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Lived Experience as the Basis of Collaborative Knowing. Inclusivity and Resistance to Stigma in Co-Research

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Abstract

Social scientific research has become increasingly aware of power asymmetries and the elitist and exclusive nature of scientific knowledge production. These debates have resulted in more inclusive and participatory research practices. In this article, we focus on co-research, which is a participatory and multi-perspective research strategy that invites the people whom the research concerns to participate as active and influential agents throughout the research process as experts on ‘the studied world.’ Co-research is increasingly being adopted in research involving people who belong to marginalised groups or who face the threat of stigmatisation. Despite its increasing applications, engaging in co-research requires reflection on several methodological and ethical questions that so far have been underexplored in the methodological literature. In this article, we address challenges in practicing inclusion and overcoming power asymmetries in co-research, particularly when it is conducted with people who inhabit societal positions with institutionalised stigma and whose participation in research is usually highly limited. In this article, building on our own experiences from different co-research projects—with care leavers, experts-by-experience with a history of crime and mental health recoverers—we aim to contribute to this literature by specifically focusing on issues of inclusion of co-researchers who face the need to negotiate with institutionally stigmatised positions. We suggest that reflexivity on positionalities and attending to plurality in identity work could provide a fruitful tool for increasing inclusivity in co- (and peer) research. We claim that such reflexivity is crucial from the very beginning of a co-research process (including ways of inviting and recruiting co-researchers) because this stage is crucial, as it forms the basis for the following stages and for the possibility of practising inclusion—even if imperfect—throughout the process.

Keywords

co-research, inclusivity, inclusion, institutionalised stigma, positionality, identity work, lived experience

Introduction

Social scientific research has become increasingly aware of power asymmetries and the elitist and exclusive nature of scientific knowledge production. These debates have resulted in more inclusive and participatory research practices.¹ In this article, we address challenges in practising inclusion and overcoming power asymmetries in co-research, particularly when it is conducted with people who inhabit societal positions with institutionalised stigma and whose participation in research is usually highly limited.

Co-research is a participatory and multi-perspective research strategy that aims to democratise knowledge

production and increase the inclusivity of research by inviting people whom the research concerns to participate as active and

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influential agents throughout the research process. These people are valued as experts in ‘the studied world.’ Knowledge generated through lived and felt experience is, thus, at the heart of co-research and should guide the co-research process from designing research to its implementation and reporting in appreciation of different skills, perspectives and therefore different forms of knowing (e.g. James & Buffel, 2022; Kulmala et al., 2023; Liddiard et al., 2022).

Co-researchers play an active role in defining *what* to study, *how* to study it and *why* in order to produce knowledge *for* a particular group of people, rather than to produce knowledge *about* a particular group of people (Hietala et al., 2023; Liddiard et al., 2022). In more traditional research settings, the professional researcher has authority over defining the research questions, producing and interpreting related data and placing the findings in the wider research context, leaving the research participants with the role of the object of the research. The key task of co-research is to counter these power asymmetries (Kulmala et al., 2023) and, as we argue in this article, to destabilise hierarchies among professionals and co-researchers (also Goodley et al., 2022).

Co-research is often concerned with the pursuit of social change in terms of real-world inequalities and exclusive access to knowledge production (e.g. Spies et al., 2022). Co-research takes a stand, often with both scientific and practical aims, and thus works to bridge the traditional division between theory and practice by seeking both understanding and change, or at least directions for change (cf. Howard et al., 2021, p. 1020).

An attempt to address inequalities and generate change often motivates the representatives of disadvantaged groups to find solutions that best serve the interests of their groups (see e.g. Whitney-Mitchell & Evans, 2022). Ideally, this process also leads to positive change at the personal level of a co-researcher in terms of a strengthened sense of agency and wellbeing. In doing so, co-research aims towards change on various levels: in its efforts to impact on the state-of-the-art regarding the studied issues to address and overcome real-world inequalities, in its attempts to increase inclusion to destabilise hierarchies in the research process and in its strive to the potential long-term empowerment of participating co-researchers.

