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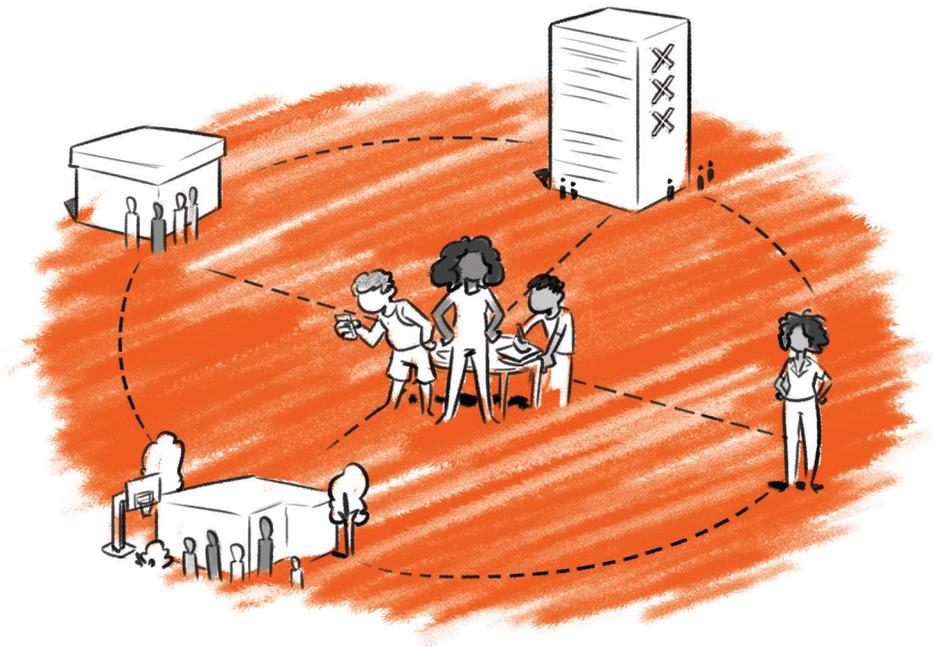
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Chapter 1

General Introduction



Background

Currently, societal participation of citizens is on the forefront of many political agendas, also in the Netherlands. Likewise, in public health practice and research, participation of the community is increasingly present and even demanded by several funding agencies[1-3]. In so-called participatory research, participants are not only involved as research subjects, but also valued as experts of their own lives and contexts. Such citizen participation can lead to empowerment and decisions that are more aligned with the needs and interests of the target group. Children have historically rarely been actively involved in research[4]. Over the last decades, participatory research has gained increased attention and popularity worldwide. A Dutch group of researchers introduced participatory research - also with children - to Dutch funding agencies, governments and research institutions. Their research shows the value of including the target group in research concerning themselves in several settings (e.g. hospitals, schools) and with different target groups (e.g. children with diabetes, children from low socioeconomic environments) (e.g.[5-9]). For children being active participants in research can have many benefits, for example children can become empowered and learn new skills[10-13]. Moreover, actions developed through participatory research may better suit their needs and interests. These positive outcomes have stimulated child participation in public health research over the last years[4, 12, 13]. Interestingly, there is large variation in the degree of child participation in research and in the definitions researchers use for child participation. In the following paragraphs of this introduction, I will shed some light on the concept 'child participation' by explaining different child participation models. Then I will highlight one specific child participation approach: Youth Participatory Action Research. Next, I will briefly introduce the project 'Kids in Action', which follows this approach and is the topic of study throughout this dissertation. The outline of this dissertation is presented at the end of the introduction.

Child participation

The large variation in the degree of child participation in research is depicted

in a variation of models (e.g. [14-23]). Broadly, these models can be divided into three categories: i) linear models, visually depicting a certain hierarchy in levels of participation; ii) models describing different forms of participation but without a hierarchic structure; and iii) descriptive models, providing more in depth information on requirements for a participatory environment.

