

## **PARTICIPATION: A combined perspective on the concept from the fields of informatics and music and health**

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‘Participation’, as it is commonly defined, appears to be a relatively trivial notion. In its everyday usage, it simply labels our interest in taking part in something. The word might derive from the Latin *participare*, to share, impart, partake of, but it might also derive from the Latin *partem carpere* – that is, specifically to take something from someone ([www.myetymology.com/latin/participare.html](http://www.myetymology.com/latin/participare.html)). The latter derivation connotes a certain dimension of power and might explain the political applications of participation – for example, as a motivating force for democracy. As a noun, participation points to the act of sharing in the activities of a group, and/or the condition of having something in common with others (as fellows, partners, etc.). Participation has also become a central construct in modern social and health science, and in ‘participatory research’, which implies that all stakeholders are actively involved in the research assumptions and processes.

The point of departure for this article is the interdisciplinary research project RHYME ([rhyme.no](http://rhyme.no)), which involves computing and musical components embedded in everyday objects, with the aim of improving the quality of life for children with special needs, their families and caretakers (Cappelen & Andersson, 2011). In RHYME, participation is apparent in many respects, including but not limited to the project’s political assignment, its theoretical foundation, and the practical implementation of user participation in the action research.

The authors of this article are three researchers in the RHYME project – two represent the discipline of informatics and one represents music and health. Before we explore the phenomenon of participation within the RHYME project over the course of this chapter, the informatics researchers Herstad and Holone and the music and health researcher Stensæth will outline the concept of participation within their respective fields. We will however begin with a short presentation of RHYME. The last part of this article derives directly from empirical data generated through RHYME, and in the concluding discussion we will suggest future possibilities for exchange between informatics and the field of music and health.

Because our fields seldom cooperate in research, we hope that our comments will be relevant to other interdisciplinary projects. We will specifically address the following research questions: *How is participation described in the disciplines of informatics and music and health, and what does participation imply in the RHYME project?* To proceed from a common ground of understanding, we will be guided by the following working questions: How does the focus on user participation in the RHYME prototype evaluations differ for informatics and health and music researchers? With regard to participation, what can the fields of music and health and informatics learn from one another?

## The RHYME project:<sup>1</sup>

RHYME is a five-year interdisciplinary research project (2010–2015) financed by the Research Council of Norway through the VERDIKT program. Its aim is to develop Internet-based, tangible interactions and multimedia resources that have a potential for promoting health and life quality. The project specifically addresses the lack of health-promoting interactive and musical information and communications technology (ICT) for families with children with severe disabilities. RHYME explores a new treatment paradigm based on collaborative, tangible, interactive Internet-based musical ‘smart things’ with multimedia capabilities. Within the project, these interactive and musical tangibles are called ‘co-creative tangibles’ (CCTs). The goal of RHYME is twofold: (1) to reduce isolation and passivity, and (2) to promote health and well-being. The RHYME research team represents a collaboration among the fields of interaction design, tangible interaction, industrial design, universal design and music and health that involves the Department of Design at the Oslo School of Architecture and Design, the Department of Informatics at the University of Oslo and the Centre for Music and Health at the Norwegian Academy of Music. The project encompasses four empirical studies and three successive and iterative generations of CCTs. The media is developed in collaboration with the Haug School and Resource Centre, the children and the families. Its user-oriented research incorporates the users’ influence on the development of the prototypes in the project. The users involve from six to ten families who have volunteered to participate, and the children with disabilities in the families range from seven to fifteen years old. The children vary considerably in terms of behavioural style, from very quiet and anxious to cheerful and rather active, but all of them become engaged in enjoyable activities when these activities are well facilitated for them. The most extreme outcomes of the variation in behavioural style relate to disability conditions, and mostly those within the autistic spectrum, which applies to four of the children. These conditions include poor (or absent) verbal language and rigidity of movement. Also, the children’s mental ages range from six months to seven years, and their physical handicaps range from being wheelchair dependent to being very mobile. The Norwegian Social Science Data Services approved the RHYME project in February 2011, provided it would gather, secure and store data according to the standards of ethics in Norwegian law.

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1 The section inside the frame below is similar in all of the RHYME articles in this anthology, Music, Health, Technology and Design by Stensæth (Ed.).

For this article it is worth noticing that one motivation for the RHYME project derives from the development of 'An Information Society for All':

The penetration of ICT in all areas of society enables many groups to gain easier access to public and private services, which paves the way for solutions, which empower many people to live more independent lives and raise quality of life. (Min. of Government Administration and Reform, 2006, p. 19).

The ideal here expressed by the state demands a process towards a more inclusive society with equal rights for all citizens (Imrie & Hall, 2001; Iwarsson, 2003; Lid, 2009).<sup>2</sup> Understood as a democratic issue, obviously, such a society would allow for *more* participation for *more* people (Ibid.).

## Participation within the field of informatics

In this section, we will present some of the history from the field of informatics with respect to participation. This will be used as background for investigating the role of participation in the RHYME project, in terms of both the children and the researchers. In particular, we will address participation within participatory design (PD), as well as computer-supported collaborative work (CSCW) and human-computer interaction (HCI).

### Computer science in the early days

Computer science is a research and development field that dates back to the 1940s. In the early days, it was informed by branches of the natural sciences such as mathematics, physics and electrical engineering. As the number of users of computing systems grew, and the computer was applied to purposes other than calculations, new disciplines such as ergonomics and psychology started to study and inform computer science as well. Alan Perlis, Allen Newell, and Herbert Simon founded the Computer Science Department at Carnegie Mellon University in the 1950s, and they defined computer science as the study of computers and the phenomena that surrounds them (Knuth, 2001). To this day, it remains true that the use of

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<sup>2</sup> In Norway, there is already a Minister of Inclusion.

computers, the users themselves, and the contexts of their use are all phenomena that concern computer science. In other words, computer science has always been a broad field, particularly given how sweeping the computer's impact has been on society and culture since its invention.