Co-research belongs to the same family of participatory approaches (James & Buffel, 2022) as, for instance, participatory action research (PAR; e.g. Fine et al., 2021) or service-user involvement in research (e.g. Beresford, 2013; Knutgård et al., 2021), which share a similar commitment to reducing societal inequalities and promoting inclusion. However, whereas PAR and service-user involvement generally aim at enacting change within a certain community or service environment and is thereby focused on a context-specific area of intervention, we characterise co-research as encompassing a broad range of approaches that aim to challenge power imbalances, especially within research processes, and which thereby can cultivate change on both personal and societal

levels (c.f. Littlechild et al., 2015). Despite its aim to promote inclusion, it has been noted that, first, minoritised people have frequently been underrepresented in co-research, and second, that co-research might not succeed in challenging the hierarchies upheld by academic institutions to the extent that it is expected to do (Cotterell & Buffel, 2023; Goodley et al., 2022; James & Buffel, 2022; Spies et al., 2022; Tanner, 2012). Co-research with marginalised or vulnerable groups in particular has been characterised as ethically and methodologically complex and thus in need of further reflection and development (Bradbury-Jones et al., 2018; Cotterell & Buffel, 2023).

These challenges resonate without our own experiences in co-research, in which we have realised that overcoming hierarchies and achieving full inclusion are difficult and, sometimes even impossible. Hietala et al. (2023) pointed to the challenge of the exclusivity of co-research (paradoxically in the name of inclusivity) if we do not carefully consider who to involve as co-researchers and based on what assumptions (see also Nind et al., 2016). It is important to ponder who are the ‘they’ whom we think the research concerns and their self-identifications. Furthermore, it is essential to become aware of co-researchers’ relationships with the studied phenomena and the other participants whom the research is supposed to concern and whom they are supposed to represent as peers. In addition, awareness of the assumptions concerning what motivates the co-researchers to participate in research and what kinds of skills we expect participants to have is relevant. These are all examples of questions connected to the (im) possibility of ‘full inclusion’ and to the related question concerning wider conditions of knowledge.

In this article, we contribute to previous literature on participatory approaches by examining the possibilities of inclusivity in co-research, drawing on concepts of positionality and positioning. We propose that careful reflection on positionality and the ways it shapes the effort to bring together various kinds of experience-based knowledge provide vital tools for co-research to grapple with these challenges. We claim that attending to context-specific positioning work that occurs in dialogues between professional and co-researchers is similarly vital because it further supports the attempts to destabilise and potentially dissolve power hierarchies in co-research.

In research with co-researchers who inhabit marginalised societal positions and who are seldom heard in research (and more widely in society), these efforts have specific significance. In particular, positions of marginality that are created under the influence of powerful institutions (often referred to as institutional categories; e.g. Bowker & Star, 1999) pose challenges for overcoming power asymmetries in research. Such institutions create marginality, for instance, via stigmatising categories that operate both on a social and psychological level and effectively hinder achieving social inclusion and empowerment (cf. also Goodley et al., 2022, p. 13). The opportunities to participate in co-research can also be restricted by context-specific structural constraints (e.g. social

policy regulations and requirements by academia), which can have a negative impact on potential co-researchers' motivations and concrete possibilities to partake in such research, as will be discussed later.

We discuss these challenges through our own experiences from several co-research projects with the representatives of institutionally categorised, often stigmatised groups, including young care leavers,² people recovering from mental health problems³ and experts-by-experience with a history of crime.⁴ Before going to this discussion, we first locate co-research in the longer history of participatory, feminist and reflexive research traditions, which link co-research to broader questions regarding the nature of knowledge and the possibilities of knowledge production (cf. Gillies & Alldred, 2012), and introduce the concepts of positionality and positioning as tools for understanding and negotiating social dynamics and power relations in co-research.

Positionality, Epistemology and Interaction in Co-Research

Co-research builds on epistemological premises that are sensitive to power imbalances in knowledge production. Co-research is on a continuum of participatory research approaches, which arose as a response to the failure of more conventional research practice to produce practically useful and applicable knowledge and as an attempt to prioritise the voices and experiences of seldom-heard and marginalised groups (Schubotz, 2022, pp. 2–3). Participatory research is anchored in alternative ways of doing research, which have evolved out of critiques of traditional positivist research traditions since the 1960s and at the heart of which lie questions about the nature of knowledge and its production (see, e.g. Vescey et al., 2023).

