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# Who is 'in' and who is 'out'? Participation of older persons in health research and the interplay between capital, habitus and field

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## ABSTRACT

Inclusion and exclusion processes in community engagement do not take place in a vacuum, but are embedded in social, political and institutional contexts. To better capture the interplay between the individual agency of community participants and organizational structures in health research, we use a Bourdieusian framework. The notions of capital, habitus and field allow us to analyse how inclusion and exclusion of older persons in a Dutch healthcare research- and improvement programme are processually shaped overtime. The findings demonstrate that due to the influence of the medical and policy field, older persons with social, cultural and symbolic capital were included in target group panels. Frail older persons lacking these types of capital were often excluded. Despite the high amount of capital, the formally 'included' participants still experienced difficulties in engaging effectively in a medical research setting. We distinguish various strategies that older persons developed during the course of the programme to deal with this problem: (1) professionalization, (2) responsabilization, (3) pluralization, (4) opting out. Using these strategies older participants were able to incrementally change the medical field by shifting the focus to quality of life and welfare. We conclude that it is by definition impossible to 'exclude exclusion' at the start of care improvement programmes. It is only in the many pragmatic and mundane choices of 'doing participation' that more inclusive engagement can be realized.

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## Introduction

Community engagement has developed into a widespread policy ideal that is viewed as intrinsically good as it promises democratic decision-making, empowerment and legitimacy (Bensing, 2000; Boote, Telford, & Cooper, 2002; Hanley, Truesdale, King, Elbourne, & Chalmers, 2001; Van de Bovenkamp, Trappenburg, & Grit, 2009). This ideal has been translated into various formats and governance structures, such as patient councils, community membership of ethics committees and funding boards (Van de Bovenkamp et al., 2009). Also in global health research, efforts to promote community engagement in the design and evaluation of research have increased in the past decade (Lavery et al., 2010). Despite the inclusive promise of engagement, however, risks of community exploitation and exclusion of patient perspectives are still pervasive (Gbadegesin & Wendler, 2006). The literature offers different explanations for the gap between policy ideal and practice as well as solutions to close this gap. Studies on health literacy

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focus on the lack of individual capacities to effectively process health information leading to exclusion of patients in decision-making (Nutbeam, 2008; Ratzan, 2001). Perceived solutions are strengthening skills and capacities via education to make patients and communities more 'health literate'. Global health researchers have developed guidelines for effective community participation, emphasizing the need for trust building, ownership by the community and co-production of knowledge (Lavery et al., 2010). In addition, organizational literature provides useful insights into specific facilitators and barriers that enable or limit inclusive participation (e.g. staff capacity, financial resources and accountability requirements) (Légaré, Ratté, Gravel, & Graham, 2008; Luxford, Safran, & Delbanco, 2011; Montori, Gafni, & Charles, 2006).

Although these bodies of literature offer valuable explanations and solutions for reducing the gap between the policy ideal of community engagement and practice, we argue that there is still too little attention for a more detailed analysis of the interplay between individual agency and organizational structures in how inclusion and exclusion are shaped in mundane practices. Engagement does not take place in a social vacuum, but is embedded in particular social, political and institutional contexts (King, Kolopack, Merritt, & Lavery, 2014). To better capture this dynamic interplay, we use the Bourdieusian framework of capital, habitus and field to analyse how inclusion and exclusion are processually shaped. This framework makes visible the relations between institutional context, embedded work routines and individual decisions of actors. Additionally, we use the concept of 'micro-advantages' (Gengler, 2014) to show how the mobilization of capital can result in subtle advantages vis-à-vis other participating actors.

We analyse a Dutch case of target group participation in the National Program of Elderly Care (NPEC). This programme aims to improve the quality of care for frail older persons with multiple conditions by the development of (1) regional networks for care and research, in which target group panels (consisting of older persons) were positioned as important network partners; (2) transition experiments and research projects to improve the quality of care; (3) the implementation of new interventions in medical care and public health. In each, older persons were actively encouraged to participate in the evaluation, design and implementation of research and interventions.

This empirical case is interesting for several reasons. First, older persons that participated in panels were generally well-educated with much managerial experience. Despite their privileged background and formal inclusion, they still experienced difficulties in effectively participating in the evaluation and design of research. From the perspective of health literacy, we cannot explain why literate older persons still faced such difficulties and sometimes felt socially excluded from decision-making despite being formally included. Second, the organizational conditions to enhance participation of older persons were ideal on paper. The NPEC was positioned as a unique programme in making participation of older persons a funding requirement for research proposals and network development. Despite these important organizational facilitators, there was a continuous struggle of participation between medical researchers and target group panels.