More specifically, computer science addresses areas as diverse as designing and studying electrical circuitry, programming languages and software engineering; among its principal paradigm shifts has been the cultural move away from stand-alone, isolated computers to networked computers, and the ubiquity of computing with which we currently live is often called the third wave of human-computer interaction, or HCI (Bødker, 2006). This particular shift will be examined below, specifically in the context of music.

### The networked computer is everywhere

Networking technology, of course, has a long history. The telephone dates back to 1876, and from the very beginning, people tried to share musical concerts using it. The telegraph is even older, and its usefulness for distributing and sharing sheet music is evident. Over the past century, rapid technological advances have come to include the development of mainframes, mini-computers, desktop computers and the now-common mobile computers (Grudin, 1994). Parallel to this line of development of computing and networking technology, the use of these technologies has become ubiquitous.

Nowadays, the development of personal, mobile technologies for making, sharing and listening to music is ongoing and addressed by various subfields of computer science, such as the 'Internet of things', 'ubiquitous computing', 'tangible and physical computing' and 'wearable computing'. Computers are remarkably capable and various in their application (Greenfield, 2006), and any user is a potential participant in the development and refinement of the technology in question, explicitly or implicitly (Carr, 2009).

With the ongoing spread of computing and communications technology, social media has arisen to accommodate yet more participation as well. In his book *Here Comes Everybody*, Clay Shirky (2009) studies user-generated content and the grassroots participation enabled by new technology, finding that users themselves are now more than ever in a position to participate, communicate and generate information from 'the wild', in this way affecting and, in some ways, changing the way our society works.

The areas within computer science that study this use of computing systems have various names, such as *interaction design* and the previously mentioned *HCI*,

as well as *user-centred design* and *PD*. In the next section, we will address some of these subfields.

## Human-computer interaction, computer-supported collaborative work, and human-centred design

Human-computer interaction (HCI) is concerned with the relationship between users and the technology they use, and, by extension, the development of interfaces and interaction mechanisms with computers (Carroll, 2003). Traditionally, this field of research has studied the *individual* user on a single computer – in the very early days, in fact, it was known simply as ergonomics. When computers were networked and began to facilitate mechanisms for communication and collaboration among more users, the subfields of computer-mediated communication (CMC) and computer-supported collaborative work (CSCW) emerged. The ‘W’ in CSCW indicates that the setting generally in question here was the work environment, though later on, non-work settings were also studied. At the European Conference on CSCW in 2013, there was, for example, a workshop on ‘boundaries between work and life’, which certainly implies contexts outside of the office.

There are many definitions of ‘collaboration’ and ‘cooperation’ within CSCW, a common theme of which is that negotiation must be part of all activities directed towards some common goal for a given group of people. Participation in this negotiation is therefore one of the conditions for the possibility of collaboration and cooperation. Yet what does ‘participation’ really mean? Various actors, users, systems developers, support personnel and others are stakeholders that ‘take part’ or participate in the development and deployment of new technologies. One subfield of computer science that focuses on various aspects of participation within systems development is participatory design (PD), and through its assumptions we might arrive at a clearer understanding of the notion itself.

### Participatory Design (PD)

In Scandinavia, computer science is sometimes known as ‘informatics’. Kristen Nygaard, one of the founders of the Department of Informatics at the University of Oslo, was involved in large-scale systems development processes when the computer was introduced to workplaces in Norway. When developers engaged with those computing systems, they tried to involve both existing and future end-users in the process, for two reasons: (1) to allow users to be part of describing, defining and deciding what the issues were; and (2) to encourage the users be part of the

design of the solutions or systems that would address those issues. The participation of various stakeholders is particularly valued in the informatics areas of PD (Schuler & Namioka, 1993) and user-centred design (Norman & Draper, 1986). One idea in PD is to involve users as co-designers rather than simply evaluators of products or services. This represents a challenge, however, because different stakeholders have different needs and priorities, as well as different backgrounds and vocabularies for describing themselves and their interests. This situation is exacerbated when one works with small children and people with special needs, as is the case with the RHYME project. Methods within PD for working with children include those described by Allsop (2010), whereas Frauenberger, Good & Keay-Bright (2011) provide a helpful review of a PD project involving children with disabilities. Druin (2002) proposes the following four roles for the children who become part of a development process: user, tester, informant and designer.

Stakeholder participation has often been accommodated through workshops that bring together systems developers and users, in the interests of strengthening workplace democracy (Bjerknes, Bratteteig & Stage, 1995). This is often called the Scandinavian School of Systems Development, and the technologies in question here are traditionally systems that, in some way, support work. Out of this context, PD arose as an alternative to technology-driven development, one that places people and activities ahead of the technology they might need. There are three main issues that dominate PD literature: (1) the politics of design; (2) the nature of participation; and (3) the methods, tools and techniques for carrying out design projects (Kensing & Blomberg, 1998).

As mentioned above, the arena for PD has traditionally been the workplace, not settings from everyday life:

The epistemological stand of PD is that these types of knowledge are developed most effectively through active cooperation between workers (and increasingly other organizational members) and designers within specific design projects (Kensing & Blomberg, 1998, p. 172).

In this case, then, PD is about engaging workers and other stakeholders in systems development, ideally by enabling them to serve as co-designers.

Ultimately, there is no straightforward way to define 'participation' in PD projects, though Greenbaum and Kyng (1991) suggest four PD ideals nevertheless: (1) mutual sharing between users and designers about their respective fields; (2) the use of tools in the design process that are familiar to users in particular; (3) the envisioning of future work situations specifically so as to allow the user to

experience how emerging technologies might affect practice (as opposed to relying on the seemingly esoteric language of systems developers); and (4) the importance of embedding the design process from the start in the practice of the user.