An important point of departure for participatory research has been the idea of situated knowledge, which highlights the impossibility of achieving objective knowledge in research (e.g. Fine et al., 2021; Haraway, 1991; Hill-Collins, 1991). The situated knowledge framework developed by Donna Haraway (1991) is an epistemological orientation that emphasises lived lives as the basis for knowledge creation. Haraway (1991) maintained that instead of assuming the position of a knower as a subject who objectively knows about an object from afar, researchers should acknowledge and value the subjectivity of knowledge and proximity instead of distance. This idea has led advocates of participatory approaches to avoid knowing on behalf of others and to attempt to broaden the possibilities of drawing on various life experiences and knowledge by inviting broader groups of people to actively participate in knowledge co-creation.

Intersectional perspectives (see, e.g. Collins & Bilge, 2016; Fine et al., 2021) have further nuanced the idea of situated knowledges, and as we argue, are beneficial for understanding the relationship between marginalised positions and possibilities for participating in knowledge co-creation. An intersectional perspective illuminates how people's possibilities to

thrive differ based on multiple intersecting category memberships, such as those based on gender, age, social class, racialisation, ethnicity, sexual orientation and ability, and how the interplay of such memberships may produce multiple forms of marginalisation. While some category memberships may be associated with marginalisation and disadvantage, others might be linked with privilege (Collins & Bilge, 2016). Furthermore, people's social positions can be seen as mutable, since instead of being treated as essentialist, unitary and stable, they are seen as constructed under the influence of various social systems. An intersectional lens therefore works against reductionist and rigid assumptions of people's identities and positions in relation to others, and by doing so provides a vital lens for understanding similarities and differences among (co-)researchers.

Recognising various category memberships and life experiences as the basis for knowledge is an integral part of attending to *positionality* in research. Positionality is a frequently used concept that refers to the centrality of reflexivity in ethically responsible research practices (Secules et al., 2021). We use the concept in our discussion on the significance of points of entry into co-research for each party, both professionals and co-researchers, and on how their societal positions and cumulated life experiences inform co-research. Furthermore, alongside the concept of positionality, we use a related concept of *positioning* (Davies, 2000, 2023), which refers to the dynamic and context-specific manner in which people see themselves and others and can adopt positions in relation to each other and the surrounding world (cf. Wetherell, 2008). Positioning occurs in relation to socially shaped and institutionally enforced categories, which may be either resisted or adopted in efforts to constitute socially recognisable identities.

Examining interaction in co-research through the lens of positionality and positioning is particularly fruitful in research with members of society who are forced to struggle with the burden of stigmatising, institutionalised categorisations, which function as the normalised and invisible exercise of power (Bowker & Star, 1999). This fruitfulness is because attending to both the burdens of these categories and the possibilities to actively resist the impact of such an exercise of power enables attending to complexity in identity negotiations. It also opens possibilities for considering what kind of practices in co-research would best support avoiding the exclusive, reductionist and stigmatising ways of making positions available for co-researchers. In sum, by attending to both positionality and positioning, it is possible to see both the particularities of situated knowledge and life histories brought into dialogue in co-research, and the active, ongoing interactive identity negotiations that occur during the research process. We argue that ethical research practice requires sensitivity to such multiplicity and mutability to avoid reproducing marginality in co-research.

The relationship that forms the basis of recognising various and fluid subjectivities and subjective knowledge in co-research can be characterised by the concept of

intersubjectivity. Intersubjectivity in co-research creates a foundation for a sufficiently shared understanding of the research object and for implementing co-research on it. However, intersubjectivity does not merely refer to shared experience and empathic understanding, as compassion and conflict are complementary poles (Jackson, 1998). This requires both recognition of the professional researcher's own positionality and a sufficient understanding of co-researchers' positionalities, especially concerning marginalisation, as it creates a foundation for mutual relations, co-operation and co-production of knowledge (see also Gjermestad et al., 2023). As we will illustrate below, these theoretical perspectives are essential for co-research because they allow for reflections on how intersectionally shaped positionality is inscribed into research practices and interactions between professionals and co-researchers (Secules et al., 2021) and among co-researchers and other participants.

Moving Towards Improved Inclusivity Through Reflexive Sensitivity

Co-research challenges us to create a new kind of awareness of the conditions of knowledge. This awareness not only concerns the professional researcher's own standpoints and characteristics but their dominant role in defining the research object (cf. Gould, 2016) and in the context of co-research, their key role in inviting co-researchers into the process. As co-research often delves into disadvantages, people often become invited due to certain institutional, often stigmatised categories, as in our own case. Unpacking and negotiating these 'assumed memberships' require particular awareness, reflexivity and sensitivity. In other words, it requires taking the positionality and positioning (identity work) of both professional and co-researchers seriously.

