is the interaction during community-based participatory design for SGs?
- What are the barriers of implementing community-based participatory design for SGs?
- How is the community represented during the community-based participatory design for SGs?
- What is the impact of implementing community-based participatory design for SGs?

#### 5. Methods

#### 5.1 Research methods

Qualitative research was conducted to evaluate the value of engaging low health literate individuals in the design phase of SGs targeted for them. The study aimed to formulate recommendations for implementing community-based participatory design in the context of SGs for low health literate individuals. To address the ambiguity of evaluation frameworks in community-based participatory design, semi-structured interviews were conducted to explore the value of community engagement in depth. The interviews utilised an interview guide (Appendix B) containing main questions and probes based on the six themes of the conceptual framework. However, the guide was used flexibly, allowing for unbiased exploration beyond the framework's themes and attributes. The interviews followed an hourglass format, starting with non-specific questions, gradually transitioning to specific questions, and concluding with another non-specific question. This format fostered rapport with the interviewees and encouraged comfortable information sharing throughout the interviews

Besides the interviews, during the study a project of a ZonMw funded consortium, concerning the development of an infection intervention SGs for people with mild intellectual disabilities, was observed. The aim of their study was to develop a SG with the use of co-design. These observations were done in an unstructured manner but were purposeful in the context of this study because their project implemented co-design. Since the consortium were in their early design stages the observations helped to gain a better understanding of the context of the study. However, it was not possible to approach the observations in a structured manner because the consortium did not yet reach the phase in which they would involve the target audience.

#### 5.2 Sampling strategies

A total of ten participants were recruited for the study using a combination of purposive sampling and snowball sampling to ensure diverse perspectives on the value of community engagement in SGs. The purposive sampling approach involved inviting a consortium member with SG experience to participate in the study and share an introductory email with relevant individuals in their network. This snowball effect generated additional candidates, and those who declined were asked to share the email within their networks as well. A Google search was conducted to identify health-related SG companies, and emails were sent to these companies or their employees to invite participation. This purposive approach yielded most of the candidates, ensuring representation of the study's context. Additionally, an introductory text was posted on LinkedIn, which was shared by others, resulting in the recruitment of participants beyond those identified through the Google search. Via these sampling strategies ten respondents were recruited and voluntarily interviewed.

Prior to the recruitment, inclusion criteria were composed and during the recruitment it was checked that all respondents complied to these criteria. To be eligible, it was necessary that the respondent had experience with SGs (a), the SGs must be health related or target an audience with low health literacy (b) and had experience with community-based participatory design (c). These second inclusion criteria guaranteed that the participant would have experience with SGs in the context of this study, either because the focus of the SG would be health related or because the target audience would comprise low health literate. Participants that did not meet the inclusion criteria or were minors were not invited.

#### 5.3 Demographics

This study was conducted in the Netherlands from February 2023 until June 2023. Table 1, gives an overview of the job in which the ten respondents had experience with SGs and the target audience of the corresponding SGs. Besides the occupation of the respondents, no demographic information of the participants was collected or stored. The ZonMw funded consortium consisted of ten members from several government bodies, research institutions and universities within the Netherlands.

Respondent number	Occupation	Target audience
R1	Game producer	People with mild intellectual disabilities
R2	Project lead	People with mild intellectual disabilities
R3	Game producer	People with mild intellectual disabilities and children
R4	Researcher	People with moderate and severe intellectual disabilities
R5	Game designer	People with moderate and severe intellectual disabilities
R6	Game developer	Healthcare professionals
R7	Game producer	People with diabetes and people with mild intellectual diabetes
R8	Project lead	Healthcare professionals, people with dementia and elderly
R9	Project lead	Youths with a psychiatric disorder
R10	Game developer	Children and adults with various health conditions as well as healthcare professionals

**Table 1:** An overview of the occupation of the respondents and the corresponding target audience of the SGs.

#### 5.4 Data collection

Semi-structured interviews were conducted online via Microsoft Teams to collect data for this study. The interviews lasted between 24 to 45 minutes, and all respondents preferred online interviews due to scheduling constraints, although in-person interviews were offered as an option. Informed consent was sent to all participants via email, and they provided digital signatures. At the start of each interview, the informed consent was briefly discussed, and verbal consent for audio-recording was obtained. Interviews were recorded using a separate device, and a transcription feature in Microsoft Teams was utilised, although it was not flawless. No notes were taken during the interviews to build rapport and maintain focus. Building rapport is shown to be important during interviews because it could lead to a higher quality of data as well as more in-depth answers, the manners and communication of the interviewer could influence the quality of data (Bell et al., 2016). In October 2022, a seminar was attended at VU Amsterdam about building rapport. The interviews were conducted in Dutch, ensuring participants' comfort and ability to express themselves verbally. Transcripts were also analysed in Dutch to minimise the risk of data loss during translation. To maintain uniformity, the same protocol and interview guide were used for all interviews. It should be

noted that the interview guide served as guidance, and the question order was not strictly followed. Questions and probes were chosen based on the flow of the interview and the respondents' answers.

The unstructured observations of the consortiums project lasted from February 2023 until mid-June 2023. The project was initiated in February 2023 and over the course of this study, they proceeded unto the pre-design phase and beginning of the design phase. During this time span observations were done solely at their bi-weekly, monthly meetings and email interactions. These interactions were only attended by members of the consortium and the target audience was not involved. The focus of these meetings was mainly on forming the research design of their project, this included deciding how the target audience should be engaged during the process. In the beginning of June, the first consultation sessions with the target audience were held by researchers of the consortium. However, these sessions have not been part of the data collection of this study.

#### 5.5 Data analyses

Each interview was transcribed while being conducted via a feature of Teams. Afterwards the audio-recording of the interview was used to revise and finalise the transcriptions. Before analyses the transcriptions were anonymised, to ensure the privacy of the respondents. Thematic analysis was performed using Atlas.ti, a qualitative research tool. The PartE conceptual framework served as a proper foundation to evaluate community engagement during the design phase of SGs (Gerard & Sosa, 2014). Since the interview guide was based on the six themes of the framework, the themes allowed one to get an in-depth understanding of community engagement in the context of SGs. The attributes of the framework were helpful to develop the probes of the interview guide. Due to the distinction between the themes, different aspects of community engagement were discussed throughout the interviews. However, at the analyses it appeared that interesting points would be lost if the coding would be based on the themes of the conceptual framework and therefore an inductive approach of coding was chosen. There are no suggestions for alterations on the conceptual framework.