Our analysis provides insights in how inclusion and exclusion processes are shaped by the interplay between individual agency and organizational structures. In the discussion, we will reflect on the implications of our analysis for the ethics and politics of community engagement in global health. First, however, we explain the concepts of capital, habitus, field and micro-advantages, showing the relevance of a Bourdieusian framework in studying participation.

## **A Bourdieusian approach: capital, field and habitus**

The work of Bourdieu is influential in sociology, but also applied productively in different health-related contexts as various as the relation between dog-ownership and walking (Degeling, Rock, Rogers, & Riley, 2016); drug use (Van Hout, 2011); vulnerabilities of marginalized sex workers (Stoebenau, 2009), patient-provider interactions (Dubbin, Chang, & Shim, 2013) and infection control (Brown, Crawford, Nerlich, & Koteyko, 2008). These studies explore relationships between individual experiences, social interactions and the institutional environment.

The concepts of field, capital and habitus are conceptual tools to understand stratification processes in social spaces (Bourdieu, 1990). Bourdieu conceptualizes society as a plurality of social fields (Siisiäinen, 2003), described as 'a series of structures, institutions, authorities and activities, all of which relate to the people acting within the field' (Rhynas, 2005, p. 181). Fields incrementally change overtime due to power dynamics that can challenge the boundaries of the field (Rhynas, 2005). Actors are considered to be simultaneously *embedded within* fields and at the same time struggle with and change these fields. Separate fields (e.g. science, medicine, politics, education) have furthermore developed their own distinctive institutional dynamics (Brown et al., 2008).

In order to obtain influence and status in a certain field, people need to mobilize capital. Bourdieu views the value of capital as context-specific: it is appreciated differently depending on the field (Bourdieu, 1990). He distinguishes various types of capital, including social capital (networks and relations), cultural capital (education and skills), financial capital (property and other resources) and symbolic capital (prestige). These forms of capital are convertible (Portes, 2000). Bourdieu originally defined social capital as 'the aggregate of the actual or potential resources which are linked to possession of a durable network of more or less institutionalized relationships of mutual acquaintance or recognition' (Bourdieu, 1985, p. 248, cited in Portes, 1998). Social capital is thus the goodwill available to individuals or groups, arising from the structure and content of someone's social relations (Adler & Kwon, 2002).

Cultural and symbolic capital are other forms of capital. Cultural capital consists of long-lasting dispositions, educational qualifications and knowledge of cultural goods (Bourdieu, 1990). It includes informal education transmitted through the family, political parties and cultural groups, but also formal education. Symbolic capital involves the attribution of prestige and credit. It includes not only displays of social standing, but also the collective judgements that shape how these displays are perceived and the consequences of such attributions (e.g. marks of recognition) (Bourdieu & Wacquant, 2013). Together these various forms of capital add up to an individual's overall capital.

In between field and capital, Bourdieu positioned the 'habitus', denoting lasting dispositions that are unconsciously embodied and internalized, thereby guiding how we collectively think and act (Bourdieu, 1990). The habitus is not only social, but also a taken-for-granted embodied reality (Rhynas, 2005). It not merely passively reproduces dominant ideology, but functions as a generative principle (Brown et al., 2008). It is durable overtime, and although its structures can be modified, this is typically a slow, accumulative process (Siisiäinen, 2003). Habitus can thus be viewed as a system of embodied dispositions that organizes the ways in which individuals perceive the social world around them and react to it. As dispositions are usually shared by people with similar backgrounds, members with a long history in a particular field have more time to internalize the socialized norms and tendencies that make-up a person's habitus (e.g. doctors).

Although Bourdieu's earlier work is criticized for its overdeterministic emphasis on structures, his later work focuses more explicitly on agency and institutional change (cf. Reay, 2004). Therefore, Bourdieu's theoretical apparatus enables a detailed analysis of how specific actors mobilize various forms of capital and interact with the routines that make-up the broader institutional field.

Bourdieu's framework offers an analytical lense to understand inclusion and exclusion processes in the participation of older persons for three reasons. First, the combined concepts of social, cultural and symbolic capital are crucial for understanding not only how some actors are able to achieve advantages, but also how others are excluded from participation and its potential benefits (Bourdieu, 1990; Gengler, 2014; Shim, 2010). Capital can also be used to constrain opportunities to non-network members, leading to disadvantages for other actors (Adler & Kwon, 2002; Portes, 1998). Second, 'engagement does not happen entirely *de novo* and the healthcare field is not just plastic to the participants' will: it imposes limits' (Brown et al., 2008, p. 1048). This implies that studies focusing on individual capacities overlook the interplay between individual agency (used here in its everyday meaning of the ability to act and make choices) and organizational structures that shape inclusion and exclusion. The notion of habitus is better able to address this interplay between agency and structures in how people negotiate change as the concept recognizes both the role of dispositions and structures that people have internalized through socialization *and* the opportunities for change (as habitus constrains but does

not fully determine thought and action). Third, the concepts are valuable for explaining differences in benefits gained from mobilizing capital. These benefits are sometimes described in terms of 'micro-advantages', denoting small gains which incrementally can lead to the acquisition of significant (health) improvements (Gengler, 2014; Shim, 2010).

