

## Business as usual?

Inequalities in patient and public involvement  
in health research

*Jonas Thorborg Stage*

*is a PhD fellow at the Center for Health Promotion and Health Strategies, Department of People and Technology, Roskilde University, Denmark and Region Zealand. He researches patient and public involvement, health and illness, and relates social action to the broader social and political context. He has also published about emotional work in health institutions.*

### Abstract

Co-creation in health research is a rising trend, as funding bodies increasingly favor research that involves citizens in the research process. Furthermore, research strategies, policy documents, and statements from Danish health institutions have begun to highlight the benefits of co-creation in health research. There is an increasing expectation and claim that citizens and users of health research should influence and take part in such research processes. Yet international studies have shown that social position matters for the inclusion and exclusion of citizens in health research. The article discusses how citizens' social position may matter for co-creation in health research by drawing on relevant research literature. Furthermore, I apply central notions of the sociologist Pierre Bourdieu (e.g., field, capital and habitus) to discuss diverse prerequisites for citizens to co-create in health research. This article focuses on the risk in patient and public involvement of reproducing health disparities through co-creation of knowledge.

**Keywords:** Bourdieu, co-creation, inclusion, social inequalities, power

## Introduction

Patient and public involvement (PPI) in health research is potentially a new space where inequalities are (re)produced. In Denmark, we see a rising focus on PPI<sup>1</sup> as a practice of co-creating research in the healthcare field. PPI in research refers to research that is “being carried out ‘with’ or ‘by’ members of the public” not just “‘to’, ‘about’ or ‘for’ them” (INVOLVE 2020). One might say there has been a change in perceptions of citizens following the rise of co-creation in health research. Citizens used to be perceived by health researchers as ‘objects’. Today, citizens are mentioned in research strategies, policy documents, and statements from health institutions or in guidelines. Citizens are now seen as ‘subjects’ that researchers need to work with for several reasons. One reason is that co-creation has the potential to validate the research and make it more relevant for patients (Beresford 2013a; Glasby and Beresford 2006) and is thus increasingly mandated by funding agencies (Patrick 2016). These are new positions for citizens to take that have emerged during the last 15 years of changes in the welfare state and health institutions. However, in the desire for more co-creation in health research, the social structures and constraints within the healthcare system in Denmark that influence researchers’ opportunities to involve citizens, can easily be overlooked.

Throughout this article, I explore PPI in health research as a phenomenon with power asymmetry between health researcher and citizen. In doing this, I make explicit the conceptual landscape in the Danish context that may constrain PPI by employing Pierre Bourdieu’s concepts of capital, habitus, and field to emphasize how powerful actors and relations of power in the healthcare field affect the process of co-creation. Thus, I seek to discuss how PPI is enacted in a structured field that renders it vulnerable and risks exclusion of disadvantaged citizens. Arnstein (1969) was an early scholar to recognize the role of power in the involvement of citizens. She visualized a ladder of participation, where involvement was manipulation at the bottom, from where it rises to a tokenistic level, to end up with the citizen’s control. Arnstein provided important insight into the different levels that PPI is enacted in. Some studies focus on understanding the contexts, where PPI in research is conducted in a context of social and power differences (Beresford

2013a; Williams et al. 2020)<sup>2</sup>. Put differently, why must we all co-create in our health institutions if such practices face constraints?

My overall research question is: How do social differences and context matter for co-creation between health researchers and citizens? Addressed to an analysis of PPI in the Danish healthcare field, we can begin to ask questions about the ways in which PPI as a phenomenon is socially situated. How do social differences and assets, such as social position and the composition of different forms of capital, matter for co-creation with citizens? The tendency towards more co-creation in the healthcare field is not only centered on people, but also on norms for the roles of citizens and health researchers. What is perhaps less obvious is whether social differences matter for who is included and excluded from these processes. For instance, how are social demands and standards of judgment predominant in the significant social role that health researchers have, when they recruit citizens?

To clarify the overall question, I present in the next section some trends in the Danish welfare state and healthcare field. I then move on to discuss consequences of social differentiation in involvement by drawing on examples from the literature on PPI in research and recruitment, in addition to Bourdieu's concepts, in order to understand contributing factors to the exclusion of citizens from PPI processes. In other words, if social merit is a criterion for inclusion in PPI in health research, why is that? In these sections I point out the potential risks and mechanisms of inequality in co-creation in health research. Greater attention needs to be paid to the resources and constraints that hinder more inclusive health research.