During analysis, an inductive coding approach was chosen to capture interesting points beyond the framework's themes. The coding process consisted of four phases. First, open coding involved labelling interesting fragments within transcripts with descriptive codes. These codes were then grouped into categories, each with an overarching name. Noteworthy quotes for the report were highlighted during this phase. Second, axial coding compared categories from each transcript to identify prominent and less prominent ones. The less prominent categories were reevaluated for inclusion. Third, selective coding examined the remaining categories and identified relationships between them, resulting in the identification of four main themes, namely co-design session, feedback, impact, and barriers and pitfalls, and their sub-themes. The fourth phase involved deductive coding to ensure comprehensive coverage of the data. Each transcript was revisited, and the identified themes were assigned to relevant fragments to verify inclusion. To avoid data loss during translation, only the final findings and quotes used in the report were translated.

#### 5.6 Reliability and validity

The reliability of this research was considered on several levels. The interviews were guided by an interview guide, which was based on the six themes that were mentioned in the conceptual framework. Due to the uniformity between the interview executions, the inter-respondent consistency increased. After the first interview small alterations were done on the interview guide to improve content of the questions. Moreover, the use of an interview guide also ensured that the study could be reproduced in a similar setting. It must be noted that the collection and analyses of data was done by one researcher this could raise researcher bias. However, to minimise researcher bias the interviews were transcribed and analysed multiple times. In addition, the interview guide was also scanned by

members of the consortium and the internship supervisor. Furthermore, the unstructured observations were also used to minimise researcher bias.

Internal validity was also considered for this study. Firstly, the topic list and interview guide were based on the conceptual framework and additional literature, this enabled the semi-structured interviews to cover the objective of this study. An advantage of the semi-structured format was that findings from the earlier interviews could be cross-checked during the last interviews. During the analyses special attention was brought on the differences and similarities between the interviews, to also minimise researcher bias. Moreover, performing data analysis synchronously as the data collection helped to identify and improve flaws in the research methods. As a result, it enhanced the construct and content validity of this research. Lastly, triangulation of the data was done by comparing the findings to the literature.

#### 5.7 Ethics

The participants were part of this study on a voluntary basis and were also not pressured to be a part of this study or to answer the questions during the interview. Additionally, they maintained the right to withdraw at any moment. In line, to protect the privacy of the participants, all data was handled anonymously. During the research, confidentiality was maintained to ensure data privacy, accordingly the researcher followed protocols on data storage and data access as mentioned in Annex A: Data management plan. The mentioned rights, anonymity and confidentiality information was also included in the informed consent form the respondents received prior to participating and was explicitly mentioned to them beforehand as well, to ensure transparency. The informed consent had to be signed by the respondents before the interview and verbal consent was also required before audio-recording. is shown in Annex C. An ethical check was performed and concluded that no additional ethical review should be asked because the study is not harmful and does not include vulnerable populations.

#### 6. Results

The research aims to evaluate the value of community engagement during the design phase of SGs. While the interview guide was based on the six themes of the conceptual framework, four additional themes emerged that incorporate the original framework's themes. These themes are the phases of engaging the target audience, the co-design session, impact, and barriers and pitfalls. Each theme will be addressed in the following subchapters, corresponding to the sub-questions of the study. Participants referred to community-based participatory design during the design phase, using terms such as co-creation or co-design. Opinions varied on the frequency of co-creation in SGs, with some participants noting its infrequent use. However, two respondents mentioned an intense iterative approach, which was rare compared to others. Other participants mentioned that co-creation is common in game development, as many game developers employ Scrum sprints and seek feedback from the target audience at the end of each sprint.

#### 6.1 Phases to engage the target audience

Despite all respondents acknowledged that the feedback that is generated during the co-design process is essential for the final product, their thoughts differed on when and for what purpose the target audience should be engaged to provide feedback or input on the SG. Four phases were identified in which the target audience could be engaged, namely the pre-design, design, evaluative and implementing phase. Three of the respondents expressed that they engage their target audience in an intensive and iterative manner during all four phases. Whereas the other respondents only involve them in certain stages or in a less intensive and structural manner. Noteworthy, two respondents explained that if you engage the target audience in a cyclic manner during each phase, they will understand the concept and purpose of the game better. As a result, they experienced that the feedback then will also be more substantial. It must be noted that these different preferences did not always seem to depend on the target audience.

#### 6.1.1 Pre-design phase

Only a couple respondents use consultations with the target audience as a main approach during the pre-design phase, where the focus mainly lies on getting to the core by understanding their problem and needs regarding the theme of the SG and whether a SG is the proper approach to address the issue. R5 explained the following:

#### "Take your time to get to know them and feel welcome. Only then you can think about what you want to achieve but first make sure that you understand how their world works"

Noteworthy, two of the respondents have experienced termination of a SG project because a SG would not properly address the needs of the target audience or because the concept was not received well by the target audience. Whereas R3 mentioned:

# *"It depends on the target audience, usually the target audience is not really involved in the beginning. A lot is based on assumptions and literature, which is a good starting point"*

More than half of the respondents agreed with their stamen and rather used assumptions and theoretical research as starting point and main approach during the pre-design phase, of which two respondents combined this approach with consultations with the target audience. Different reasons for this preference were given such as the SG was initiated by an organisation that could provide feedback, the target audience is already engaged at later phases and then the assumptions can be verified as well, it is difficult to have ethical clearance for in-depth consultations with the target audience or they have enough expertise on the subject. However, four respondents noted that this is one of the most crucial stages to engage the target audience because otherwise you could develop a SG that does not address the issue according to the target audiences' point of view or need to alter a lot in the latter stages. For instance, R8 mentioned

"One time, I worked with designers that were still a bit unfamiliar with the co-design approach. So we did it but not enough. So you see the designers start to develop a lot and also very fast and they are then very enthusiastic. But actually you miss a couple steps and then you notice that what they eventually produce aligns less with needs and possibilities of course the target audience".

#### 6.1.2 Design phase

During the design phase all respondents have experience with engaging the target audience but their viewpoints differ. Despite these differences, all agreed that receiving feedback is a necessity because they have learned from experience that their assumptions are often not valid. As explained by R4:

"It's important to receive feedback in an iterative manner and build a prototype from that. For instance, some of our assumptions are often not accurate."