An example of a hierarchical model is Hart's (1992) ladder of children's participation[14], which is based on Arnstein's (1969) ladder of citizen's participation[24], and which is frequently used in scientific literature. Hart's ladder was designed to portrait participation typologies and more specifically, to separate participation from non-participation. It implies that not all participatory research has to be on the highest rung of child-initiated research with shared decision making with adults, but researchers have to be conscious and transparent about the level of child participation. Also, researchers have to enable children to participate at the level of their choosing and ability[14, 25]. Unfortunately, we continue to see studies that claim a level of child participation, while children actually lacked an active role in the decision making process. For example, children participated in a drawing contest, sat on a panel, or participated in focus groups, but their input was collected by adults who turned it into policy without further involvement of the children. In essence these methods are not 'wrong', but researchers have to be transparent about the actual role of children and be careful with phrasing their research as participatory, for instance by creating certain standards in the reporting of participatory research[4, 13].

Shier (2001) developed another hierarchical model that specifies five levels of child-participation and three stages of commitment researchers/ implementers need to have towards empowerment of children[15]. Shier's five levels of participation are: 1) Children are listened to; 2) Children are supported in expressing their views; 3) Children's views are taken into account; 4) Children are involved in decision making processes; 5) Children share power and responsibility for decision making. At each of these levels of participation, three stages of commitment are considered: *openings*, *opportunities* and *obligations*. When there is an *opening*, an individual or organization wants to work on a level so is committed, but there might not yet be the opportunity towards action. When there is *opportunity*, the

needs are met to work on a certain level of participation; the environment is created to operate on that level. When there is *obligation*, working on a level of participation is built into the system, as policy prescribes participation on a certain level. Shier's model clearly builds on Hart's ladder, but by adding the levels of commitment more specifically, Shier's model confronts researchers with their willingness to share responsibilities with children and to what extent their policies support that.

The second category of participation models moves away from the hierarchic structure that may – visually – imply that levels of participation are linear and that child-driven participation is the aim[18]. It has been argued that for empowerment, children need to develop certain skills and thought processes and when that is not reachable – for example when working with very young children – adults need to take on certain tasks[18, 21]. Therefore, certain models try to avoid a hierarchic structure. Treseder (1997) proposes a model with five participation types, depicted in a circle: 'assigned but informed'; 'consulted and informed'; 'adult-initiated, shared decisions with children'; 'child-initiated, shared decisions with adults'; 'child-initiated and directed'[19]. With this model Treseder implies that different situations require different types of participation. Furthermore, children first need to be empowered to enable full participation at the appropriate level. The TYPE pyramid builds on this line of thinking, taking empowerment as a framework and describing benefits that can come from collaborations between children and adults[18]. This pyramid-model describes research with adult control, child control and shared control. The highest level of empowerment is reached when there is shared control between children and adults, with children having a voice and an active role. When children or adults have total control it is supposed that children become less empowered than when children and adults share control. Interaction between children and adults, besides only sharing power, leads to real participation in the public sphere[21].

The third category of participation models are more descriptive about requirements for a participatory environment (e.g. [16, 17, 20, 23, 26]). Jans & de Backer (2002) for example describe three basic conditions that need to be balanced for youth's active participation: *challenge*, *connection* and

capacity[20]. When a context is created where youth feel *challenged*, *capable* to make a difference, and *connected* to their environment, successful participation can occur and youth become interested in active participation. The model of White (1996) is more descriptive about the relationships of stakeholders and their interests in the participatory process[26]. Even though this model is not specific for child participation in research, it can be applied to it. White (1996) argues that it is necessary to take into account what motivates implementers to collaborate with the target group. White's model depicts four types of participation: nominal, instrumental, representative and transformative participation. All types are characterized by the interests of the implementers, what the target group wants to gain from being a participant and what function participation has for them. With nominal participation, researchers and children are not too interested in a high level of children's participation. As a result, participation serves the function of display, or non-participation. With instrumental participation, the interest of researchers is that the study can benefit from children's time, energy and expertise. Children see their time investment in the project as a cost, but they feel participation has a function to reach results. With representative participation, researchers see children's participation as beneficial both for the study and for the children, as the study will better suit the needs and interests of children, thereby promoting sustainability of the study's initiatives. Children are taken seriously and participation serves the function of children actually having a voice in the study. With transformative participation, the interest of both researchers and children is to develop children's empowerment. This leads to participation functioning as a means as well as an end, to reach empowerment. The model of White (1996) relates to Hart's (1992) model, as both models include forms of non-participation. White (1996) explains that in participatory research, researchers need to be cautious to not slip into non-participation. As all involved stakeholders may have different interests that they unconsciously or consciously do not share, the risk of non-participation exists. This may lead to misunderstandings and conflicts. White's model is designed to show the politics of participation and that conflicts are bound to occur between stakeholders, due to different interests at stake.