Based on this theoretical framework, this paper investigates the following question: How is the inclusion and exclusion of older persons in the NPEC processually shaped through the interplay between individual agency and organizational structures?

## Methods

Our analysis is based on qualitative research of the National Program of Elderly Care (NPEC) that took place between 2008 and 2016. With a total budget of over 80 million euros, it was one of the largest care improvement programmes in the Netherlands. The NPEC is funded through the Ministry of Health, Welfare and Sports, who commissioned the Netherlands Organisation for Health Research and Development (a large funding body for health research and innovation) to further develop and monitor the programme. In the development of the programme, a national programme committee – responsible for the operational governance – was established by the funding body. Members of this committee had a high public profile and were viewed as experts in research, policy and healthcare.

As researchers, we were commissioned by the Netherlands Organisation for Health Research and Development to evaluate the NPEC. In this role, we conducted 53 semi-structured interviews with 63 respondents, ranging from 50 to 150 minutes per interview, 90 minutes average. We interviewed different stakeholders, including older persons of the target group panels and national representatives of elderly associations ( $n = 21$ ). We also interviewed medical researchers and representatives of medical associations, national policy-makers at the Ministry of Health, Welfare and Sports and the funding body, network coordinators and other stakeholders. The interviews with older persons focused on the participants' backgrounds, their experiences with evaluating/monitoring research projects, the workload of participating, required skills and their interactions with researchers. To supplement the interview data, we conducted observations of meetings of the target group panels and analysed relevant documents pertaining to target group participation.

All interviews were transcribed verbatim. For the analysis, we used social, cultural and symbolic capital, habitus, field and micro-advantages as 'sensitizing concepts' (Blumer, 1954). Key themes that inductively emerged from the analysis were the ways inclusion and exclusion was shaped, the different strategies older participants developed to deal with participation in a predominantly medical domain, and the consequences of these strategies.

## Results

### *The organization of the programme and the selection of participants*

The goal of the NPEC was to improve care for 'frail older persons', operationalized in terms of older persons having multiple mental and/or physical problems (e.g. medical diseases, housing problems and loneliness). To achieve this goal, more scientific substantiation of effective interventions and evidence-based methods was considered to be necessary by the funding body (ZonMw, 2008). To shape the research required for this, regional networks ( $n = 9$ ) were developed in which University Medical Centres (UMCs) were appointed as network leaders that invited other public service organizations (e.g. in care and well-being) to join. Important aims of the regional networks were integration of service provision for frail older persons, promotion of target group participation, research and the implementation of interventions as diverse as integrated care pathways, screening instruments for frailty and neighbourhood community engagement.

An important emancipatory ideal of the funding body was to give frail older persons 'voice' and 'choice' in the design, evaluation and monitoring of research. Although there were no strict criteria

for 'successful engagement', the programme documentation highlights that the funding body saw active involvement of older persons as important *means* for developing more relevant research that better fits the needs of this group. The final programme document explicitly mentions the consultation of target group panels as an important requirement for the regional networks' eligibility for funding (ZonMw, 2008).

To meet this requirement, the UMC's took the lead in setting-up target group panels and recruiting participants for these panels. The participants had a professional history in various domains, including social work, politics, labour unions and private companies. Additionally, some informal caregivers also participated in target group panels. The age range of participants was between 55 and 90 years.<sup>1</sup> The number of participants of target group panels varied from  $n = 8$  to  $n = 15$ . The general number of active participants in all target group panels and governance boards of regional networks gradually increased to  $n = 175$ . Ethnic minorities were severely underrepresented in this number.<sup>2</sup>

Although the goal of the NPEC was formulated in terms of care improvement for frail older persons, in practice *frail* older persons were largely excluded from participation in target group panels, whereas relatively 'resilient' older persons in terms of health status and social-economic background were over-represented. This selection of relatively resilient older persons was highly structured by the medical and policy field in which the programme was developed. Although many respondents argued that the UMC's medical focus did not align with the broader focus on well-being that mattered for older persons, they were nevertheless made responsible for the development of the regional networks and, therefore, also for the set-up of target group panels. The UMC's leading role can be explained in terms of the strongly established medical field they are part of and the strong social, cultural and symbolic capital that flows from this.