At the design phase, the concepts generated at the pre-design phase are translated into a SG therefore the content of the game as well as the design of the game needs to be developed. It became evident that the target audience could be engaged to provide feedback on either the content or the design elements of the game as well as both. The feedback could be obtained by observing the target audience or asking direct feedback. Most often the target audience were engaged for a specific objective chosen by the SG developers. For instance, R10 stated:

"We never really design together. As designers we have expertise, which makes it difficult to co-create the design elements. However, it is really useful on content level"

This respondent argued that the target audience should be less engaged regarding the design elements of the game because they do not have sufficient knowledge on that compared to the designers of the game. In agreement, others mentioned that their target audience or initiators of the SG primarily provide input on the game's content and seek feedback on the look, feel, and game design once a prototype is developed. Respondents targeting intellectually disabled individuals highlighted the importance of requesting feedback on prototypes instead of concepts because they could be too difficult to understand. Interestingly, two respondents mentioned using Scrum sprints during the design phase, resulting in feedback being sought from the target audience at the end of each sprint. In contrast, two respondents preferred involving the target audience in both content and game design from an early stage. It was also noted that target audience input on content might be bypassed if other team members possessed expertise in the subject. Additionally, all respondents indicated that feedback received was processed before subsequent co-design sessions. Prototypes were tested, changes were made based on feedback, and further testing with the target audience was conducted, allowing most feedback to be directly incorporated into the final product.

#### 6.1.3 Evaluative and implementing phase

The evaluative and implementing phase were only briefly mentioned during the interviews because this study primarily concerns the design phase. However, during the evaluative phase it seemed normative to engage the target audience to pre-test the product and for most this would be the final phase in which they would engage the target audience. Only some respondents engage the target audience during the implementation phase, the focus then for instance lies on how the product should be best distributed among the population.

#### 6.2 The co-creation session

The co-creation session was an overarching theme that has been identified during the analyses of the interviews. It refers to the structure of a co-creation session and it touches upon the practices used during sessions as described in the conceptual framework mentioned earlier of Gerard and Sosa (2014). Throughout the interviews it became clear that most respondents did not have a clear protocol or guideline regarding the co-creation sessions and the methods used were not described in depth. However, the co-creation sessions' theme was mostly expressed in terms of the duration, frequency and structure of the sessions.

#### 6.2.1 Duration

The duration of the sessions has been found to be an important attribute of the co-creation sessions because it influences the contribution and attention of the participants. All respondents agreed that a session should not be too long because it otherwise would be too taxing for the participants, and you would lose their interest and attention. The sessions were approximately between half an hour until two hours max and are accustomed to the attention span of their target audiences. For instance, the respondents that have people with an intellectual disability or dementia as a target audience all agreed

that a session should be around half an hour and the maximum is one hour if needed. Whereas the respondents that have experience with a target audience that doesn't have health concerns said that their sessions usually last between an hour and a half and two hours with a short break. Contrary, respondent 9 said that their sessions usually last half an hour and sometimes an hour depending on what kind of SG is being developed and the type of output they want from the sessions instead of depending on the target audience.

#### 6.2.2 Frequency

The frequency and total number of co-creation sessions that are needed remains indeterminate. Most respondents either did not mention it or said it depended on how many were necessary but they did not clarify how that is decided or when saturation is reached. However, one respondent did mention that for their project sessions were held biweekly and 7 in total. Whereas another respondent mentioned that five iterations are usually needed before a SG is released. Correspondingly, another respondent mentioned that on average five iterations are needed but it does sometimes happen that a SG is immediately received well and only three iterations are needed, where on the other hand it also happens that up till 10 are needed.

#### 6.2.3 Group size

As far as the group size of a co-creation session, 8 of the respondents mentioned that the size should not be too large. The sizes differed between 4 and 10 participants. This did not depend on the target audience but to some degree on the availability and appearance rate of the participants. Since, all participants engaged on a voluntary basis. Additionally, one participant mentioned that it is best to begin with a small group of participants and as the development progresses the number of participants also must increase. Half of the respondents mentioned that they usually work with a set group of participants, which is the same for all the sessions. Only one mentioned that they most often work with a set group but actually prefer to combine the set group with a rotation of participants as well. By doing so, the set group of participants could guide the newer participants which would make it easier for the newer participants to understand the purpose of the session and it would give room for fresh perspectives.

#### 6.2.4 Practice

The practice of the co-creation sessions remained indistinct. Although most sessions appeared to be approached as a type of focus group setting, in which prototypes were tested or discussed, existing games were played, surveys were conducted, or interviews were held related to the input and design of the SGs. Strikingly, it became evident that visualising is the most important attribute of having an effective co-creation session regardless of the type of target audience. Almost all respondents agreed that this is due to the lower level of abstraction of the participants regarding the concept of a SG or even a game in general. For instance, R6 stated:

"They really need a lot of visualisation and graphical support and less text. Yes, that works best. "

Interestingly, R9 mentioned:

"At the latter sessions they provided specific examples but in the first session they didn't. Which was fun because they said 'come up with an example yourself'." Visualisation or graphical support for example through the use of showing prototypes, visible and specific examples such as pictures, or playing existing games as reference, would make it easier for the participants to give feedback on. Compared to asking feedback from the participants solely based on textual descriptions such as pitching a concept or describing relevant theory because then they could not fully comprehend or imagine what the designers meant. Noteworthy, two respondents did explain that a target audience is often more capable than one might expect, as long as you make yourself understandable within their frame of reference. Another attribute of having an effective session was to incorporate creativity in the sessions because otherwise the engagement of the participants would be lower and their interest would fade faster. It showed that if the participants would be creatively active or stimulated in a session the session would be more productive and the feedback received would be richer as well.

#### 6.3 Impact

Impact was already defined in the conceptual model as the short-term, long-term, and indirect outcomes of implementing community-based participatory design (Gerard & Sosa, 2014). During the interviews the impact of using co-creation during the development of a SG was described either in terms of the overall impact or the impact it had on the participants of a co-creation session.