## Summing up

With this introduction, we have shown that participation is a central concept in the design and implementation of information systems. The Scandinavian informatics community, in particular, has a long history of participation from multiple stakeholders as a central methodological component of its work. Participation is at the very heart of user-centred design, and PD researchers and practitioners study it directly.

## Participation in the field of music and health

In this section, we will present some of the history of the field of music and health with respect to participation.<sup>3</sup> As in the previous section, we will look to the historical past to establish a context for investigating the role of participation in the RHYME project. First, however, we need to compare the (scientific) approaches of these two respective fields of interest.

Whereas the field of informatics addresses the interaction between humans and information systems in relation to the construction of computer interfaces, the field of music and health keeps computers themselves well in the background, or even out of sight altogether.<sup>4</sup> This is perhaps surprising, given the ubiquity of music in everyday technology and social media as well as the historical dominance of Musical Instrument Digital Interface (MIDI) technology, which made it possible already in 1982 for digital musical instruments to ‘talk’ to one another, and to interact with small computers.

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3 In this article, we use notions like ‘music and health’ and ‘music therapy’ almost synonymously, but there are basic differences between them, one being that music and health describes only a field of knowledge, whereas music therapy constitutes a field, a discipline and a profession. Stige points out, “Music therapy as a discipline is defined as “the study and learning of the relationship between music and health”. As professional practice it has “situated health musicking in a planned process of collaboration between client and therapist” (Stige, 2002, p.198-200). Because the RHYME artifacts are meant for home settings, not professional settings, we have positioned the project within the field of music and health and everyday life. We draw upon theory from music therapy to deepen our understanding of project results, however.

4 Magee (2013) provides a useful overview of the technology and computer programs that are being used in the field.

In part, this tendency to exclude things like computers stems from the field's origins in the humanities and the social sciences (Ruud, 2010),<sup>5</sup> where people, not technology, are thought to dictate the relevant aspects (and impacts) of participation. This conviction does not necessarily prohibit an interest in computers or ICT, but it does privilege philosophical practices that clarify and deepen our understanding of these things as refracted through our human engagement with them. Rather than the causes and effects of our relations to things, the field of music and health aims to understand humans and their experiences through their interactions with things. This recalls Dilthey (1976), who said, 'We *explain* nature, but human life we must *understand*'. Dilthey argues that human experience encompasses a dual orientation: towards the surrounding natural world, in which 'objective necessity' rules, and towards inner experience, which is characterised by sovereignty of the will, responsibility for actions, a capacity to subject everything to thinking and to resist everything within the fortress of freedom of his/her own person (Ibid.). As we shall see later on, the music and health perspective on participation in RHYME adopts this humanistic and hermeneutic view as its basis for its empirical investigations. Next, we will look at the ways in which participation is described in areas related to music and health.

## Looking back

As a concept, participation has become a central construct in health care, rehabilitation and various forms of therapy, often as a means of describing involvement in various life areas (Berg, 2009; Imrie & Hall, 2001; Law, 2002). Participation in these areas is assumed to be a vital part of the human condition that produces life satisfaction and a sense of competence in relation to psychological, emotional and skill development. From a humanities perspective, participation is also seen as important, specifically in the sense that it has positive influence on health and well-being. The increasing emphasis on participation from the WHO, various national governments, and other health and social systems makes it all the more important to understand participation – what it means, how we measure it and what it facilitates. To help us approach the RHYME project in this regard, we will try to narrow this focus a little more by positioning participation in relation to health and disability.

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<sup>5</sup> Here, we refer to the Norwegian situation in particular.



## Participation, health and disability

Although the UN defines participation as a human right, it remains unclear what impact this determination has on the reality faced by people with disabilities. The International Classification of Functioning, Disability and Health (ICFDH) is categorised according to the following domains: learning and applying knowledge, general tasks and demands, and communication, social, and civic life (WHO, 2007/2001/1948). Here, participation is defined as ‘involvement in a life situation’, because, since 1999, the 1980 terms ‘impairment’, ‘disability’ and ‘handicap’ have been (mostly) updated to ‘impairment’, ‘activity’ and ‘participation’. Disability, that is, has become the unavoidable result of modified participation due to a ‘defect’ and an ‘activity limitation’.

Current research from the CanChild Centre for Childhood Disability Research distinguishes between two types of participation: (1) formal activities – that is, structured activities involving rules or goals that have a formally designated coach, leader or instructor (e.g. music or art lessons, organised sports), and (2) informal activities – that is, activities with little or no planning that are often initiated by the person herself (reading, hanging out with friends, playing).<sup>6</sup> In either case, participation is assigned several aspects: a person’s preferences and interests; what he or she does, where, and with whom; and how much enjoyment and satisfaction he or she finds. Data measurement takes place at the various intersections between person, environment and occupation. For this kind of participation to be meaningful, as well, there must be a sense of choice or control over the activity, a supportive environment to facilitate the person’s attention, a focus on the task at hand rather than the long-term consequences, a sense of challenge from the activity, and a sense of mastery over it. Therapists often refer to this as the ‘just right challenge’.

Research shows that children with disabilities tend to engage in less varied leisure activities and in quieter recreational activities (Berg, 2009). In general, they participate in fewer social interactions, especially those of a spontaneous character. In a comparative study of youth with and without disabilities, Henry (1998) found many similarities in the interests of these two groups, whose top four pastimes were listening to music, hanging out with friends, watching TV, and talking on the phone. Studies also indicate that participation level changes as children with disabilities move into adolescence, in that there are fewer activities that occur outside the home (Ibid.; Berg, 2009). This suggests a significant correlation between the

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<sup>6</sup> See [www.canchild.ca/en/ourresearch/participation.asp](http://www.canchild.ca/en/ourresearch/participation.asp).

severity of one's disability and one's social isolation, which is a potential hazard for the children participating in RHYME.