Whichever model is preferred, participation models may help researchers consider how they wish to collaborate with children and vice versa, but also whether this is attainable in the local context and with the available resources.

"Essentially all models are wrong, but some are useful" (George Box, 1979)

Youth Participatory Action Research

Youth Participatory Action Research (YPAR) is a form of participatory research in which children are actively involved in research in collaboration with researchers[27, 28]. Instead of *research on* or *research about*, YPAR advocates *research with* and *by* children[29]. According to Kelett (2010), research conducted by children has four major benefits[30]. Firstly, children have *access* to their peers in a way that adults would never have[30]. In YPAR, children are trained in research methods and become co-researchers in the study. Children conduct research to identify problems in their community and can involve peers that are difficult to reach by researchers. Secondly, data from children's research adds to the literature because it portrays problems/contexts from a *child's perspective*[30]. As the gap between researchers and participants fades away, problem identification should be a better representation of the reality of the child[28]. Thirdly, children are owners of their own research and can spread their own results which is good for the *child voice*[30]. Fourthly, being part of research is an *empowering process* in which children can learn many new skills which can benefit different parts of their lives[30]. In YPAR taking action is part of the research design and children have shared or full decision making power over actions to be developed (e.g. [28, 31, 32]). Children become change agents and strive for improvement of the lives of themselves, their peers and/or community. As children are involved in the entire process from problem identification, implementation, to evaluation, they can become empowered by seeing results from their efforts. Empowerment is a complex construct and many theories have been developed to decipher its meaning and application, some of which also applicable to children's empowerment in relation to YPAR[33]. For example, researchers describe empowerment as a process and as an outcome, where empowering processes may focus on skill building and involvement

in decision making, and empowering outcomes may look at the effects of individual involvement on a community or organizational level[34, 35]. This links to another categorization, as empowerment can be on an individual, organizational and community level and those can again be subdivided into categories[35-37]. In the introduction and discussion we will not go into the details of empowerment theory as it falls outside of its scope; we have a more overarching scope related to YPAR, participation models and health behaviors.

YPAR has often been conducted in the school setting in the United States, where children could choose to do research on a certain topic[12]. Children mainly focused on education, social inequalities, health, violence, and safety[12]. In the Netherlands, participatory research with children has also gained increasing popularity, both applied in health care (e.g. [38-40]) as well as health promotion[41-43], which is the area of study of this dissertation. The rapid increase in popularity of participatory research has shown challenges in upholding the principles of participatory research[44]. For example because it spread to fields where knowledge of those principles and training in participatory research are scarce, or partners without experience in participatory research expect results with limited resources and time. Experienced PAR scholars recommend making use of published principles and handbooks for conducting participatory research with children, to reach valuable participation and limit the risk of tokenism[21, 44-47]. In YPAR, different levels of child participation occur and different terminology is used. Frerichs et al. (2016) and Larsson et al. (2018), examined studies that classified themselves as participating with children, and evaluated the form of participation applied[10, 11]. In a systematic review, Frerichs et al. (2016) summarized child and youth participatory intervention studies aimed at stimulating healthy behaviors[11]. Inclusion criteria were that children were involved in intervention design or implementation. Studies were excluded if involvement of children was limited to a few children in a larger adult group, children were underrepresented, or when only information was extracted from children, for example through interviews. Four out of eighteen studies used interactive participatory approaches to design and implement health promotion interventions. The other studies involved children in the

implementation of already developed interventions. In a scoping review, Larsson et al. (2018) evaluated 41 studies involving child participation in the development of interventions in health and well-being, and identified the levels of child participation, according to Shier's (2001) model [10, 15]. Only three studies met the criteria for the fifth and highest level of participation, where children and adults share power and responsibilities [10]. Seven articles met the criteria for level four, where children are involved in the decision-making processes. The majority – 28 studies – met the criteria for level three, where children's views are taken into account in the development of interventions. Three articles only met the criteria for level two, where the view of children is supported. Studies that only met level one, where children are listened to but they or their views are not included in intervention development, were not included in this review.