#### 6.3.1 Overall impact

It immediately became evident that the usage of co-creation has a positive impact on the end-product of the SG. Nine out of ten respondents have had pleasant experiences and agreed that by implementing co-creation during their development process it generates a SG that will be of better quality, more effective and will be received better. Namely, due to opportunity the target audience has to voice their opinion during the co-creation and test sessions the developers are able to generate a SG that aligns better with the needs, capabilities, expectations and experiences of the end-users. The implementation of co-creation and the feedback that it provides therefore helps to prevent the development of a SG that in the end does not resonate well. Contrary, only one participant mentioned that the outcomes of a co-creation session they attended did not give new insights and the outcome could also be generated if one had immersed themself in the theme of the SG. However, R8 mentioned the following:

#### "The better a target audience is involved, the more successful the product will be.".

A different reason that explains the preference of co-creation was given by two respondents, they expressed that co-creation enables the SG to be created and implemented from bottom-up instead of top-down. Especially, in settings where it could be difficult to implement the SG or where the target audience is hesitant it could be helpful if a sample of the target audience were already involved during the development process. These sample participants could then become ambassadors of the game and promote the game within their setting or organisation. Accordingly, another respondent mentioned that it is more worthwhile for the process to create a bond with the one's involved in a co-creation session instead of seeing them solely as participants. Furthermore, a couple respondents emphasised the importance of co-creation by highlighting that it empowers the participants and the target audience by offering them a chance to express themself.

#### 6.3.2 Impact on the participants

Besides the overall impact, the impact the co-creation sessions had on the participants was also touched upon by nine out of ten participants. Noteworthy, some respondents mentioned that they usually do not analyse or think about this impact so the following points are mostly their own interpretations of what the participants could have experienced. Strikingly, one respondent did not think that the sessions have any direct effect on the participants with a severe intellectual disability and implied that it might inspire the care providers that support a participant during a session but even that was uncertain. Conversely, seven participants instantly expressed that the sessions often aroused enthusiasm and the participants were energised. Although, it must be noted that the level of enthusiasm also depends on the set-up of the sessions and how engaged the participants are as mentioned earlier. To illustrate, R1 mentioned:

"The more sessions you do, the more enthusiastic they become and that they also really. Well yes, for instance one participant also really says: "Yes, I am co-developer" and that is also true. They really feel as part of the team"

In agreement, another respondent noted that in the first session, participants lost enthusiasm as the respondent mainly pitched and spoke to them. However, in subsequent sessions with a more creative and active setup, enthusiasm immediately increased. It became evident that participants could gain knowledge and enhance their skills through these sessions. Three respondents mentioned that focus group discussions during the initial phase and regarding the input of the game indirectly taught participants about the subject of the SG, helping them better understand the problem and providing valuable insights not just for developers, but for participants as well. Additionally, sessions with clickable prototypes or later stages of development were mentioned by respondents to potentially improve participants' digital skills, critical thinking, and game knowledge. Four respondents emphasised that being part of the sessions gave participants a sense of fulfilment and empowerment. When participants were iteratively engaged throughout the process, they felt genuinely involved in the project and believed their feedback was listened to. One respondent mentioned that participants with mild intellectual disabilities proudly referred to themselves as co-designers of the SG, acknowledging their contribution to the game's development.

#### 6.4 Barriers and pitfalls

Barrier was also a theme in the conceptual framework but the interviews showed that the barriers are related to other attributes, namely the participants, budget and time (Gerard & Sosa, 2014). Pitfalls were also identified as a recurring theme throughout the interviews and comprises the learned lessons and difficulties that are faced during co-creation. Throughout the interviews it appeared that effective co-creation cannot be reached without trial and error, especially for a first timer or with an unfamiliar target audience.

#### 6.4.1 Barriers

Actually, not many barriers were identified and those that were identified did not seem to discourage the respondents to implement co-creation. As far as the participants, the most difficult is to gather the participants because their involvement is on a voluntary basis and often without compensation. It becomes even more difficult if the game targets a vulnerable population. Since, those populations are often less populated and harder to reach. It became evident that even when you gathered all participants you must take into account that there will always be absentees or people that drop out, especially when it concerns a health-related SG because of the fast-paced and unpredictable environment of the health care sector. These weak points as a result sometimes hinder co-creation sessions to have an adequate representation of the target audience. Ultimately, co-creation sessions heavily depend on the participants, and you therefore need enthusiastic people because a session would not be possible without them. Budget and time were also mentioned by three respondents as potential barriers because the respondents expressed that it asks a lot of time from the developers as well as from the participants to partake in the sessions the more intensive and frequent they become. For instance, R5 expressed:

"It's not as rosy as it sounds. Time?! You are dependent on the people that are enthusiastic to participate. You really need to be flexible"

Whereas R10 argued:

"Well, it takes time to test in an iterative manner. But you gain so much more from it"

It must be noted that throughout the interviews it appeared that the good outweighs the bad and it is important to utilise co-creation within your capabilities. To illustrate, R9 mentioned the following:

"Co-creation is always possible, we sometimes underestimate what people in psychiatry or with an intellectual disability can do. We have the urge to quickly talk about people instead of involving those people and doing it together.".

#### 6.4.2 Pitfalls

The pitfalls associated with co-creation for SGs primarily revolved around feedback and representation of the target audience. While all respondents recognized the importance of engaging the target audience, some noted that the feedback received during co-creation could be flawed. Participants might provide socially desirable answers, which was observed for both intellectually disabled individuals and healthcare professionals as the target audience. Despite this, cross-checking feedback mitigated major concerns regarding potential noise. Most respondents acknowledged the value of having team members with expertise in both the target audience and SGs. It also became apparent that there is a risk of co-creation sessions lacking a true representation of the target audience. Voluntary participation meant that participants were motivated or enthusiastic, potentially excluding the less enthusiastic or harder-to-reach segment of the target audience. However, some respondents stressed the importance of an accurate representation during the sessions to ensure alignment of the end-product with the target audience.

#### 7. Discussion

This study aimed to answer whether it is valuable to engage the community during the design phase of SGs targeted for low health literate. This was done by evaluating community-based participatory design for SGs based on the themes of the PartE framework (Gerard & Sosa, 2014). The evaluation led to the emergence of four themes which were described in the result section. Based on these results, three key findings were identified during this study. Firstly, the importance of visualisation was emphasised by all respondents. It appeared to be related to the effectiveness of a session, quality of feedback and level of engagement of the target audience. The second key finding concerns the different levels of intensity to engage the target audience even though most respondents were in favour of co-creation. Especially, that engagement at the pre-design phase was thought to be essential by several respondents. The theoretical background already highlighted the different approaches to implement community-based participatory design for SGs and the findings showcased these differences as well. However, the majority of the respondents stated that the more intensive the target audience is engaged, the better the final product will be. Additionally, it became evident that receiving

feedback is a necessity because the assumptions of the game developers are often invalid. The third key finding was that the effects co-design has on the final product and participants outweighs the barriers or pitfalls that could arise. Noteworthy, most barriers did not obstruct the decision of involving the target audience. Hence, nine out of ten respondents emphasised the importance of engaging the target audience during the development of a SG. Even despite their different viewpoints on the manner in which the target audience should be engaged. This chapter will discuss the key findings and their practical and academic implications. The recommendations based on these findings will also be presented. Moreover, the strengths and limitations of this study will be touched upon as well as suggestions for further research.