In 2001, as introduced above, the WHO emphasised the rights of citizens with disabilities to participate fully in society. Along with their 'new' perspective on participation, ICFDH also changed their view on health, from considering it a 'consequences of disease' classification (1980 version) to considering it a 'component of health' classification (WHO, 2001, p. 4). This more integrated understanding of health in turn became a central component in participation, fuelling a social model which included more environmental factors, organised in sequence from the individual's most immediate environment to the larger communal environment (encompassing both social and institutional structures) (Ibid.).

Critical voices claim that dimensions like autonomy and subjectivity are lacking in the ICFDH reports. Wade and Halligan (2003), for example, observe that people with disabilities are often inhibited from directing their own daily lives or making their own decisions about personal questions. Of course, autonomy has both an objective (societal) and a subjective (personal) side, and Wade and Halligan insist that the best judge of successful participation must remain the respondent him/herself rather than the professional. They acknowledge however that the inner world is hard to observe.

## Music and health

The use of participation in music and health is generally similar to its use in the humanities and social sciences, though it is clearly also treated as a component of health. This salutogenetic perspective, inspired by Antonovsky (1987), sees health as a personal experience (and an ongoing process) rather than a biomedical state. Factors that support and promote well-being are seen as essential from this perspective – for example, a sense of confidence in the fundamental coherence of the world. Participation thus becomes a means of experiencing (good) health. The 'opposite' view is the pathogenic perspective on health, which focuses on the factors that cause disease. This perspective, which is common in many medical settings, is important in order to understand the link between illness/disease/disabilities and life conditions, but it does not say anything about how to increase quality of life, for example.

Ruud (2014) takes the salutogenetic health perspective further. He calls the experiential focus on health an interpretivist perspective and asserts that such a notion of health does not allow it to be regarded as a fixed state but rather as a fluid state that can be influenced, for example, by regular participation in

meaningful musical activities. In this case, there is a strong conceptual connection between the state of well-being and the ability to act (Nordenfelt, 1991). Music as participation comes to represent a way to *experience* the feeling of being part of something meaningful and larger (such as one's community). In the context of the present study, then, music is positioned as a capacity for action and a practice that engages subjective feelings and the experience of participation.

Following these lines of thoughts, we see that the doing becomes crucial. In RHYME, we have found Small's (1998) notion of 'musicking' to be particularly evocative in this regard, precisely because it emphasises music as *doing*:

To music is to take part, in any capacity, in a musical performance, whether by performing, by listening, by rehearsing or practicing, by providing material for performance (what is called composing), or by dancing (Small, 1998, p. 8).

For Small, musicking is an active means of relating to – and participating in – the rest of the world: The act of musicking establishes, in the place where it is happening, a set of relationships, and it is in those relationships that the meaning of the act lies. They are to be found not only between those organized sounds which are conventionally thought of as being the stuff of musical meaning but also between the people who are taking part, in whatever capacity, in the performance; and they model, or stand as metaphor for, ideal relationships as the participants in the performance imagine them to be: relationships between person and person, between individual and society, between humanity and the natural world and even perhaps the supernatural world (Ibid.; Small, 1977).

Stige's notion of 'health musicking' combines Small's musicking as a social model with our salutogenetic or interpretivist perspectives on health (see Stige, 2012, 2006). Ultimately, health musicking sees participation as a resource or form of social capital – it is about building social networks and providing meaning and 'coherence in life' (e.g. Antonovsky, 1987).

We see here how a music and health perspective on participation moves among notions like integration, inclusion and exclusion/marginalisation, and empowerment. Matell, in her master's thesis on the notion of participation in music therapy, finds that inclusion, participation and empowerment are used synonymously, and often without any critical reflection (Matell, 2011). Empowerment, Matell responds, should be seen as a *source for* social participation, whereas inclusion describes the *preconditions that enable* participation. Rolvsjord (2004) links empowerment to a resource-oriented perspective on music therapy, which likewise

focuses upon the client's personal resource and strengths or potential, rather than his or her limitations (such as disabilities). The collaboration (and implied equality) in the relationship between the client and the music and health worker becomes important here and could even be positioned as a first step in the process towards social participation.<sup>7</sup>

Ultimately, the most comprehensive treatment of the notion of participation in the field of music and health is found in the work of Stige (2012; 2006; 2005; 2002 Stige, Ansdell, Elefant, & Pavlicevic, 2010). In the article 'The notion of participation in music therapy' (2006), Stige reviews the literature on learning, music and health and develops the following definition as a platform for further discussion:

Participation is a process of *communal experience and mutual recognition* where individuals *collaborate* in a socially and culturally organized structure (a community), *create goods* indigenous to this structure, *develop relationships* to the activities, artefacts, agents, arenas and agendas involved, and *negotiate our values* that may reproduce or transform the community (Stige, 2006, p. 134).

Stige here explores a notion of participation that takes context into account and is not limited to the act of 'joining in', which is a prominent aspect of the societal dimension of music and health practices. He further distinguishes between participation as 'individual activity' and 'collaborative activity', the latter of which encompasses both 'communal experience' and 'political action' (Loc. cit.). Stige (2003) argues that community music therapy, a theory that focuses on the collaboration of music therapists with the community in the interests of common goals for individuals, is promising in light of its promotion of sociocultural and communal change through a participatory approach.

## Summing up part 2

We have seen that the notion of participation has become a central construct in music and health and other related areas. Participation is described as ecological and empowering – that is, as something active, processual, personal, subjective, relational, experiential and potentially health promoting. Stige's elaboration of the notion makes it possible to distinguish participation as an individual activity from

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<sup>7</sup> The idea that empowerment is intrinsic to (and a consequence of) music and health practice is also implied: see <https://normt.uib.no/index.php/voices/article/view/283/208>.

participation as a collaborative activity. As an individual activity, participation is the act of 'joining in', which is the most prominent action within most music and health practices. However, the societal dimension, and participation as a collaborative activity (as described by the community music therapy theory), expands our means of reflecting upon participation, especially as political action.