In this section, we consider the choices and practices of co-research that significantly affect the inclusivity of the process. First, we discuss the necessary reflexivity at the initial stages of co-research on professional researchers' positionality and presuppositions and then move to the practices and challenges of creating inclusive and open invitations for co-researchers. We also pay attention to the importance of recognising co-researchers' own motivations and interests in participating and challenging the notion of peerhood.

Our discussion builds on our experiences in several co-research projects with different institutionally stigmatised groups (see for the details in Footnotes 2–4). One of the projects involved people recovering from mental health problems who participated in the local communities of Clubhouses in Finland. The co-researchers in this project have participated in generating research interest, designing both quantitative survey and qualitative interview questions, conducting interviews and experience-driven joint analyses of them, and writing and disseminating the results. Another co-research project engaged experts-by-experience with the

history of crime to create novel ways of cooperation between professionals and clients in the social service sector. The co-researchers reported their own experiences of collaboration with different social sector professionals in diaries. We also draw on a co-research project in which young care leavers conducted life-cyclic qualitative interviews with their peers to investigate enablers and constraints on agency in terms of the future plans of this particular group of young people. Before and in between the interviews, the young co-researchers participated in training sessions and after the process, they participated in focus group discussions on their experiences of participating in the project, which allowed them to reflect on the child protection system in question. Although the starting points and research practices varied widely in these projects, they shared common efforts to include members from certain institutionally categorised and, to a certain extent, stigmatised social groups. We argue that they offer a good premise for discussing the above-listed issues essentially connected to inclusivity.

The Strive Towards Reflexivity on Professional Researcher's Positionality and Presuppositions

Reflecting on the researcher's positionality in relation to the research topic, phenomena and groups of people assumed to represent these issues is a starting point for building a reciprocal relationship with potential co-researchers. It requires reflection not only on one's own social, economic and cultural positions but also on the pre-assumptions of a professional researcher concerning the topic and phenomena under investigation and the social group which the research is assumed to concern.

It is important to reflect on how people participating in co-research are defined by dominant discourses. As a rule, it is a professional researcher who determines whom to invite as co-researchers, that is, who are those people, groups and communities whom the research concerns, and whose experiences thus are central to the research. In this process, participants might become positioned through pre-determined and normalised institutional categories, for instance, as users of a particular service or recipients of certain assistance. These institutional categories create assumptions not only on the participants' needs or diagnoses but also on their capabilities. Importantly, such categories also define their normality or abnormality, and thus have the power to evoke stigmatisation and create barriers to participation (Beresford, 2013, p. 36; Loseke, 2017; also Goodley et al., 2022).

Professional researchers frequently come to co-research from their more or less privileged—highly educated and middle class—positions. Such privileges and the limits they may pose for understanding the lifeworlds of marginalised participants need to be addressed. A professional researcher might also adopt a certain position towards the assumed group: they might see themselves as an advocate for the

disadvantaged, a defender of justice or perhaps an empowerer of the weak. This is imbued with the risk of paternalism and objectifying co-researchers, which turns into limiting instead of supporting their empowerment (cf. Skeggs, 1994). It is necessary to discuss on what basis co-researchers would participate and what motivates them to do so, as we discuss later in this article. Co-researchers might not identify with, or they may even resist the positions based on which they were invited into the research process. If interpreted through the lens of active positioning of oneself as a form of constant identity work (Wetherell, 2008), this can be seen as an effort to resist being positioned from the outside as belonging to a marginalised and often also potentially stigmatised category, and instead (re)claiming the right to position oneself in alignment with one's own interests, goals and desires (also Goodley et al., 2022; Whitney-Mitchell & Evans, 2022).

It is also important to reflect on the assumed similarity among the co-researchers and their relationship with the studied phenomena and social groups, as further discussed below. Thus, from the beginning of the research process, the professional researchers should consider the diversity of the included lifeworlds. Moreover, seeing behind and into the categories can generate new insights into the phenomenon under study, for example, into the social construction of what is labelled exclusion or inclusion (Hietala et al., 2023). We would therefore like to challenge professional researchers to ask, who makes the definitions of the social groups and categories involved in the research and what are the similarities and differences among people who are recruited or otherwise invited to participate in the research? We maintain that it is not necessary to abandon or try to hide the categorisations and groupings that inform the invitations to participate, but together with co-researchers, to learn to reflect and question them.