#### 7.1 Visualisation

This study identified visualisation as an important attribute of the co-creation sessions. The terms visualisation or graphical support were a recurring theme while discussing the structure and effectiveness of the sessions as well as the quality of the feedback. The importance of visual support was acknowledged by all respondents of the interview. Visualisation was used to refer to graphical images or videos, prototypes, existing games or other tangible tools. Similar to one of the respondents, the study of Nicholas et al. (2012) used a version of an existing game as foundation of the co-creation sessions. Noteworthy, while using visualisation it is important that the tools are suited for both the goals of the designers and the reference frame of the participants (Jessen et al., 2018). Therefore, the needs, abstraction level and preferences of the target audience need to be taken into account while deciding the structure of the sessions including the visualisation tools (Deterding, 2015). In line, the study of Albadra et al. (2020) stated that the amount of detail should also be considered while choosing the visualisation tools because too much specification could shift their attention to irrelevant parts of the tools. The findings indicated that the use of visualisation tools at the sessions are essential because the target audience often has a low abstraction level. Without using visualisation, it would be more difficult for the target audience to understand the concepts, feedback would be shallower or misplaced, and they would lose their attention faster. These findings are also supported by several studies, which noted that the use of visualisation has helped to increase the engagement of the participants throughout the sessions, facilitate a better understanding of the concepts and activities and overcome misunderstandings by facilitating a common language between the participants and SG developers (Belinda et al., 2022; Rygh & Clatworthy, 2018; Albadra et al., 2020). Other benefits of using visual support during co-design were found in literature, namely that it stimulates discussion, facilitates the transfer of knowledge, initiates inspiration and creativity, comforts the participant and makes it easier for them to express themself (Lanezki et al., 2020; Jessen et al., 2018; Rygh & Clatworthy, 2018).

#### 7.2 The intensity in which the target audience is engaged

The second comprises the different intensity levels and phases in which community engagement is implemented. Four different phases were identified of which all respondents engaged the target audience via pre-testing at the evaluative phase. The viewpoints mainly differed on the way(s) in which the target audience should be engaged during the pre-design and design phase. The study of Lanezki et al. (2020) states that the target audience could be engaged as users, testers, informants or design partners , which is similar to what was mentioned in the theoretical background. Based on the findings, it seems that the respondents usually use the target audience as informats during either the pre-design or design phase or both and as testers during the evaluative phase. As informants the target audience do not make decisions but could be consulted to provide input and feedback at different stages of the development process (Lanezki et al., 2020). Compared to engaging them as design

partners, this role is less time-consuming for the target audience and more adaptable to implement because the designers are free to decide when they should be engaged. The majority of respondents agreed that it is best to engage the target audience in an iterative cycle, which is also supported by some studies (Martin et al., 2020; Gugerell & Zuidema, 2017). However, it is important that the methods used are tailored to the different stages of the cycle and capabilities of the target audience. By doing so, the chances of receiving valuable and reliable feedback from the target audience increases (Lanezki et al., 2020; Wanick & Bitelo, 2020). For instance, visual probes and ethnographic methods could be suitable for the pre-design phase, prototypes and creative participatory design methods at the design phase and interviews or questionnaires at the evaluative phase. Besides, the chosen methods by involving the target audience as informants it is also important to have a clear objective on what aspects their feedback is needed, therefore their involvement could be more fruitful. Lastly, only some of the respondents emphasised the importance of engaging the target audience at an early stage. However, the study Hauge et al. (2020) supports their viewpoints by stating that it is essential to involve the target audience at an early stage to establish realism. Moreover, involving them intensely from an early stage enables the designers to understand and process the feedback better (Haan & Van Der Voort, 2018).

#### 7.3 Impact vs. barriers and pitfalls

In this study, both the impact and barriers of community engagement for SGs for low health literate were touched upon. The main impact found in this study was that the developed SG will align better with the target audience. Strikingly, the study of DeSmet et al. (2016) found that co-creation does not have a significant impact on the effectiveness of SGs. Whereas other studies stated that participatory design increases the satisfaction rate among the target audience and that their involvement is important for the end product (Jessen et al., 2018; Albadra et al., 2020, Göbl et al., 2020; Cederved et al., 2022). Moreover, co-creation for SGs allows a more efficient development of the SG because the designers benefit from the perspectives and iterative feedback of the target audience (Labonté-LeMoyne et al., 2017). The findings showed that adequate stakeholder representation is related to the effectiveness of co-design. This is also supported by literature, which states that the diversity of stakeholders allows a variety of perspectives that complement the SG (Labonté-LeMoyne et al., 2017). Noteworthy, most studies only focus on the impact co-creation has on the final product rather than it has on the participants. The study of Menestrina et al. (2021) noted that participatory design for SGs enables mutual learning between the participants and designers, which the respondents of this study also experienced.

Despite the barriers and pitfalls the respondents emphasised the positive effect community engagement has on SGs. However, in line with the findings literature mentions that co-creation could be a demanding process that could be constrained by time or other limited resources (Billger et al., 2020; DeSmet et al., 2016). It appeared that the sessions are time constraining for both the designers and the participants and influences their willingness to participate. The co-creation process does ask a lot of patience, compassion, and flexibility of the designers if they want the implementation to succeed. Interestingly, the study of Khaled and Vassalou (2014) noted that one of the main barriers of using co-creation for SGs was that the target audience lacked knowledge on content and game design. Opposed to their statement, the respondents of this study expressed that from their experience this actually does not cause major concerns. The findings showed that the main concerns with the feedback was that it could be biassed or have noise but therefore it is important to cross-check the feedback with relevant literature and evidence regarding design and content of the SG (Jessen et al., 2018; Derks et al., 2021).