### **Transformation of the healthcare field**

Danish health services are primarily provided through the healthcare system, which is financed through taxes as part of the welfare state. The Danish welfare state has its roots in the Scandinavian social democratic model, which involves social citizenship (Esping-Andersen 1990). Therefore, health services are seen as a right for every citizen and the welfare state has the key responsibility to provide equal access to healthcare. However, the last 20 years have seen a transformation taking place, as the welfare state has been changed through new public management reforms and more work-oriented requirements for recipients of health-related bene-

fits (Harsløf, Søbjerg Nielsen and Feiring 2017). The austerity measures and the increased desire for greater efficiency in healthcare delivery cause increasing strain on healthcare professionals (Roenn-Smidt et al. 2019). This transformation is described as part of a move from a social democratic state to a neoliberal state where an economical logic to a larger degree takes over health and social care, which is then dominated by an economic and regulatory function (Bourdieu 2001; Collyer 2018; Roenn-Smidt et al. 2019; Vrangbæk 2020). These studies describe how such transformation affects health institutions, where an economic logic dominates a social logic. PPI in research may be seen as structured by this logic, when enacted in this field. As Collyer et al. (2017, 11) state, the healthcare field is shaped by:

...powerful institutions of medicine; organizations such as hospitals, consumer advocacy associations, medical schools and Royal Societies; industries both small and large; a plethora of governance bodies; and occupational groups from specialist doctors and health educators to pharmaceutical salespeople and ward attendants.

At the same time, access to funding of health research to produce better health services depends on internal and external relations. As mentioned earlier, the new pattern in funding is another element in transforming the healthcare field and funding actors have access to economic capital, which may matter for opportunities to co-create. Moreover, given the predominance in the healthcare system of cost-effectiveness and data-intensive work, co-creation is likely to be a “hard sell” to researchers, funders, and policymakers worried about limited resources and timeframes (Filipe et al. 2017). The reality of the academic sector with funding and research production systems may push citizens to the margins (Boaz et al. 2021, 8), with tight deadlines set by funders which contributes to repeated exclusion (Rai et al., 2021). Citizens are involved to make research more relevant, but co-production is not an isolated phenomenon. Institutions, as well as people, are relationally connected to each other and shape the structures of the healthcare field.

## **Bourdieu and patient and public involvement**

Social dimensions are often forgotten when citizens are invited to participate, e.g., in the research community in health research. People are shaped by living their lives under different conditions.

The sociology of Pierre Bourdieu (Bourdieu, 1992; Bourdieu and Wacquant 1992) focuses on the interplay between the concepts of habitus, capital, and field. This triad informs an analysis of the relationship between agency and structure and is useful to clarify social processes that lie behind expressions of power, the societal and relationality (Emirbayer 1997), which are dimensions of PPI (Beresford 2013a).

For Pierre Bourdieu, society is perceived as 'fields'. According to Bourdieu, a field is not a static thing, but the boundaries between fields are understood as boundaries that are drawn within the field itself. Bourdieu states: "... The field, the objective context, [is] a site of struggles and forces" (Bourdieu 1993, 30). According to Bourdieu, society can be seen as a social space maintained by structures relating to class but also political ideas and values, which in the shape of knowledge and in the creation of fields all together contribute to the reproduction of social differentiation. In other words, the rising trend of co-creation in the healthcare system can therefore only be explained as an ongoing structuring and restructuring of fields, which illustrates developments and history, and thereby gives context and explanation to constraints to the levels of involvement and interaction between citizens and health researchers.

According to Bourdieu, habitus is understood as a system of embodied disposition along with a scheme of perception, which organizes practices and relationships (Bourdieu 1993). In this way, habitus guides people, such as health professionals and citizens, when they act, when they think and in their strategies. What is important here is that these strategies are immersed and enacted on the level of bodily logic. Habitus is seen as stable, but also malleable (Bourdieu 1984, 169-225; Bourdieu and Wacquant 1992). In Bourdieu's own words, academia is seen as "a habitus which disposes agents to retreat to their ivory towers and think and act as if the world were an idea to be contemplated and discussed, rather than a series of problems and issues affecting the everyday lives of people" (2002, 19). Moreover, academia has a distinctive habitus. As researchers we live and (re)produce this reality; there are norms

and rules (written and unwritten) for doings and sayings, which are expressed in practices of writing articles, writing applications for funding, and our organization of formal meetings with the use of agendas and minutes. As Michel Lamont points out, there are different *epistemological styles* in different research fields, as researchers have different *habitus*, i.e., “preferences for particular ways of understanding how to build knowledge, as well as beliefs in the very possibility of proving those theories” (2009, 54). Citizens may encounter different views about what constitutes ‘excellent’ health research, where a high degree of involvement may not be an important factor. Louise Locock et al. notice in their study that PPI seeks to disrupt the *habitus* of academia by inviting citizens with their everyday life into the ivory tower, “... but this remains inviting people into the researchers’ world rather than meeting on neutral ground” (2016, 837). Therefore, some citizens may feel more like “a fish in water” during PPI activities, at least insofar as their *habitus* navigates them in alignment with the field’s values. They will know what to do, and how to do it, according to what is perceived as being appropriate for that specific position in the social space (Bourdieu 1984). In a Bourdieusian approach, it is valuable to emphasize the different prerequisites that enable some citizens to be better positioned to participate in health research. Returning to the questions of power and involvement (Arnstein 1969), involvement of citizens can be related to resources that are perceived as legitimate. Therefore, if we take our understanding of the healthcare system as a field and consider co-creation as structured by it, citizens’ *habitus* may be subject to a process of exclusion, if they do not ‘fit’.