## Participation in RHYME

We have seen that the fields of informatics and music and health approach the notion of participation differently. In the former, participation is described as experiences between humans and the objective and 'natural' world (of things and computer technology and science). In the field of music and health, participation is an end in itself, and the primary value of technology is to promote health. The question, then, now becomes as follows: *What does participation imply in RHYME?*

In general, all concerned readily derive a sense of community or partnership from the concept of RHYME, and we recognise that participation in RHYME resonates with the social intention of a health outcome for all. This intention encompasses an active taking part and/or sharing in the testing, the development of the CCTs, and the research process by everyone. The hope is that the children and their 'close others', the research group, *and* the CCTs are all 'involved' in this participatory work,<sup>8</sup> so that the final product incorporates the intended function of the CCTs, the researchers' observations about the data, and the participating users' personal experience of the actions. In the following, we will look at how these ideals of RHYME participation were dealt with in the design and use of the CCTs, and in the research work that came before and after. To ground the discussion, we will sometimes refer to empirical data derived from the project.

### Participation in design and use

The RHYME prototypes were tested at the school of the children who took part during the spring of 2011, 2012 and 2013. Stensæth and Ruud (2014) and Stensæth (2014a, b) provide detailed descriptions of the testing of three generations of the RHYME prototypes: ORFI, WAVE and REFLECT. At these test sessions,

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<sup>8</sup> A child with disabilities is generally accompanied by a family member or helper (in this case, from the special education school where some of the research actions were carried out) who will be referred to as a 'close other'.

researchers from the project were present and carried out or oversaw direct observation, video recordings, questionnaires and interviews with the children, their families and expert professionals at the school. Later, the session notes, interview transcriptions and video recordings were analysed by the researchers.

We will now describe and analyse two ways of understanding participation in design and use. We will look at the participation of the children according to the three aspects of participation identified by Kensing and Blomberg (1998) and Stige (2006): the politics of design, the nature of participation, and the methods and tools.

### Politics of design

Participatory design (PD) is inherently concerned with levelling out power structures, ideally enabling all stakeholders to contribute equally to the design of new artefacts and services. In projects such as RHYME, however, this is a challenging ideal, and certain shortcuts and adaptations were required. For example, expectations regarding what the children can and cannot (or will not) do can influence the design process. Given that many of the children have difficulty grasping abstract concepts or verbally expressing their own needs, the preconceptions of others tend to fill these voids. Of course, the use of close others as interpreters, gateways or proxies for the children in the design process can partly address the problem. In this case, the child's voice is heard through the close other, which is better than nothing, though it submits the child's reactions to the close other's interpretation. Thankfully, because the close other knows the child and his or her complex needs and desires very well, the close other can generally produce good descriptions of useful solutions regarding the development of the CCTs for the particular child.

The use of a close other does not entirely eliminate the imbalance of power in terms of PD in RHYME, though, because what the close other says must necessarily derive from his or her own subjective impressions about the child's desires and opinions. The voice of the close other is *mediated* communication (Holone & Herstad, 2013) and must therefore be treated as an interpretation or representation, not a firsthand account.<sup>9</sup>

Another issue with respect to the politics of design relates to the families' participation in the testing process. The shift from passive end user to co-designer is not easy to accomplish (Ibid.), and it is by no means a given that either the children

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<sup>9</sup> The challenges regarding the use of communication through a third party are discussed in an earlier paper by Holone & Herstad (2013).

or their families are prepared for the informatics ideal of democratisation of everyday activities and decisions. They first and foremost concentrated on their exploring of the CCTs and participated in this sense as equals during the testing. Still, we could say that the participating families in RHYME were more mentally prepared for this dynamic in some ways, because they were already accustomed to fighting for the rights of their children with disabilities. In the interviews some of them were also quite articulate and comfortable with speaking up.

### The nature of participation

According to Kensing & Blomberg (1998, p. 172), it is of central importance in PD to develop ‘meaningful and productive relations between those charged with technology design and those who must live with its consequences’. Developing those relations among stakeholders in a PD project is always challenging, and perhaps especially so when the central stakeholder group is composed of children with severe disabilities (Holone & Herstad, 2013). For example, the PD ideal of rapid prototyping is undermined by the additional amount of time that is required to properly understand and communicate with this group. In addition, the use of close others to facilitate communication can introduce misunderstandings and even promote stereotypes of the needs and desires of these children. In the RHYME project, the participating families did not spend much time with the researchers and the CCTs before the testing sessions. It helped, however, that some of the participating children and their parents knew one of the RHYME researchers from her work as a music therapist at the school where the testing took place. Thanks to this level of familiarity, they ‘trusted’ the other researchers and their implementation of the RHYME actions, and more was accomplished as a result. It is perhaps also true that if we had allowed the users to spend more time with the CCTs, we might have derived other results.

In RHYME, in general, the children have not been an explicit part of the design process as such. However, through their interactions with the prototypes during the test actions, they have provided valuable input into the revision process.<sup>10</sup> Also, the microanalyses of the RHYME testing-session video recordings (Stensæth & Ruud, 2014; Stensæth, 2014a, b) of the children and their close others interacting with the CCTs have supplied project researchers with detailed information about the requirements attendant upon individual programming. They showed, for

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<sup>10</sup> A similar but quicker approach was recently articulated by Larsen & Hedvall (2012), who used basic yet interactive design artifacts to enable children to provide input to the design through their actions.

example, the lag time of the temporally shifted response in the CCTs that was right for each child. This was important to adjust in order to suit those children with disabilities who have unusual perceptions of time, for example (Stensæth, 2013).