#### 7.4 Implications of the findings

This study has shown the value of engaging the community during the design phase of SGs by touching upon the impact it has on the end product and target audience. To validate this value the barriers and pitfalls related to this were also discussed. Moreover, the practicalities of a co-design session were touched upon. The variety of themes within the findings have brought an interesting understanding of community engagement during the design phase of SGs for low health literate and shown a more in-depth view on how community engagement is perceived by different stakeholders with different target audiences. Importantly, this study has generated recommendations regarding the implementation of community engagement in the context of SGs for low health literate. This study builds upon the recent rise of studies regarding SGs and co-creation, which are still limited. The findings and recommendations of this study might be of interest to other researchers, people working in the (serious) gaming industry as well as healthcare professionals. Especially, people that intend to develop a SG for low health literate or other marginalised populations.

#### 7.5 Strengths and limitations

Both the practices used and findings from this study could serve as a foundation for future research and work on SGs for low health literate. The findings and practices might be generalisable for other target audiences of SGs because the respondents were professionals instead of low health literate and some of their target audiences were also non low health literate. However, due to the inclusion criteria of the respondents, any generalisations or statements regarding the viewpoint of low health literacy on community engagement for SGs is not possible. Yet, we can conclude that the viewpoint of SG professionals on community engagement for SGs is positive and the chosen methods worked well to explore the value of community engagement. It was intended to include interviews with low health literate, as well as participatory observations of co-creation sessions but due to ethical clearance delays and project stagnation, these could not be conducted within the study's timeframe. Furthermore, the small sample size may be considered a limitation as saturation was almost reached. It must be noted that all respondents were actively recruited. However, it was difficult to find people that fulfilled the inclusion criteria since health-related SGs and SGs for low health literate are still limited. Also, many eligible people declined or disregarded the invitation to participate in this study. Nonetheless, the heterogeneity of the respondents in terms of their jobs, target audience and gender allowed us to discuss community engagement from different viewpoints.

#### 7.6 Further research

Based on this study we recommend further exploration of the value of community engagement during the design phase of SGs of low health literacy. Since, this study has only explored the viewpoints of professionals that have experience with SGs rather than the viewpoints of the target audience and especially the participants. Further research could conduct individual interviews with members of the target audience regarding their viewpoints of community engagement for SGs. Their experiences could be compared to the findings of this study to assess whether the value remains the same. A second option for further exploration is to perform an ethnographic study, where the development process of a SG is observed to assess the value of community engagement. This option would provide the most in-depth understanding of community engagement and considers the viewpoints of all stakeholders. Lastly, quantitative research could be performed on how frequent and in what manner community engagement for SGs is used to signify the value of community and the findings of this study.

#### 7.7 Recommendations

Based on the findings and triangulation with literate, three recommendations regarding co-creation for SGs for low health literate have been formulated. This study identified that engaging the target audience during the development of SGs is essential for the final product. However, both in literature and the findings no uniform protocol has yet been found. The recommendations are therefore related to the structure, intensity, and engagement level of co-creation for SGs for low health literate.

#### 7.7.1 The earlier, the better

To ensure an efficient development of SGs, it is important that the target audience is engaged from the pre-design phase and onwards. By using ethnographic research to identify the problem and needs of the target audience that one wants to address with the SG, it ensures that the SG will align with the capabilities and experiences of the target audience. It also gives the opportunity to verify whether a SG would be a proper approach for the target audience, which will save a lot of money and time in the end. Furthermore, it provides the designers with a clear objective and outline of the SGs. However, it is important that their input will still be validated by literature or other stakeholders with expertise because there is still a possibility of noise and bias in their feedback. Moreover, their engagement from an early stage allows a more efficient development process because otherwise developers need to make a lot of adjustments based on their feedback at later stages. Which made the designers work backwards instead of forward in an iterative and labour-saving manner. A possible barrier to adhere to this recommendation could be limited resources or time but their input could be derived via (online) interviews, focus groups, observations or questionnaires subject to availability of resources.

#### 7.7.2 Facilitate different levels of engagement

As previously mentioned, it is essential that the target audience and stakeholders are engaged in an iterative manner during the different phases of the development process. However, time was also identified as a barrier on the participants' side. Offering different levels of participation, differing between testers and informants with the possibility to choose when to be involved, respects the limited time of the target audience (Ampatzidou, 2020). Moreover, by accommodating these different levels the target audience could also decide how intensely they want to be engaged, which will improve their enthusiasm and attention span at the co-creation sessions. Furthermore, these different levels will also be beneficial on the designers' side because then they will not have as many absentees at the co-creation sessions. Additionally, a proper stakeholder analysis is needed to ensure that the right participants are involved at each stage of the development process because that influences the alignment of the final product as well. Despite how intense the target audience is involved, they should not solely be seen as participants but a warm bond should be created between the participants and designers. This could be done by processing and incorporating the feedback of each session into the next session, if for some reason the feedback is not implemented this should also be explained to the target audience. By doing so, the participants also truly feel as part of the team and that their feedback has been listened to.

#### 7.7.3 Clear objective and protocol for each co-creation sessions

To have effective co-creation sessions and receive valuable feedback it is important that the designers have a clear objective and protocol for the session. Since, the structure and desired feedback depend on the phase and stage of the development process it essential that these are taken into account for each individual co-creation session. Moreover, by having a clear objective and protocol that is tailored to the objective for each session, the feedback received will have less noise and there will be a minimised risk that the attention of the target audience will shift to less important parts. Another

important requirement is that the visualisation tools are also aligned with the objective and capabilities of the target audience to receive the best feedback.

#### 7.8 Researcher reflexivity

As this study was conducted by a single researcher, there is a potential for subjectivity to impact its validity. To address this risk of researcher bias, the researcher engaged in iterative reflections throughout the study. This critical self-reflection allowed for an examination of how their role and characteristics influenced the study's findings and practices. The researcher had limited prior knowledge of SGs and participatory design, which helped minimise assumptions and biases related to these concepts. Familiarity with these concepts was gained through literature and interviews conducted during the study. The research question was inspired by a project of the consortium, which focused on SGs for individuals with mild intellectual disabilities. It should be noted that the researcher was not familiar with the concept of low health literacy prior to this study. However, a course on "Disability and Development" taken a month before the study increased the researcher's understanding of the importance of self-advocacy for people with disabilities and the barriers they face. These perspectives, however, did not influence the interview process or cloud the researcher's judgement during analysis. Additionally, to minimise the risk of misinterpretation, the researcher often summarised respondents' statements back to them to ensure accurate understanding.