Described above as 'a series of structures, institutions, authorities and activities' (Rhynas, 2005, p. 181), the UMCs are key institutions and have a strong, historically developed, authoritative position in medicine. Supported by a strong umbrella organization to coordinate efforts and negotiate with policy-makers, the UMCs have become important institutions in the medical field. Many actors also developed the cultural capital to write research proposals that matched the criteria and the more implicit demands (correct language and terminology) of the funding body. The field of welfare, on the other hand, was much more fragmented and did not have a strong umbrella organization. Furthermore, many actors in this field lacked the cultural capital to quickly produce research proposals that met the formal and informal criteria of the funding body. These aspects help explain why the UMCs 'took the lead' in the regional networks, which consequentially shaped the selection of particular older participants for the panels (i.e. those who had acquired some forms of capital, see below) (Interview with member of the programme committee, representative of the mental care domain, male).

The influence of the policy field becomes visible in the time pressure the UMCs experienced at the start of the NPEC to set-up the required target group panels, as a result of the predominant logic in this field: the logic that policy programmes run for four years and that a certain percentage of the budget needs to be attributed in the first year.<sup>3</sup> Therefore, many research calls were organized in the first year, placing the networks under heavy time pressure. Consequentially, UMCs often pragmatically selected older persons from their own personal networks (e.g. retired university lecturers) or through professional patient platforms. Thus, especially older persons with a large amount of social capital were selected for the panels. This social capital could consist of an established network with medical researchers through previous work experience or of a network established by other means (elderly associations, unions or political/managerial experience). Although these forms of social capital do not necessarily provide expertise in reviewing research proposals nor presuppose health literacy, they were appreciated by medical researchers as important qualities for participation.

Despite the importance of capital for *inclusion* in target group panels, exclusion of frail older persons in those panels cannot solely be explained by a lack of capital. Significantly, the format of participating in committee meetings and panels also seems to preclude a part of the target group of frail older persons. Problems of physical access to meeting locations and the need to travel across the country also played

an important role in shaping formal exclusion. People having difficulties following conversations due to their condition were also less likely to be able to participate.

### **Experimenting with participation of older persons**

The analysis above showed the influence of established fields (medical and policy) on how participation of older persons was shaped in the beginning of the programme, leading to the inclusion of persons with specific forms of social capital and the exclusion of persons lacking this capital. Processes of inclusion and exclusion are not static, however, and continued to be shaped in the course of the programme through the interplay between the various forms of capital, habitus and field.

In the early days of the programme, medical researchers had particular ideas about what constitutes a 'good' participant. Older persons with executive networks (social capital) and high education (cultural capital) were valued as legitimate actors in the medical field because they were viewed as more effective (Interview with medical researcher, female). At the same time, the experiences of older persons were often discredited because they were expressed in a style that made generalization hard (several respondents talked about the 'N = 1 elderly' in this case). A programme committee member expresses her difficulties with the way in which older persons often expressed their experiences:

I deeply respect those professors for their patience, because sometimes it drives you mad!

*What aspects drove you mad?*

Well, if as a researcher you ask older persons: what do you think is important? Well, ok: 'the mother of my granddad has this and this', you know what it's like, that's the way you talk with your neighbour on the birthday of your sister. But you need to be able to look beyond your own casuistry. The ones that can do this are the older persons that have studied more. And when you haven't (studied) you get stuck in your own casuistry. They also raise good points, but well, the *energy* that you have to put into it ... (Interview with former coordinator NPEC, policy maker, female)

This quote shows that individual experiences of older persons are not immediately considered valuable in the medical field; they require much additional work that is not appreciated.

Older participants were thus implicitly expected to make the 'right' kinds of argument, which means seeing the bigger picture and refraining from 'nit-picking' (Interview with medical researcher, female). In terms of cultural capital, older persons were required to be knowledgeable about the 'appropriate' conversational and argumentative style (to argue beyond individual cases). Older persons that have acquired this cultural capital are valued more by medical researchers, consequentially increasing their symbolic capital as well.

These examples point to how older persons learn to become active members by following the rules of engagement. Such rules of engagement turn out to be hard to change. They have a long history in the way the funding body facilitates and organizes participation of target groups and they also fit in the Dutch deliberative policy tradition. The notions of habitus and field thus help explain why participation is organized in this deliberative manner: the rules of engagement for participation have obtained a kind of obduracy that is the result of a Dutch policy tradition and bureaucratic ways of working that have historically developed and have become both institutionalized in procedures and routines and internalized by many persons as socialized norms about how deliberation should be organized.