Reflection on the professional researcher's presuppositions about the studied phenomenon and the people connected to it is not only a proactive way to become aware of these aspects but also a resource for enriching co-research. At best, this reflectivity helps researchers find ways to enable mutual, multidirectional learning and expand the experiential basis for knowing from the very beginning until the end of the process. This ability is strengthened, challenged and deepened throughout the research process because the understanding of the individual and subjective aspects on the one hand, and the collective, shared aspects of lived experiences on the other, develops as the collaboration process evolves.

Efforts Towards Inclusive Invitations to Co-Research

Professional researchers should pay attention to the means through which potential co-researchers are informed, invited and recruited to the co-research process. It is important to do so to avoid (unintentionally) setting thresholds for participation or strengthening stigmatising definitions and objectifying positionings and to make room for multiple, perhaps

even competing lived experiences and voices. Below, we consider the language used in describing the research, the openness of the recruitment process and the various capacities that co-researchers might have or lack from the viewpoint of improving the inclusivity of invitations to participate in co-research.

The *language* used is an important aspect of inclusivity (Strnadová et al., 2020). We have noticed that the invitation to participate in co-research should be in an easily understood, common language. One should be aware that the concepts used in describing the research, its topic and purpose, and the ways these are communicated have certain consequences regarding why and who might be interested in becoming a co-researcher. The invitation may, for example, contain overt or hidden references to categories that appeal to certain kinds of people and exclude others.

However, these are all questions that can still be discussed and negotiated during the process. For instance, in the TUBEDU co-research project on young people's mental health (see Footnote 2) sounded too stigmatising for the participants, which is why the topic of the research was shifted to address mental wellbeing and mental health skills (see also Liddiard et al., 2018). However, there is an on-going discussion to use the term 'mental health' for the purpose of destigmatising mental health related issues. For co-researchers with a history of crime who were mostly less educated than in other referred projects, there was a continuous concern whether adequate and understandable information had been provided for the co-researchers to make an informed decision about participating in the research, which, as such, was something quite unfamiliar to them.

Distributing invitations to participate in co-research *openly as possible* would be ideal; however, in reality, professional researchers most often tend to rely on a more closed invitation strategy. Quite often, co-research is conducted in collaboration with some organisations that reach out to the people whom the study is assumed to concern. Often, such mediators are familiar and trustworthy among potential co-researchers and thus facilitate access to these people in the beginning. In co-research with young care leavers, for instance, it was considered necessary to have a contact point during the course of the co-research as these co-researchers and the young people they peer-interviewed had most likely experienced severe hardships in their lives. They wanted to be supported by an organisation with vast experience in working with children and young people under child protection, which these young people trusted and with which the professional researchers had a confidential relationship (see also Kulmala et al., 2021; Kulmala & Fomina, 2022).

In the TUBEDU co-research project concerned with young people's mental health, the recruitment of young co-researchers was outsourced to a hired coordinator working in a student mental health NGO, as it was believed that it was easier for young people interested in becoming co-researchers to contact and communicate with a coordinator of almost the

same age and familiar with the different social media channels that young people preferred for their communication and mental health advice. However, the strong involvement of this particular NGO affected the fact that most of the recruited co-researchers came from higher education institutions.

The recruitment of co-researchers with a history of crime took place through the organisations with the practice of hiring experts-by-experience with a history of crime and was driven by the research permits instead of an inclusive practice. However, to maximise inclusivity, the invitation to participate was sent to all organisations with a similar practice (which were not many). One of these organisations did not reply and one chose not to get involved. Among the organisations that agreed with the research, almost all the experts-by-experience were offered the choice of participating in the research. Most of them joined (although one later left). Participation in this co-research was in addition to their regular duties, so those who decided not to participate were seemingly too busy with other activities. There was also a limit to how many co-researchers the project could afford to pay; therefore, co-researchers' participation also depended on the resources of the research project and upper-level organisational decisions.

Co-research in the Clubhouse communities with people recovering from mental health challenges serves as an example of an open invitation. An invitation to participate in co-research, written in a common language as much as possible, was sent to all twenty-three communities of the Finnish Clubhouse Coalition (see Footnote 3). In the invitation, their members, that is, individuals recovering from mental health issues, were offered the opportunity to work as co-researchers in the co-research project in question. Even though the invitation was openly discussed in the community meetings, practically all participants were recruited based on suggestions by a staff member who knew the recovery stages, educational levels and work histories of the recruits and saw their participation in co-research as something meaningful and providing empowerment and employment opportunities for them. A similar pattern was observed in the co-research project involving care leavers. In the end, in both of these projects, all the co-researchers were or had been studying in higher education.