## 8. Final thoughts

In this study, semi-structured interviews with SG professionals that develop SGs for people with health conditions, were conducted to evaluate community engagement for SGs in-depth. By doing so, this study aimed to answer: "*What is the value of community-based participatory design during the development of SGs for people with low health literacy*?". The findings showed that engagement of the target audience during the design of SGs has a positive impact on the quality and alignment of the SG. Besides, visualisation seems to be an important attribute of the impact. Due to the heterogeneity of the respondents, these findings might be generalizable. Many of the findings were also in line with literature regarding participatory design and co-creation but not always with studies in the context of SGs. However, the identified practices, impact, and barriers do add to the rising body of studies concerning co-creation for SGs. The validation of these findings is strongly recommended as well as further exploration of community engagement from the viewpoints of the target audience. Both the methods and results of this study could be used as starting points for further research.

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#### Annex

#### Annex A: Data Management Plan

The data that will be generated and processed during this will follow four principles, namely being findable, accessible, interoperable and reasonable (FAIR). During this study data will be generated to evaluate the value of implementing community-based participatory design during serious games development for people with low health literacy. The data that will be generated during this study is essential because there is still a lack of studies concerning this population, especially within the context of serious games. Since this study only evaluates the value of a process instead of focusing on an individual level, only generic data will be collected such as the relevant occupation of the participant. Meaning that no personal data of the participants will be collected and stored. Moreover, only qualitative data relevant to this study or the project of the ZonMw funded consortium will be collected and stored. The consortium has their own data management plan, that will also cover the ethical considerations and privacy guidelines regarding the data of this study. The qualitative data will consist of interviews, researcher notes as well as interview transcripts. All raw data that will be generated will afterwards be anonymized, and stored in a secured shared drive of the Vrije Universiteit. All participants will sign an informed consent form before the data collection will start, in case a participant will be part of multiple data collection sessions they will sign a form each time before the start. The informed consent form will also include an explanation of the aim of the study and will be written in a manner that will be understandable by the participants. All data will be stored in a secured environment of the Vrije Universiteit, which can only be accessed by the researcher that is part of this study. Third parties do not have access to the data. The data will be stored there for a maximum of one year.

# Annex B: Interview guide

Торіс	Vraag	Probes
Algemeen: LVB	Wat is uw relatie met mensen met een licht verstandelijke beperking?	<ul> <li>Welke leeftijdscategorie meest bekend</li> <li>Welke setting u de doelgroep het meest tegenkomt?</li> <li>Zit er overlap met andere settings/contexten wat betreft de doelgroep</li> </ul>
Algemeen: Serious Games	Wat is uw ervaring met serious games?	<ul> <li>Positieve of negatieve ervaringen?</li> <li>Om welke serious games gaat het?</li> </ul>
Algemeen: Serious Games	Wat is uw rol tijdens het ontwikkelen van serious games?	Bent u zelf dan ook in contact met de doelgroep?
Community-based participatory design	Hoe gebruikelijk is het om participatieve design methoden te gebruiken tijdens het ontwikkelen van serious games?	<ul> <li>Merkt u dat daar verschil in zit als het gaat om de lvb-doelgroep?</li> <li>Zo ja, waar zou dat aan liggen?</li> </ul>
Objective	Met welke redenen wordt er gekozen om participatieve methoden in te zetten?	<ul> <li>Zijn de beweegredenen meer gericht op het belang van de doelgroep of de ontwerpers?</li> <li>Worden deze doelen/redenen uiteindelijk ook behaald/verwezenlijkt?</li> </ul>
Methoden	Op wat voor manieren worden participatieve design methoden ingezet bij serious games?	<ul> <li>End-user testing, co-creatie of end-user als informant?</li> <li>Hoe zou u de rol van de verschillende partijen omschrijven die betrokken/aanwezig zijn tijdens een sessie?</li> </ul>
Methoden	Hoe ziet zo'n sessie eruit?	<ul> <li>Van welke middelen wordt er gebruikgemaakt?         <ul> <li>Bestaande methoden of nieuwe methoden?</li> </ul> </li> <li>Wordt er rekening gehouden met doelgroep?</li> <li>Is het aangepast aan de doelgroep?</li> </ul>
Methoden/interactie	Denkt u dat met de huidige methoden de doelgroep invloed heeft op het uiteindelijke ontwerp van de serious game?	Heeft u een voorbeeld ter verduidelijking?
Interactie	Wat voor bijdrage leveren de doelgroep en andere betrokkennen tijdens de sessie?	<ul> <li>Leren beide partijen iets uit de sessies?</li> <li>Geven beide partijen evenveel input of deelt alleen één partij zijn meningen/informatie?</li> <li>Hoe zou u de communicatie tussen de verschillende betrokkenen omschrijven</li> </ul>

		tijdens de sessie?
Barriers	Welke belemmeringen of struikelblokken zijn er om participatieve methoden te gebruiken bij mensen met Ivb voor serious games?	<ul> <li>Denk hierbij aan economische, politieke, sociale of individuele belemmeringen.</li> <li>Hebben zich weleens moeilijkheden voorgedaan tijdens een sessie?</li> <li>Hoe wordt er met deze belemmeringer omgegaan?</li> <li>Zijn er moeilijkheden voor de designers om de input van de doelgroep te vertalen in de game?</li> <li>Brengt het educatieve karakter van serious games moeilijkheden als de doelgroep wordt betrokken.</li> </ul>
Representatie	Hoe wordt de doelgroep vertegenwoordigd tijdens de participatieve methoden?	<ul> <li>Melden de deelnemers zich zelf aan of wordt er voor specifieke vertegenwoordigers gekozen?</li> <li>Intersectionality: wordt er rekening gehouden met categorieën als afkomst man/vrouwverhouding.</li> </ul>
Representatie	Denkt u dat de gekozen deelnemers de gehele Ivb groep weergeven?	<ul> <li>Hoe wordt er gewaarborgd dat er geen onder- of overrepresentatie plaatsvindt van de doelgroep?</li> <li>Dat de focus niet alleen ligt op hun beperking.</li> <li>Op basis van welke ervaringen deelt u deze mening?</li> </ul>