## Methods, tools and techniques for carrying out design projects

In RHYME, the children have mostly been involved in the testing phase of each design cycle, and interviews with family members and caretakers have helped inform the design process as well. Further follow-up interviews provide useful perspective on revised prototypes. The design process in RHYME is iterative, comprising a yearly cycle of prototype design and development with corresponding tests, and participation in design among the researchers has, to a great extent, consisted of discussions before, during and after the test sessions. MusicalFieldsForever, the design team that designed the first prototype, ORFI, has continued to work on revisions in the context of stakeholder participation throughout the RHYME project.

## Research participation

During the test activities, RHYME researchers were primarily interested in the interaction between the children and the prototypes, but the interaction between the children and close others (including parents or siblings) has also been important.

In the family interviews, these close others have offered valuable suggestions, generally based upon what they feel would improve the experience for their own children. After the first RHYME actions, for example, they pointed to the need for the CCTs to feature strong or marked sensory responses (see Stensæth, 2014a). The parents of two children with poorly developed sensory capacities proposed that the design of the CCTs should incorporate powerful vibration to physically arouse them and help them to become mentally 'accessible' to the outside world's impulses, impressions and interactions. Vibration was therefore introduced into the WAVE prototype (see Stensæth, 2014a), but it was not strong enough and had a limited effect.

Another family request was to develop a prototype that would engage the (hyper) active children's gross motor skills, not just their fine motor skills. In order to allow the child to use his or her whole body – climbing, rolling, dancing, and jumping and so on – the CCTs would have to be very solid and able to tolerate rough treatment, the parents admitted. Parents applauded the student product called COVE as especially successful in this respect (see picture and video of COVE



at [http://rhyme.no/?page\\_id=2808](http://rhyme.no/?page_id=2808)). COVE was one of several added student products that families could explore after they had tested the REFLECT prototype during the third RHYME actions in 2013.<sup>11</sup> Also, Stensæth and Ruud (2014) found that ORFI engaged the children at a gross motor level but that it needed to be sturdier to tolerate drooling and 'wild' play.

Families were also contacted directly for comments on the CCTs. Before the development of the prototype called REFLECT (see Stensæth, 2014b), designers asked families what kind of music they would prefer to be programmed into it. Some parents suggested that it would be good to include favorite (children's) songs; others suggested classical music, to help children and close others relax together (see Stensæth, 2014b).

Families did not seek changes or improvements in the prototypes specifically to enhance participation as a collaborative activity (e.g. Stige 2006) but rather out of a general interest in the developments of 'such media' (their words). They were grateful for the opportunity to participate in a project like RHYME. As long as their children were attending school, the parents said, they were in good hands in terms of activity and stimulation (a reference to structured activities involving rules or goals that are led by professionals). But it was harder to provide proper stimulation during informal everyday activities in the home setting (activities involving little or no planning that are initiated by the child or the family member, such as reading, hanging out with friends, playing). Outside of school, then, there seemed to be very little for the family to do together that was meaningful for all at the same time. One mother of a girl with severe physical and mental handicaps said: 'At home we need things to do – together – things that are easily enjoyable and meaningful!' (Stensæth, 2013).

Another mother sought meaningful solo activities for her daughter with Down Syndrome and mental retardation. In an interview, she said that her daughter took little initiative to involve herself in leisure activities (Stensæth, 2014b) except for play that the mother saw as just repetitive actions without any value for 'learning and development' (Ibid.). Their need as a family was 'for her to be active on her own, over a longer time', the mother said (Stensæth, 2014b). If RHYME could improve the quality of co-activity in these situations, she would be grateful.

Of course, it is difficult to devise design solutions during RHYME prototype development that would accommodate every family technically, musically and

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<sup>11</sup> Students participated in a course titled Sensorial and Musical Interaction that was given by RHYME designers at the Department of Design at the Oslo School of Architecture and Design in 2012.

Among the results of this course was COVE, an interactive musical rocking chair for the whole family designed by the students Luciene and Berit.

materially. Yet these concerns and interests are nevertheless extremely valid in terms of the politics of design, and we continue to ask ourselves the same question as time goes on: How can the subjective voices of the families (including the voice of the child with disabilities) become more influential in the design process? By engaging families, RHYME researchers have, to some degree, ensured subjectivity and autonomy (which, we remember, the ICF were criticised for leaving out of their reports). Importantly, this participation emphasises the need for making the RHYME artefacts as *flexible* as possible to accommodate a range of unique needs.

## Discussion

RHYME as a research project has allowed for rich interdisciplinary interaction, and scholars from different areas have taken on roles as developers, program designers, observers, interviewers and facilitators. All of the material, including video footage, interviews and observations, has been shared among the researchers. During data collection, ideas from different fields are introduced, observations are discussed from various perspectives, and associations across disciplines emerge. This interaction during the preparation and implementation of the test activities has impacted the way we think and write about the project, as the present article attests.

In the following, we will look closely at how participation has been encouraged within RHYME from the perspectives of both music and health and informatics. To reconnect with the empirical material, we have assembled clips from the video analyses done by Stensæth & Ruud (2014) from a music and health perspective. The situations described below derive from a setting where two children ('Ulla' and 'Frode') and their close others interact with the prototype called ORFI. Both children have severe disabilities to varying degrees; they are enthusiastic and physically active but have no words.

### *Ulla, Clip 1:*

'Conscious action when she bends the wings on the pillows, as if she knows that there will be a sound response. Addresses A (her close other) and expects that A will "play" with her. Becomes bodily and mentally stimulated, senses a surplus, and seems like she at times dances to the sound and with the pillows'.