YPAR studies focusing on health promotion have been qualitatively and quantitatively evaluated on their effectiveness, with life skills as the most frequently reported outcome. A systematic review on outcomes of YPAR studies in the United States included 67 papers on 63 distinct studies and found improvements in several skills, including agency and leadership skills (in 75% of the included studies) and academic or career (in 56% of the included studies) [12]. An integrative review summarized outcomes on the individual, organizational and community level of studies conducting participatory action research in collaboration with youth and children [13]. The review included 45 studies with most reporting on changes in organizational culture towards child and youth inclusion (in fourteen of the included studies), infrastructural changes in the community (in thirteen of the included studies), social-emotional and cognitive development (in twelve of the included studies), and sensitivity of programs to children's needs (in twelve of the included studies). Also beneficial effects on diet, physical activity and weight status have been found [11]. However, due to variation in study characteristics, methodology, and outcomes, it is unclear which mechanisms have led to which outcomes. Thus, there are many indications that participation of children in intervention design/implementation can lead to effective health behavior change, but more research is needed into requirements for optimal participation as well as effective behavior change strategies.

Kids in Action

Combating childhood overweight and obesity is high on the public health agenda, also in Amsterdam. At the start of the Kids in Action study in 2015, 22% of 10-year-old children in Amsterdam had overweight or obesity, while this was 28-31% in children from low socioeconomic positions[48]. Engaging children from low socioeconomic positions in healthy lifestyle interventions is generally challenging, even though they need such interventions most. Therefore Kids in Action applied YPAR to collaborate with 9-12-year old children of a low socioeconomic neighborhood in the North of Amsterdam, to improve children's energy balance-related behaviors, physical fitness and self-rated health. Throughout the study, children were involved as co-researchers, from assessing the health needs in the community to designing, implementing and evaluating actions. We used Intervention Mapping in addition to YPAR, to structure the research process. We hypothesized that shared decision-making would result in actions that suited children's needs and interests, thereby increasing the effects on children's energy balance-related behaviors. A process and effect evaluation were conducted to evaluate the YPAR process, and effects on children's empowerment, dietary behavior, physical activity, sedentary behavior, sports and outdoor play participation, neuromotor fitness, and self-rated health.

Outline dissertation

This dissertation describes the Kids in Action study in six chapters. Chapter two describes the needs assessment that formed the basis for actions promoting healthy behaviors. Together with children, parents and community partners, health needs of children in the community were identified. Based on the needs assessment, a study protocol was designed for the following three years of the Kids in Action study. This study protocol is presented in chapter three and describes the procedures of our YPAR process with children, as well as the design of the process and effect evaluation. Chapter four describes a review to provide insight in effective intervention strategies to improve physical activity, sedentary behavior or dietary behavior in 9-12-

year old children living in low socioeconomic environments. Insights from this review could be used in the design of actions within Kids in Action. The process of developing actions with children using YPAR in combination with Intervention Mapping is described in chapter five. Chapter six describes the process evaluation which was guided by empowerment theory and the RE-AIM framework. The process evaluation included focus groups with children and interviews with community partners. The effects of Kids in Action on dietary behavior, physical activity, sedentary behavior, sports and outdoor play participation, neuromotor fitness, and self-rated health, are described in chapter seven. Chapter eight, the general discussion, provides a critical reflection on the Kids in Action study using participation models described in this introduction. Additionally, valuable lessons learned are described that can benefit future YPAR studies aimed to improve energy balance-related behaviors in children, and recommendations for policy and practice are given.

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