#### Annex C: Informed consent

#### Toestemmingsformulier

Mijn naam is Nesrin Danning en ik ben masterstudent Biomedical Technology & Physics aan de Vrije Universiteit Amsterdam. Leest u alstublieft zorgvuldig de onderstaande informatie door en aarzel niet om vragen te stellen. Vragen kunnen worden gesteld aan de onderzoeker van wie u dit document heeft ontvangen. Mijn afstudeeronderzoek genaamd 'The value of community engagement during the development of serious games : Concerning people with low health literacy' gaat over de waarde van het co-creëren van een serious game samen met mensen met lage gezondheidsvaardigheden. Voor mijn afstudeeronderzoek loop ik stage bij de Universiteit van Amsterdam (UvA) voor het project 'Serious Game - voorkomen van verspreiding van infectieziekten'. Dit project is een samenwerking tussen onderzoekers van het Verwey-Jonker instituut, het Radboud UMC, de Universiteit Maastricht, de UvA, de Open Universiteit, GGD Midden-Gelderland, GGD Zuid-Limburg en Zuyd Hogeschool. Het consortium project ontwikkelt een serious game samen met MediaJungle voor preventief gezondheidsgedrag voor mensen met een licht verstandelijke beperking. Met mijn onderzoek willen we uiteindelijk bijdragen aan meer gelijkheid en inclusiviteit voor mensen met lage gezondheidsvaardigheden in de samenleving.

*Procedures:* Ik wil u graag interviewen over het gebruik van participatieve design methoden tijdens het ontwikkelen van serious games. Dit interview zal online plaatsvinden via Teams. Het interview duurt ongeveer 30-45 minuten. Voor dit onderzoek zullen naast individuele interviews met experts en professionals, ook focusgroepgesprekken van het consortium project met professionals en de doelgroep worden geobserveerd. De interviewvragen zijn gericht op uw ervaringen met serious games in combinatie met het inzetten van participatieve design methoden bij mensen met lage gezondheidsvaardigheden en/of mensen met een licht verstandelijke beperking.

*Vertrouwelijkheid:* Met uw toestemming zal er een audio-opname van het interview worden gemaakt, om ervoor te zorgen dat niets uit verband wordt getrokken van wat u deelt. De opname zal beveiligd worden opgeslagen en wordt na het transcriberen onmiddellijk verwijderd. Audio-opnamen, transcripten en notities die tijdens en na het interview worden gemaakt, worden vertrouwelijk behandeld en zijn enkel toegankelijk voor de interviewer. Bovendien wordt alle verzamelde data geanonimiseerd en zijn ze niet te herleiden tot individuen. Uw antwoorden en persoonlijke informatie zullen niet worden verstrekt aan derden, tevens zal uw persoonlijke informatie niet worden opgeslagen en ook niet worden gedeeld in publicaties. Hiermee wordt gegarandeerd dat alleen de interviewer weet van uw deelname aan het onderzoek. De interviewer zal de verzamelde gegevens veilig bewaren en risico's minimaliseren door uw gegevens te versleutelen en te beveiligen. Transcripten en andere documenten die als onderdeel van deze studie zijn verzameld, worden binnen 6 maanden na afloop van de studie vernietigd.

*Risico's, ongemakken en recht op intrekking:* Deelname aan dit onderzoek zal geen fysieke, juridische, economische of overige noemenswaardige risico's met zich meebrengen. Verder zal er geen moedwillige misleiding plaatsvinden en zal u tijdens het interview niet met expliciet aanstootgevend materiaal worden geconfronteerd. U heeft geen verplichting om de vragen te beantwoorden. Uw deelname aan deze studie is volledig vrijwillig en u bent vrij om op elk moment zonder opgaaf van reden en zonder negatieve gevolgen uw deelname te beëindigen. U heeft ook het recht om uw deelname binnen 24 uur na het interview in te trekken. In dat geval worden al uw gegevens en verzamelde data onmiddellijk verwijderd.

#### Verklaring deelname interview

Het onderzoek is onderdeel van het afstudeerproject van Nesrin Danning vanuit de Faculteit der Bètawetenschappen van de Vrije Universiteit Amsterdam (VU) en Athena Instituut. Verder is het onderzoek in opdracht van de afdeling Sociale Wetenschappen van de UvA. De geanonimiseerde data uit dit interview wordt meegenomen in de scriptie van Nesrin Danning. De geanonimiseerde resultaten kunnen daarnaast worden meegenomen in het bovengenoemd consortium project.

Uw handtekening geeft aan dat u ten minste 18 jaar oud bent; u heeft dit toestemmingsformulier gelezen of heeft het laten voorlezen; uw vragen zijn naar tevredenheid beantwoord en u stemt vrijwillig in met deelname aan dit onderzoek.

- 1. Ik heb voldoende informatie gekregen over dit onderzoeksproject. Het doel van mijn deelname als geïnterviewde in dit project is duidelijk.
- 2. Mijn deelname als geïnterviewde in dit project is vrijwillig. Er is geen expliciete of impliciete dwang om deel te nemen.
- 3. Deelname omvat een interview met een (student) onderzoeker aan de Bètafaculteit van de Vrije Universiteit Amsterdam. Het interview zal ongeveer 30-45 minuten duren.
- 4. Ik sta toe dat de onderzoeker aantekeningen mag maken tijdens het interview. Ik sta ook toe dat het interview wordt opgenomen (beveiligde audio-opname).
- 5. Indien gewenst, kan de geluidsopname ook tijdelijk uitgezet worden indien u off-the-record wenst te spreken.
- 6. Ik heb het recht om geen van de vragen te beantwoorden. Ik heb ook het recht om op elk moment, zonder opgaaf van redenen en zonder negatieve gevolgen, terug te trekken uit deelname aan dit onderzoek.
- 7. Ik ben gegarandeerd dat de onderzoeker mij niet zal identificeren bij naam, functie en bedrijfsnaam in enige rapporten die informatie uit dit interview gebruiken, en dat mijn vertrouwelijkheid als deelnemer aan dit onderzoek veilig zal blijven.

Ik heb de bovenstaande punten gelezen en verklaar dat ik akkoord ga met het deelnemen aan deze studie. Ik stem vrijwillig in met deelname aan dit interview.

Datum: Naam: Handtekening:

> Indien u verdere vragen heeft, of een klacht heeft, kunt u contact opnemen met de student onderzoeker: Nesrin Destiny Danning | n.d.danning@student.vu.nl