*Frode, Clip 1:*

'Is attentive and wandering while he explores the pillows, the screen and the interrelation between them. He tries out several ways to handle the pillows. Are they heavy? He seems to think that this is exciting and wants to communicate this to A (his close other). He wants A to share this experience with him – he both wants and needs validation from A? Speaks and gesticulates through the pillow (when he "bends-points" with it). Is excited and wants to share feelings with A.'

In the empirical material, Stensæth & Ruud (2014) describe the selection criteria for the video clips with Frode and Ulla as follows: 'We ultimately chose the video clips based upon the inclusion of those glimpses and camera angles which most clearly demonstrated varied activity, including actions and both physical and emotional reactions'. The informatics researcher, who is also interested in the interaction with technology and the reactions of the children as they engage with the CCTs, could have applied the same criteria, but the focus of the interpretations, however, would be quite different. We will briefly review the analysis from a music and health perspective, then do the same from an informatics perspective, and finally look at how they complement one another.

Interestingly, the above analysis sees the CCTs as 'given' – that is, they exist as is. The focus, then, is on the people and their interactions, and particularly on the relationship between the child with disabilities and a close other. Their participation is interpreted as communicative sharing. In another study, Stensæth & Ruud (2012; see also 2014) predict that the greatest potential of the CCTs is as a means of communication and a social tool intended to enhance well-being and life quality. This interest, in turn, aligns the design of the CCTs to the promotion of interpersonal interaction and the sharing of meaningful experiences, primarily between subjects, and secondarily between the subjects and the objects. From a music and health perspective, two aspects are more prominent than others in the RHYME actions – the role of the close other and the degree of intersubjectivity (which relates to the first). We will discuss these aspects shortly.

The child, who is vulnerable or even helpless, is to some degree dependent upon the close other, who must be well qualified. A 'good' close other becomes so through kinship, interest, education, experience and the relational history with the child. Horgen (2010) says that a close other is there for the child with disabilities to share his or her experiences, engage in his or her world and *meet* the child by encouraging communication, self-expression, development, and empowerment. The task for the close other is 'to put him/herself into play for the child' (Horgen, 2010). In a sense,

the close other becomes an instrument of the child's self – a premise for the child's very ability to respond to the CCTs. The close other is needed for direct support, as a pivotal link between the children and the objects, and helps the child with a disability become *response-able*, in the most literal sense, by ensuring that the child with disabilities can share and participate in the activity.<sup>12</sup> The role of the close other in professional contexts is even characterised as a 'prosthesis', a 'co-experiencer' (Lorentzen, 2010) or a therapist – ultimately, as one who accompanies the child in life through empathic 'co-travelling' (Yalom, 2001/2002).

The relation between the child and the close other is also understood as fundamental to the promotion of health musicking. This finding does not surprise the music and health researcher, because it has been shown that we are all born to be sociable – to both communicate and share meaning (on Trevarthen and Bråten in Stensæth & Trondalen, 2012). This aspect is sometimes also referred to as intersubjectivity, or the sharing of subjective states by two or more individuals. It encompasses shared emotion (attunement), shared attention and shared intention (Stern, 2000). In the field of music and health, it is sometimes called 'communicative musicality' (after Malloch & Trevarthen, 2008), and it encompasses the earliest relational communication, such as the 'dialogue' between newborn and parent via musical parameters such as rhythm, melody, intonation, timbre and intensity. This theory demonstrates that the need to communicate is inherent to people regardless of the presence of a disability, but that it must be accommodated. If this form of participation is denied, people tend to develop other strategies (such as aggressive or destructive behaviour) to compensate for their isolation (see Matell, 2011). A human being is born to *seek* intersubjectivity and engage in cultural learning through companionship (Stensæth & Trondalen, 2012; Stern, 2010). In fact, the intersubjective relation is seen to have health potential in itself (see Johns, 2012; Trondalen, 2008).

Methodologically, and with respect to the users such as Ulla and Frode, who lack words, it is difficult when the distance between the children's inner experiences and the researchers' interpretations is passed through interpretations a third party. In order to strengthen the validation of the close others' interpretations, however, the music and health researchers in RHYME have used method triangulation. In Stensæth (2014b) and Eide (2013), for example, the close others' interpretations were compared

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12 In her dissertation, Stensæth (2008) discusses 'musical answerability' in the context of defining music therapy improvisation (which encompasses all of the relations among therapist, client and music). Music therapy improvisation is a means through which to transform isolated human utterances into intentional communicative expressions.

to comments from experts and peers. Units of meaning were derived from a technique called 'systematic text condensation' (Malterud, 2011; see also Eide, 2013).<sup>13</sup>

The focus on the subject–subject relationship relegates the objects to the background from the music and health perspective. The role of the CCTs is simply to offer a space, or field, for the primary participation. From the perspective of informatics, technology is seen as more present, and as highly adaptable. The CCTs are not just tools but active participants that are engaging in a dialogue with the child (see Cappelen & Andersson, 2011).

In HCI, one locates the interaction between the computer system and the user at an interface, like a terminal with a screen and a keyboard. This interface accepts input from the user, through, for example, the pressing of a key; the computer program processes that input and produces its output through the interface as well, on a screen or through a loudspeaker (Winograd, 1997).

In RHYME, the CCTs are deliberately designed to be flexible, both in terms of the physical appearance of the artefact and the behaviour of the system (Gaver, Beaver & Benford, 2003). In a classic computer system, one expects a predictable, consistent relationship between user input and computer system output. In the RHYME prototypes, a certain amount of unpredictability (and computer agency) is built into the system, which is very different from what one would tolerate from, say, an accounting system. Nevertheless, when evaluating the interaction between the user and the computer system, the informatics researcher will look at the system as a computer with an interface. A well-known method for evaluating human computer interaction is Fitt's Law (see Accot & Zhai, 1997), where the precision and efficiency of pointing devices, such as the computer mouse, are measured in milliseconds and millimetres.