The cognitive *capacities* of people recovering from mental illness—or of care leavers with many kinds of challenges in their lives—were perhaps considered by the gatekeepers an obstacle to participating in research, as research is traditionally seen as an intellectual activity requiring many skills and resources (cf. Nind et al., 2016, on researching with intellectually disabled persons). Afterwards, it felt useful to consider who would have joined *if* the recruitment process in these communities had been different and less reliant on the proposals of staff members or other partners. Another kind of practice might have allowed recruiting a more diverse group of co-researchers with different interests, intersecting positionings and lived experiences.

The selectiveness based on the presumption of certain capacities can turn into the reproduction of intersectional distinctions that maintain the privilege linked, for instance, with being highly educated while leaving those with marginalised positions less represented in research (also Liddiard & Watts, 2022, p. 31). Therefore, participation in co-research does not become the privilege of only the highly educated; this should be taken into account by implementing, as much as possible, an open and threshold-free recruitment process and by searching in advance for new methods that enable participation for those co-researchers who have, for example, challenges with cognitive and interaction-related skills. The predominant emphasis on textual materials and reading and writing seems to have created an image of an ideal actor that is exclusive and thus works against the principle of inclusion (Nind et al., 2016). Thus, less concentration on textual materials and more use of visual materials instead—throughout the research process—would obviously be an option for improving inclusivity (Hietala et al., 2023). Gjermestad et al. (2023) have also pointed out that especially in co-research with people with profound and multiple learning disabilities, an emphasis on verbal communication skills should be replaced by a broader view that sees also sensory and emotional expressions as forms of communication that allow for participation.

Whitney-Mitchell and Evans (2022) have stressed the value of using technologies that enable co-research in virtual environments for marginalised people who experience barriers in the physical and social world. In the project involving co-researchers with a history of crime, for instance, one co-researcher was allowed to record a spoken diary after expressing their concern about the written diary-keeping format. In addition, young co-researchers of mental health in the TUBEDU project have been encouraged to use audio and automated transcription tools. However, the use of technologies requires certain technical skills and, thus, instead of improving inclusion it might create exclusion. In sum, in co-research everyone should be able to participate according to their resources and strengths. Whitney-Mitchell and Evans (2022, p. 39) have aptly reminded that 'giving a voice' means also giving the appropriate means that enable participation and communication. It is the responsibility of professional researchers to ensure that co-researchers with diverse capacities are provided adequate support and concrete means for participation (also Beresford, 2013, pp. 51–52). Taking care of sufficient support for co-researchers promotes trust between them and professional researchers, and therefore has both concrete and affective significance (cf. Knutagård et al., 2021).

Ideally, co-researchers should also be compensated for their work (Strnadová et al., 2020). However, professional researchers need to be aware of the possible risks and unintended consequences of paid participation in co-research. For example, if co-researchers receive monetary compensation for their work, they might lose their entitlement for social benefits entirely or

the payments might become delayed. Overall, at the beginning of the co-research, it might be impossible to consider all of the discussed aspects of inclusivity or the consequences of participation. Many of the issues become revealed only over the course of time, which is why sensitivity to reflexivity must be maintained throughout the process. Similarly to providing the means of participation to begin with, it is the responsibility of professional researchers to identify challenges at different stages and to offer co-researchers sufficient support to navigate through different challenges.

From Recognition of Co-Researchers' Motives and Identity Work Towards Personalised Co-Research Projects

The co-researchers' *motives* for participating in co-research often differ from those of professional researchers and their related assumptions. As we discuss below, these motives may vary, which in turn shape the *positions* co-researchers are likely to adopt in their participation. These may include positions (or a mix of positions) based on efforts to adapt, submissive and activist positions or resistant positions. Participation may also be driven by an interest in drawing on and building upon one's pre-existing competence and finding possibilities for social mobility and further self-development. For instance, one co-researcher in the context of child protection research found participation in the project beneficial in their studies, as this provided experiences relevant to their future professions; one of them considered it a process of self-development during a stage of life. This co-researcher wanted to devote their efforts to learning more about themselves.