Another useful way of understanding inequality is, as described by Friedmann and Laurison in their study of the class ceiling in the UK (2020), that access to an institution can be seen in terms of ‘*getting in*’ (recruited) and ‘*getting on*’, which means staying, rising in hierarchies, and having influence. They point out, across different institutions, how it matters to be privileged. People from socioeconomically privileged or disadvantaged positions have different career trajectories, because of their different opportunities. Even though the study by Friedmann and Laurison is not concerned with the healthcare sector and knowledge production *per se*, the social mechanism they identify may be of use in the discussion of power,

because there is a debate about whether people who participate in co-creation of health research are well-off, well-educated and well-networked (Beresford 2013b). Here, Bourdieu's notion of capital allows us to understand subtle forms of domination that concern the privileged and aspects of power in involvement.

For example, Locock et al. have studied symbolic capital concerning PPI in health research in UK. "One of the most unequal of all distributions, and probably, in any case, the most cruel, is the distribution of symbolic capital, that is, of social importance and of reasons for living" (Bourdieu 2000, 241). Locock et al. focus on how possession and display of prestige, status, and authority leave citizens less vulnerable to actions by health researchers that would otherwise devalue or discredit their contribution (2016, 843). In other words, citizens who can invoke other forms of capital that are valued in the field (e.g. tertiary education, experience of committee work, familiarity with health research) may actually bolster their symbolic capital. Thus, their accumulation of symbolic capital protects their status in the group from devaluing behavior, while other citizens are more vulnerable to such behavior, which may well deprive them of their status. In this way, Bourdieu's concept of capital makes it interesting to explore how different forms of capital have a legitimizing effect in PPI and can be understood as an expression of power, which allows privileged citizens to keep participating, while others are denied influence. Going further, we can therefore consider whether the habitual dispositions that constitute capital (symbolic and material) are perceived as valued in the field. The way people accumulate and convert capital is strongly related to access to the dominant position in the existing class structure of the field (Darmon 2020; Bourdieu 1986, 1998). Fran Collyer points out that patients' access, availability, and 'choice' of health services is in practice limited since private and public hospitals keep an eye on the bottom line, which creates a gatekeeping situation where negotiations are conducted (Collyer 2018). In the Danish context, if economic capital is perceived as a value that prevails and influences the outcome of PPI, PPI can be structured by the habitus of a field, which may constrain its enactment at a higher level of partnership (Arnstein 1969) for economic reasons.

If we draw on Bourdieu's framework, we can see that the risk of PPI being an inclusive or exclusive practice may depend on the so-

cial positions of the health researchers and the citizen in the health-care field. We can seek to outline what forms of capital (e.g., economic, social, cultural, or symbolic capital) may be mobilized and transacted with, as citizens and health researchers negotiate their way through the research community in the healthcare field in order to improve their position in the field.

### Merits for co-creation

Recruitment to co-creation can be understood as a sampling method, but also as a social practice, or a ‘who gets in’ question. But what influences who is recruited into health research? There is a body of international sociological literature that points to the importance of ‘taste’ in forming professional networks in different cases and across countries. This is especially prominent in elite networks such as medicine, law, and accountancy, and is a dynamic known as ‘homophily’ (Friedman and Laurison 2020; Rivera 2012, 2015). People tend to like people who are like themselves in terms of racial identity, gender, and class background. In the words of Sara Ahmed: “The ‘hey you’ is not just addressed to anybody: some bodies more than others are recruited, those that can inherit and reproduce the character of the organization, by reflecting its image back to itself, by having a ‘good likeness’.” (2012, 51)

What this could mean for PPI in health research is that citizens’ chance to be recruited is not only valued according to illness characteristics (e.g., being a person with lived experience with a given disease). Recruitment is also rooted in merits in terms of class and cultural similarities. Therefore, if we pay attention to the ‘who gets in’ question, we can highlight a space that plays a significant role in accessing different knowledge and resources.