With the emergence of the third wave of HCI (Bødker, 2006), as described above, the focus of the informatics researcher moved beyond the direct interaction between the user and technology to the effects of the use upon the user – the emotions it evokes, for example, and the ways in which the technology fits into the use situation as a whole. In summary, the informatics researcher will look at the technology as something *malleable*, and the purpose of prototype evaluation is to identify possible changes and improvements to the technology to better fit the use situation.

We could say, then, that the RHYME project is useful in that it generates insight into participation on the individual level. Sometimes this insight resonates with broader theories, such as theories like the already mentioned 'community music therapy' and 'communicative musicality'. Participation in RHYME can therefore be viewed as a social model that encompasses environmental factors ranging from the

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<sup>13</sup> This is a method whereby data points are coded into units of meaning. For more, see Eide (2013).

individual's immediate environment to the general environment (including both social and institutional structures).

### Combined perspectives on participation

The model of participation that we have described so far highlights the complementary qualities of the two perspectives in play here. Our interest in the relevance of both perspectives to the pursuit of an improved quality of life for the children and their close others through the introduction of new music technology foregrounds the ethical commitment that we all share to recognise other people's needs, whether they have disabilities or not. Despite HCI research encompassing the human qualities of our interaction with computers, there are obvious limitations to what the informatics researcher is able to see in terms of the role that technology has in the use situation, such as in the clips with Frode and Ulla described before.

Conversely, the music and health researcher has an in-depth understanding of the child and his or her relation to self and world but less awareness of the possibilities residing in the malleability of the technology.

The RHYME project's strength and distinctiveness derives from its combination of these two perspectives – it is only through a shared understanding of the child's participation in the use situation that we can best understand the complex interaction between the child and the environment (including the CCTs). The music and health researcher's in-depth understanding of the child's actions, coupled with the informatics researcher's view of technology as malleable, make it possible to achieve a better quality of life for children and their close others through the introduction of this new technology.

The two fields have overlapping areas of interest and expertise, as seen in the following table:

Informatics	Shared	Music and health
Participatory design Information technology Development Human-computer interaction (HCI)	Participation Use Affect Natural settings/everyday life Professional settings/workplace settings	Subjectivity Intersubjectivity Relation Health musicking

**Figure 1:** Areas of interest and expertise in the fields of informatics and music and health

In the next section, we will propose possible further interactions between the research fields of informatics and health and music. This list is not meant to be complete or exhaustive.

#### Possible contributions from informatics:

- Learning from the history of informatics: The study of the development and use of computers has a history dating back to the 1950s. By getting to know a bit of this history, we might uncover further common areas of concern, such as participation in relation to ethical and democratic reasons (i.e., the politics of design).
- Current technology development: New areas within informatics, such as wearable computing, change the pragmatics of participation – that is, they suggest new means of participation and collaboration. RHYME is an example of a project through which we can investigate novel ways of interaction with computers and participation through new technologies.
- A deeper understanding of technological development. By better understanding the possibilities and limitations of the technology in question, music and health researchers will be better equipped to actively contribute to the system design of the CCTs.
- The integration of musical and interactive technological objects through participation: A better understanding of the potential use of this technology in the artefacts surrounding us daily would allow music and health researchers to broaden their ways of engaging users regarding health musicking.

#### Possible contributions from music and health:

- The implementation of the notion of musicking: The understanding of music as *doing* (as well as a powerful way to promote positive group dynamics on all levels) may have direct implications for participation in the design of informatics systems.
- Awareness of health perspectives: The salutogenetic perspective applied in RHYME, which views health as a personal experience and an ongoing process rather than a biomedical state, might complement the pathogenic health perspective that still dominates the informatics

in the development of information systems and infrastructures, such as patient journals, minimal invasive technology.

- The perspective of health musicking: Combining musicking and a salutogenetic health approach, health musicking might help the informatics researcher to design informatics systems that provide social capital and create coherence in the life of the users.
- Workplace studies and everyday life settings: When one moves from workplace design to the design of technologies for natural settings, the everyday home use of music might provide further perspective on the informatics involved. In RHYME, for example, we have seen that musicking with objects like CCTs can regulate users' moods and quicken them to act (as was the case with Frode and Ulla).
- The awareness of relation and intersubjectivity: The relation philosophy, especially between a vulnerable participant and a guiding participant, can help the informatics researcher to account for the former in the design process. RHYME, as a research case, shows how listening to the children with no words and limited communication capacity becomes possible through the interpretation of the close others' empathic understanding of the children's needs and interests.

These suggested contributions indicate that there are areas where more exchange between the two fields could be beneficial to both.

## Conclusion

This article addressed the following research questions: *How is participation described in the disciplines of informatics and music and health, and what does participation imply in the RHYME project?* We have described some issues regarding participation that have emerged through the RHYME project. First, we presented some history and an overview from the disciplines of informatics and music and health concerning participation. Then we presented possibilities for these disciplines' combined perspectives on participation. We have also listed what the fields contribute to each other with respect to participation.

The collaboration between professions is challenging and important to any multidisciplinary research project. In order to reach the goals set in the RHYME project – to improve health and well-being – we must rely on the core competencies of



various disciplines. This study describes both participation between children and their close others, who are the primary users, and participation among researchers. With fruitful exchange across disciplines, we can understand more about the relationships among the children, the technology, the family and close others, and the environment. The music and health professionals' in-depth understanding of and interest in the activities of the children, and the informatics professionals' understanding of the malleability of the technology, together comprise a better foundation for shaping an improved quality of life and health for these children and their families. It is also clear that the participating families' individual needs provide a broad spectrum for further development of the RHYME artefacts that could address needs for agency, mastery and life quality in the future. In this way RHYME could contribute to the promotion of participation in a very important life area – the home setting.

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