The co-researcher, who contributed to the writing of this article, completed her studies at the university before becoming a co-researcher. Her research interest concerns the meaning of the Clubhouse community for students. She was interested in co-research, which she considered an opportunity not only to get a job but also to focus on research that was personally important. In hindsight, she felt that as a co-researcher, she had the opportunity to strengthen both her agency and wellbeing and to rise a little higher on the social status scale. For her, co-research was also meaningful because she felt accepted, capable and important. In addition, she was paid for her input. This led to a positive change in how she perceived her own position. She could now see herself as a productive member of society, as due to her history with mental illness, she had become aware of prevailing notions that those who are unemployed or on sick pensions are usually seen as less valuable than those who work.

Other co-researchers from the Clubhouse community had varying motivations and orientations towards the co-research. One of them, for example, had been working in public services before becoming unable to work and being placed on a disability pension due to mental illness. For this co-researcher, membership in the community was a replacement for collegial relations and the sense of belonging she had lost after leaving her

work. She joined this co-research project because she wanted to explore a sense of belonging in the context of this specific community, as she thought it would provide useful knowledge to strengthen the community. This had consequences for the ways in which she related to the participants of this co-research and the types of lived experiences she could gain.

It is conceivable that these co-researchers' participation served as an emancipatory attempt and a tool to escape being positioned as psychiatric patients or recoverees. It provided an opportunity to strengthen aspects of their identities that had been overshadowed by both mental illness and psychiatric treatment. Becoming a co-researcher provided the possibility of improving their social status and mitigating or distancing themselves from such stigmatised positions.

If co-researchers enter the research unilaterally as representatives of a particular social group, they may seek in different ways to challenge this externally imposed identity. For example, as co-research with the care leavers proceeded, it became evident that one co-researcher had spent their whole life trying to avoid situations in which she was labelled based on her past in child protection custody. For example, during her studies, she did not receive certain benefits that she would have been otherwise entitled to. In retrospect, one can critically question whether her recruitment as a co-researcher based on her categorisation as a care leaver in light of her past was ethically correct. On the other hand, we found that the struggle against a stigmatising label became a resource that strengthened the young person's active agency and self-efficacy in relation to her future goals and choices. She also felt that the research provided her with a range of useful tools, particularly for her future career (as a journalist). (See also [Hietala et al., 2023](#)).

Co-researchers' attempts to resist stigmatising positionings can also be associated with identifying more strongly with the world outside the community and less with their assumed peers. Identifying more strongly with professional researchers is also possible. For example, one co-researcher from the Clubhouse community aimed at entering working life and pursuing an academic career. She never allowed her name to be published as a co-researcher in this context of mental health. Nowadays, she works at a university.

At best, the co-researcher's personal history and their lived experiences—in other words, their positionalities—form a starting point for the formulation of personal research interest. Because of this, it is recommendable to allow the co-researchers to define their own agendas and interests in co-research (cf. [Mubeen & Tokola, 2021](#)). This applies at multiple levels: It is important that the co-researchers are allowed to pose questions and find answers that are meaningful to them (cf. [Whitney-Mitchell & Evans, 2022](#)). Being able to carry out their own agenda can be seen as a crucial condition for achieving ownership in relation to the research process. Furthermore, co-research may thus provide support for efforts to resist being reduced to stigmatising categories by opening up alternative positions with which to identify. At the same

time, co-research can reveal, both to professional and co-researchers, that knowledge about a category that was previously perceived as valid was in fact outdated. One of the aims of co-research can therefore be moving towards mental decolonisation, which attempts to replace any socially harmful consequences of research with emancipatory consequences (cf. Koskinen, 2021, p. 65).

The examples above illustrate the variety of motivations that can drive co-researchers' participation. Cultivating such variety is crucial for practising inclusivity. If the goals of co-research are defined in a manner that avoids assuming the existence of a coherent group (Desmond, 2014, p. 551), but rather enables plurality of goals and sub-projects, co-investigators are then perceived as agentic actors and multidimensional subjects. They are then also likely to be able to build their identities with more flexibility during the research process and to reach out and articulate worlds of experience that are otherwise easily overlooked in research. This flexibility on the positionings that are opened up to them promotes the dissolution of hierarchies and the reification of differences between professional and co-researchers. At the same time, it makes room for the diversity of peer relations among co-researchers. It is important to recognise that, whereas some motives and modes of participation may be empowering on a personal level, they might potentially sharpen the differences among co-researchers and the members from those groups the research concerns. These challenges and advantages regarding peerhood are discussed next.