Even older persons with much social and cultural capital had difficulties in participating in such settings, because of different customs in the medical field and institutional barriers in the policy field. First, they emphasized the inaccessibility of scientific terminology:

[The projects] have to lead to improvement of elderly care. That perspective is indeed included, but it remained very far removed from (older persons). [...] The terminology .... I am no pussycat, but you almost need to have a dictionary at your disposal. Jargon! (Interview with member of elderly advocacy group, male)

The use of scientific jargon makes it more difficult for many older persons to participate effectively in panels. This jargon is not only part of the 'rules' of the medical field (as specific terms and criteria for research apply, including medical terminology and methodological precision), but also closely tied to the policy field, where the established procedure is to find scientific experts for peer reviewing the

content of the proposals without necessarily taking into account the lay criteria through which older persons define good research (such as relevance and the link between medical care and welfare).

A second difficulty is the narrow time schedule in which many projects had to be developed. Target group panels were only involved in the evaluation of research proposals that were almost finished with the submission deadline approaching fast. This made dissenting opinions less likely:

There is enormous time pressure on those meetings, so if you take a formalistic stance you only frustrate the discussion (Interview with former member of target group panel, male)

This quote shows that although *formally* target group panels were considered important for judging the proposals, established work routines in the medical field, in combination with the limited symbolic capital of older persons in relation to medical researchers, made it hard, if not impossible, in this stage for older persons to 'keep their foot down' (i.e. taking a 'formalistic stance').

A major consequence of these difficulties was that representatives in target group panels increasingly experienced that their perspective was used instrumentally. A respondent vividly recalls his frustration vented during one of the meetings:

Where did all the money go in the first two years (of NPEC)? I said that in 2010. The bomb exploded.

*How did people respond to what you said?*

Dead quiet. I said in a loud voice: 'We are not here to promote people with a university degree to doctor, we are here for older persons'. Quiet. Very quiet it became. Then someone responded: 'you are right X'. (...). At a certain moment I said: 'give us the opportunity to think for ourselves and take charge for once. Of course, we have ideas ourselves, we are here for a reason!' (Interview with member of target group panel, male)

This frustration was experienced by more participants. Feelings of exclusion were further strengthened because research proposals initiated bottom-up by target group panels were often not funded by the funding body, that used scientific evaluation criteria to assess the worth of proposals (see above). Formal criteria for receiving funding conflicted here with the 'lay' perspective of target group panels.

In sum, the medical and policy field turned out to be hard to change without the necessary cultural capital (e.g. procedural knowledge about how regular procedures work and how 'normal' research proposals should be written and evaluated).

### **Strategies to participate in the medical field**

Although the analysis thus far seems to point out that the 'voice' of older participants was limited and that the older persons involved in the panels were not able to destabilize existing power relations, such a conclusion would be too bleak. During the course of the programme, we saw that the voice of community members gradually led to substantive changes. The programme committee and the funding body became increasingly aware of the frustrations of target group panels and the shortcomings of this particular form of engagement. They did not significantly alter the structure of engagement, but they did support target group panels by organizing theme-based conferences about engagement and by more tailored funding opportunities.

Target group panels themselves also developed responses to the difficulties they experienced. We distinguish four strategies. Some of these strategies highlight how older persons have internalized some of the tacit rules of the medical field as part of their habitus, whereas other strategies show older persons ignoring or attempting to change the status quo. To strengthen the position of the target group panels and counterbalance the dominance of the medical field, *professionalization* of older persons was a frequently used strategy. Professionalization entailed the coaching of target group representatives in order to develop the 'right' cultural capital to participate in the medical field. This strategy was also supported by the programme committee of the NPEC, who initiated a specific project called 'Powerful Client Perspective'. This project aimed to strengthen the voice of older persons and included various training sessions for target group panels, in order to learn how to lobby and effectively frame talking points during meetings with medical researchers. Additionally, the umbrella organization for elderly associations wrote a handbook on 'how to' participate for the community of older persons.



Although professionalization can strengthen the lay perspective vis-à-vis the medical perspective through the enhancement of participants' cultural capital (both formal, through the trainings, and informal, through peer discussions), this strategy still takes the medical field as a starting point. In some occasions, this led to the well-known risk of 'proto-professionalization' (De Swaan, 1988; Dent, 2006) when target group panels adopted scientific jargon and selected 'professional' candidates for target group panels:

A: Tomorrow I have an interview with someone who wants to become member. That person has a wonderful CV. Since I became chair (of the target group panel) I say: 'before we hire someone, I want a CV. It doesn't have to be 3 pages, 1 page will do' (...)

B: We put that on paper beforehand: what are the criteria that a member of the target group panel will have to meet?

*What are the criteria?*

B: uh well, at a minimum you need to be able to talk well, to have executive experience, to be able to think in policy terms, have a network, those kind of elements.