We know that the dominant actors in the healthcare field (e.g., health professionals, researchers, practitioners such as doctors, nurses, and managers) are overwhelmingly middle-class. This means that they set the standards for perceptions and tacit knowledge, which become embedded in organizational structures of power and resources (Ridgeway 2014, 11; Church et al. 2002; Martin 2008; Faulkner et al. 2015). Thus, we can begin to understand that ‘getting in’ and ‘getting on’ in health research are affected by social merits in terms of citizens’ greater opportunity if they possess and communicate the same valued information and preferences that are legiti-



mized by health researchers. For example, if 'small talk' during PPI activities is about cultural consumption of travel, fine dining, or modern art, which are typical of people of higher socioeconomic status, citizens from underprivileged positions risk being excluded from the dialog. They may even be stigmatized to some extent. In Bourdieu's terminology, if citizens' social position and composition of capital are a good fit, e.g., they are familiar with the healthcare system as a form of cultural capital or they share similar cultural preferences, they may be able to 'grease' the interaction. As mentioned earlier, this could strengthen their symbolic capital, thus keeping them in to enable 'getting on'.

Other international studies point out how knowledge production is socially stratified in PPI in health research (Ocloo and Matthews 2016; Martin 2008; Cheng et al., 2013). This means that citizens' social position in the healthcare system matters for their capacity to influence decision-making. For example, a study on PPI in clinical commissioning groups showed how citizens' social position created unequal chances to influence decision-making and be listened to (O'Shea et al. 2019).

To sum up, with Bourdieu, I have outlined some elements of a historical construction and transformation of the healthcare field, which co-creation is a part of. This transformation may require citizens' habitus to be aligned with researchers' habitus to be effective in co-creation. In this perspective, what health researchers highlight as measures of "recruitability" (Ahmed, 2012, 50) could be seen as the social merits involved. To extend a Bourdieusian perspective to PPI is an inquiry that emphasizes the social nature of human activities and the significant role that co-creation could play in the development of our healthcare system by paying attention to one of many places in which choices and decisions of citizens and researchers face constraints. If it is true, as Collyer (2017, 2) and de Maio (2010, 93-4) argue, that our healthcare systems mirror the dominant values of society and are "... outcomes of political struggle; they reflect the end result of competition between complex forces", there is a need for better knowledge about the relationships that organize our health system, how PPI is enacted, and an understanding of how central actors in the health system and external structures are relevant to the growing interest in PPI in health research.

## **Towards a sociological study of inequalities in co-(re)production of knowledge in health research in the welfare state**

In this article, I have examined how social differences and social structures can influence PPI in health research in the context of the public healthcare system of the Danish welfare state, which in principle aims to provide healthcare to all citizens.

By using Bourdieu's concept of field, we can see health research in the public healthcare system as affected by external pressure. By drawing on research, I point to an ongoing transformation of the healthcare system (patterns of funding, neoliberal reforms, pressure on health researchers) that structure and organize PPI and outline dimensions of how power and involvement (Arnstein 1969) may work in the healthcare field. While it would have been ideal to discuss other social structures that may influence the transformation process (e.g., clinical structure, research structures), this article, nonetheless, draws attention to structural constraints that seem to be missing from the debate on PPI in research. Citizens and health researchers are expected to participate together in deliberative fora to develop better healthcare in the system in Denmark. But under what conditions?

By further drawing on Bourdieu's concept of habitus and capital and other literature, I discuss how some citizens' voices risk being excluded or deemed less important because they are perceived to lack resources and social merits, which is rooted in their underprivileged position. Hence, meeting these requirements for citizens' habitus to 'get in' and 'get on' may signal an unequal distribution of resources in the healthcare field, which sets social standards based on current social normativity. As mentioned above, research shows that the healthcare sector is largely occupied by middle-class people. The social normativity may affect citizens in the sense that they are devalued based on middle-class criteria, which becomes a mechanism for exclusion if they are ill-adjusted with their dispositions to participate in knowledge production. I find it interesting that social differentiation in involvement, i.e., systemic inequalities and social processes of exclusion and discrimination, which stem from relationships of power, stands in opposition to a more principled and instructive way of talking about involvement of citizens in research.

Future studies could adopt Bourdieu's framework to study power and involvement and identify the significant forms of capital involved in PPI in health research. Studies could also relate legitimized forms of capital to how institutional standards form and constrain PPI practices to empirically investigate social differentiation. To address the social inequalities at play in PPI in health research in Denmark, we need studies that outline the social structures that constrain both health researchers and citizens by situating PPI activities to their social position in the healthcare field.

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### Notes

- 1 In this article I use “PPI” and “co-creation” interchangeably for the sake of readability. However, distinct differences exist between the two regarding the degree of involvement in decision-making processes (see Ives et al. 2013)
- 2 For example, Mary Madden and Ewen Speed (2017) also point out a normative shift toward PPI, which has taken place within a neoliberal policy context.