A: and you need to be involved. These are more or less 8 criteria that we have listed. Those are the things we are looking for (Interview with two members of target group panel, male and female).

This quote shows how professionalized target group panels were complicit in the further exclusion of older persons with little social and cultural capital.

A second strategy is *responsibilization*. This refers to a governing technique to mould responsible citizens who then internalize certain duties and govern themselves accordingly (Dean, 1999). Through their long-time participation in the NPEC, some older persons seemed to have internalized the tacit rules of the medical field as part of their habitus through their continuous socialization into the field-specific rules. This resulted in a heightened sense of responsibility of older persons who have internalized their participatory duties. Responsibilization became manifest in how target group panels deal with 'participatory work'. This includes carefully reading all minutes from previous meetings, dividing tasks into different 'work groups', 'doing your homework' (some older persons came with large stacks of notes to the meetings) and in general being 'well-prepared'. This requires much time: some respondents emphasized that they spent up to 30 hours per week. A second example of responsibilization is the corrective behaviour between peers. Members of target group panels correct each other if they feel someone doesn't take participation duties seriously:

One of the older persons asks a question about a topic that apparently was already discussed in the previous meeting. The chairperson indicates that the topic will not be discussed further because it was already discussed in-depth. The person coining the question clearly shows she is displeased and claims she was absent the previous meeting. The chairperson corrects her in clear terms: 'but a report about the meeting was made and it's your own responsibility to read those reports'. (Excerpt observation target group panel)

Hence, participation creates obligations and expectations. The strategy of responsibilization can be understood as an attempt to increase symbolic capital, i.e. to become more trustworthy and valued in the medical field by signifying that participation 'duties' are taken seriously.

A third strategy is *pluralization*: i.e. the development of alternative work methods and new fora for target group participation that challenge existing institutional logics. By setting-up alternative fora for participation, some regional networks attempted to prioritize informal work methods, thereby creating more room for the perspective of older persons. The 'regional tables' that were developed in the north of the Netherlands are an example of a small-scale forum in which older persons and professionals exchanged ideas about improving elderly care without a pre-set research agenda or the use of scientific jargon. The goal of these regional tables was to gain more bottom-up input and ideas from older persons and local care and welfare professionals:

Through older persons I think that different topics are being introduced. They have, for instance, introduced the theme of empathy. What can you do at home for your partner as an informal caregiver, and what do you want yourself, as a person? How do you experience the care you receive? Those were themes older persons introduced and that also encouraged reflection amongst healthcare professionals. (Interview with network coordinator, female)

Rather than following nationally set research themes, the regional tables promoted collaboration between local professionals and older persons and defined improvement themes in a bottom-up way. A consequence of this strategy was that academic research and funding became less the driving force behind participation of older persons. This strategy thus explicitly rejected the subordination of the elderly perspective to the medical field. Although this strategy seemed more useful to enhance the input of older persons, finding enough financial resources to safeguard continuity remained a challenge.

The fourth strategy of *opting out* was used when older persons no longer perceived opportunities to meaningfully engage. Older persons that opted out questioned the dominance of the medical field and the reactive nature of their participation:

The target group panel was a requirement for the functioning of the projects; it was one of the NPEC requirements. But I felt like 'ok guys, this is not something I want to contribute to'.

*Can you explain why you left?*

Well, in general, people (members of target group panels) were fine with commenting on plans (...). But when I was thinking about how to spend my time, I said: 'I don't expect any innovations and the little energy I have left I want to spend on other things (...). The most striking thing is that many people in institutes and public governments don't have a clue how to deal with citizen participation. (Interview with former member of target group panel, male)

When tokenism was expected, opting out seemed the only viable strategy. An important organization for older immigrants for instance turned down requests for involvement from researchers as previous experiences showed that their involvement became a 'check-box' affair (Interview with member of migrant elderly organization, female). The problem of tokenism is well known in literature about community engagement, especially in relation to global health (Arnstein, 1969; Ocloo & Matthews, 2016; Tindana et al., 2007). In the case of the NPEC, one response of older persons experiencing such tokenism was to opt out. While older persons using the strategy of pluralization are attempting to develop alternatives to the predominant rules in the medical field, opting out is more radical and points to a high level of frustration.

These four strategies point to different ways in which members of target group panels have developed responses to the difficulties they experienced in participating. This had some effect: most older persons participating in the panels emphasized that the instrumental view of participation overtime changed for the better. Target group panels were able to gradually change the medical field. This became evident when the funding agency developed specific calls for welfare and started to decline funding to research projects without a connection between health and welfare. Older persons have thus been able to partially adjust the purely medical focus of research that was a consequence of the dominant medical field.

A second effect relates to how older persons were able to convince (part of) the medical community about the importance of their participation. A director of an association for older persons reflects on how the national federation of UMCs eventually published a brochure in which they 'confessed' to the added value of participation:

The Dutch Federation of University Medical Centres published a brochure (...) about participation of older persons. (In this brochure) they write themselves that they found (this) a nuisance in the beginning: 'and we were annoyed that we had to do this because of NPEC. But we came to love those older persons and we do see the added value now'. So that is a nice brochure because they make a kind of confession, a religious confession: 'it was counterintuitive that we did it, but it proved to be very valuable'. So many of those researchers do say: 'by taking seriously the participation of older persons in my research (...) I have come to see the added value'. (Interview with director of association for older persons, male)

This example shows how older participants have been able to adjust the medical field at least temporarily. Significantly, this 'public confession' of an organization that is an established part of the medical field can also be understood in terms of increased symbolic capital for the community of older participants.

### **Micro-advantages and disadvantages**

The interplay between capital, habitus and field and the strategies employed to deal with tensions in this interplay resulted in the obtainment of certain micro-advantages for particular groups. Especially, the strategies of professionalization and responsabilization turned out to be important in terms of increased social, cultural and symbolic capital. Older persons that were professionalized by training and education were less overwhelmed by medical researchers and the routines in the medical field.

Also, some target group panels were granted specific institutional privileges that increased symbolic capital and enabled further professionalization and responsabilization. One specific target group panel was granted a 'veto-right', which meant that a research proposal would not be submitted for funding if the target group panel decided it was irrelevant. Although this led to criticism from medical researchers, the veto-right increased the symbolic capital (older persons were taken seriously). Consequentially, this also led to an increased sense of responsibility amongst panel members:

In the beginning, they [the older participants] were distrustful about whether they actually had a veto-right. [...] But now they noticed that they were taken very seriously and that had as a consequence that they also took it [the participation] very seriously.

*How did this show?*

Well because they had very good discussions and very good arguments about what could work and what wouldn't. So they took their own role [in judging proposals] very seriously. (Interview former network coordinator, female)

Our research also shows that older persons with a large amount of social capital (in terms of a large network to draw on) gained further micro-advantages during the programme. Having a political-managerial network enabled older persons to participate more effectively as they have easy access to relevant organizations (Interview two members of target group panel, both male). Importantly, this also led to an increase in symbolic capital in the medical field as easy access was valued in terms of opportunities for data collection.

Micro-advantages can also work the other way. This can be seen in the way one important member of the national committee, who was a well-respected former politician now taking place in this committee to bring in an elderly perspective, constantly frames herself as ignorant in order to press researchers to change their routines:

Looking back what surprised me most is the aloofness of a couple of professors (...). Slowly that was getting better. I have emphasized frequently: 'I am a regular girl, I don't get it' (...). They have all studied. I think you need someone from the common folk, like I am. I keep saying that consciously. (Interview elderly representative program committee NPEC, female)

This quote shows that the acquired symbolic capital this respondent gained through her political career in the Dutch Senate allows her to voice a lack of understanding and discipline researchers into changing their routines and jargon.

In sum, having social, cultural and symbolic capital can lead to several micro-advantages, which have the effect that participating older persons are taken more seriously in the medical field. There is also a downside, however: participants lacking the right capital face 'micro-disadvantages' as a consequence of the highly specialized and professional field in which they were operating. For instance, the input of some participants was not taken seriously because they did not use the right jargon or were not able to express their thoughts in a politically sensitive way (Excerpt observation target group panel). This also led to further exclusion processes in which not only researchers, but also participants in target group panels were complicit.

### **Discussion and conclusion**

This paper investigated the following question: How is the inclusion and exclusion of older persons in the NPEC processually shaped through the interplay between individual agency and organizational structures? We have analysed this case of target group participation using the Bourdieusian conceptual

framework of capital, habitus and field. We focused on disentangling the relations between institutional context, work routines and the decisions and activities that individual actors employ.

The analysis showed the influence of established fields (medical and policy) on how participation of older persons was shaped in the beginning of the programme, leading to the inclusion of persons with specific forms of social capital and the exclusion of persons lacking this capital. The rules of engagement turned out to be hard to change. Even older persons with much social and cultural capital had difficulties in participating, leading to an increasing recognition that their perspective was used instrumentally. Members of the target group panels developed different strategies to respond to these difficulties. Overall, the voice of community members gradually led to substantive changes in the programme. The strategies of professionalization and responsabilization led to increased social, cultural and symbolic capital for particular groups, along with the obtainment of further micro-advantages. The downside is that participants lacking the right capital face 'micro-disadvantages' as a consequence of the highly specialized and professional field in which they were operating.

In relation to existing participation literature, our study shows similarities and differences. Important similarities can be seen in questions concerning representativeness of the participating group (Trappenburg, 2008; Van de Bovenkamp et al., 2009). The sub-group of literate older persons with a relatively high socio-economic status was not representative in terms of health problems. The question of representativeness becomes more urgent when taking into account the large age differences of older persons involved in the programme, given the differences between the generally more 'resilient' persons of relatively younger age and the more vulnerable and frail groups of very high age that were almost totally precluded from participation. Another similarity can be seen in the strategy of professionalization. The benefits (increased empowerment) and risks (loss of lay perspective) of professionalization are in line with the literature (Callaghan & Wistow, 2006; Van de Bovenkamp et al., 2009). Our analysis shows, however, that the consequences of professionalization cannot be seen as separate from the institutional context and work routines. Additionally, our study shows that other strategies were used by older persons. These strategies led to different micro-advantages and disadvantages (Gengler, 2014). In line with El Enany, Currie, and Lockett (2013), our study demonstrates that not only professionals, but also older persons are complicit in the exclusion of particular user groups.

The Bourdieusian framework offers several analytical advantages. The notions of capital, field and habitus are helpful in exploring the dynamics of inclusion and exclusion, as these processes are neither static nor develop in a social and organizational vacuum. Particularly relevant in this regard is Adler and Kwon's (2002) distinction between 'bridging' and 'bonding' forms of social capital, respectively, foregrounding external relations or internal ties. As the medical field is well established, it consists largely of 'bonding forms' of social capital focusing on internal ties. Older participants lacking such established disciplines developed 'bridging forms' of social capital to connect to the medical field.

Our analysis of Dutch target group participation in health has wider implications for community engagement in global health. There is a growing recognition that attention for ethics and politics are crucial for the development of 'good' community engagement practices in research. This is evidenced by the increasing number of ethical guidelines for community engagement (Lavery et al., 2010). Yet the impact of these guidelines on biomedical research has been modest (Hasnida et al., 2017; Lavery et al., 2010). Our Bourdieusian framework offers an explanation why ethical guidelines in themselves are insufficient for guaranteeing inclusive engagement. A strongly established institutional field of global health research funding leaves marginalized actors with the need to perform continuous work to have their voices taken seriously. In order to change this, we need more than just ethical guidelines and entrepreneurial individuals. Institutional work needs to be conducted on many levels, including the level of funding (creating new funding structures), research (establishing and maintaining local research infrastructures) and community (new tools and instruments for the embedding of experience-based knowledge can strengthen the capital needed for inclusive engagement).

An important limitation of our framework is that it focuses primarily on talk and action. The concepts allow us to identify what strategies actors develop, what they do and how they talk. Missing from this analysis is a focus on *material* aspects of participation. Especially in the case of frail older persons, such

materialities are important as they can give rise to additional exclusion practices (if there is no elevator in the building, participation becomes a practical impossibility).

Our analysis shows that inclusion and exclusion are not static terms but processes that change in the course of a programme. Institutional contexts and disciplinary routines have a major influence on the ways participation is shaped, and it takes time and skill to incrementally change these contexts. We conclude that it is by definition impossible to 'exclude exclusion' at the start of care improvement programmes. It is only in the many pragmatic and mundane choices of 'doing participation' that exclusion and inclusion practices are shaped. Research would therefore benefit from a processual approach in which these mundane practices are followed overtime. Participation is ongoing work and never finished.

## Notes

1. It is important to point out that this age range is not the consequence of explicit criteria, but the result of more pragmatic choices by the UMCs to look for 'suitable' participants in their own networks first. Of course, this age range is very broad and has significant consequences. As one reviewer pointed out, people in different age categories are likely to have different priorities, concerns and levels of health. This is something the program committee did not immediately take into account, although recognition of the differences between the more general categories of 'frail' older persons and 'resilient' older persons did become important over the course of the program. While we do not have exact numbers available, we can infer from our interviews and observations that most older persons involved in the target group panels are likely to be between the age of 65 and 80, with some exceptions towards higher and lower ages. There are still large differences and the consequences are reflected upon in the discussion-section.
2. The exact reasons for this are hard to disentangle and also have not been the focus of our research. Tentatively, we can point to three intertwined reasons. First, UMCs primarily searched for pragmatic reasons (such as time pressure) in their own networks, in which ethnic minorities are also likely to be underrepresented. Second, a well-known migrant organization refused to cooperate as they were dissatisfied with the results of previous calls for involvement of minority perspectives in other programs. Third, a wide range of social science research shows that it is difficult to motivate and engage people from minority backgrounds to participate in research activities.
3. The duration of the NPEC was extended to a total of 10 years.

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