Addressing the Advantages and Challenges of Peerhood

An assumed peerhood can work both as a significant resource for inclusion and empowerment as well as a reification of difference, which arises from stigmatising positionings that align with institutional categorisations, according to which those who have the same diagnosis or are the clients of the same services would share the same experiences and thus identify with each other. Sometimes, co-researchers perceive themselves as belonging to the same group as their assumed peers, while sometimes differences inhibit the formation of an identity on the basis of a shared group membership (cf. Paerregaard, 2002, p. 320). All this has an impact on which kind of voices, lived experiences and sub-realities are represented and which ones remain obscured or hidden. At its best, peerhood enables the development of reciprocal relations and the constitution of mutual perceptions of the phenomenon under consideration, but it does not necessarily or automatically do so, which is why it needs to be sensitively reflected.

The aim towards inclusivity obliges us researchers to ask to what extent it is possible to assume a shared experience as the basis for co-research (cf. Hastrup & Hervik, 1995). It is also worth asking how deeply or systematically co-researchers should be expected to analyse their positionality and positionings, even if co-researchers' reflections on these would be central to the contextualisation of the knowledge produced by

the research and would enable grasping both shared elements in lived experiences and those that create differences.

The co-researcher, who contributed to the writing of this article, completed her MA degree at the university one year before becoming a co-researcher. During the co-research process, she recognised that she had the closest relations with those members who were interested in getting ahead in their lives through studying, some of whom had joined the community hoping to get support for their studies. Whenever she met other students in the community and talked with them about her own studies and particular area of expertise, she felt really good, almost as 'normal' and capable—an expert in her field—instead of *just* being a mental health recoveree. She also recognised that she rarely identified with members whose motives for joining the community were significantly different. As she analysed the interviews that she had conducted in the community, she found that for many of the student members, similar identification with other students in the community was important. For them, the community felt like a safe environment where their special needs were recognised and met, but at the same time as a place where one could strengthen their identity as a valued student.

She pondered her ability to identify with and reach the experiences of those who had joined the Clubhouse community for other kinds of reasons or who were facing more severe cognitive difficulties than herself at the time of the research. Many members struggled with daily survival. She, however, concluded that even though she had consciously tried to overcome and forget the 'dark' phases and struggles of her life, she could still recall and recognise the feelings linked to that past. Therefore, she felt that it was easier for the interviewed members to talk to her than to professional researchers with no (obvious) mental health history. She saw her own mental health history as a resource that enabled her to become sensitive to marginalised experiences and voices and especially to recognise the meaning of the community for its student members.

In the co-research with the care leavers, the co-researchers were a rather homogeneous group and they connected well as peers. While conducting the interviews among their 'peers,' that is, young adults who have a history of being placed in alternative care by child protection services, the co-researchers to a certain extent might have felt annoyed and amazed, a sort of superiority over the interviewees due to the 'bad choices' they had made. However, as one of the co-researchers described, during the co-research process they stopped assessing people's choices and focused on differences: different stories and choices. Another young co-researcher, in turn, described how they, over the course of the co-research, adopted the position of an expert who was able to provide support and advice to the interviewees.

Due to the multi-layered dynamics of privilege and stigma, it is very challenging to think about the question of peerhood among co-researchers with a history of crime. As a rule, these co-researchers did not identify themselves as being peers or representatives for those who had a similar history of crime. One of them preferred not to be labelled as an expert-by-

experience or a person with a history of crime. This person simply wanted to be seen as ‘anyone else.’ Generally, being trained and employed as experts-by-experience and being hired as co-researchers seemed to elevate these people as more privileged compared to ‘anyone’ with a history of crime; however, because the position of such people with a history of crime is often marginalised and stigmatised in society, in the wider community of experts-by-experience, these people are positioned at the margins. Due to methodological choices of data production through individual diaries, questions about peerhood and shared experiences have not been at the forefront (so far). The situation would have been different if the choice had been to conduct peer interviews, for instance. However, these would become actualised as the project progressed to its analysis stages. The power asymmetries and distrust-related issues that came up were about the co-researchers’ relationships with the professionals in the social and correctional services and the NGOs working in this field.

Based on the above, we argue that it is essential to recognise that peerhood can be both an opportunity and a challenge in co-research. Notably, it is something that cannot be imposed from the outside. Instead of assuming and insisting that co-researchers have a shared identity based on group membership, the task of a professional researcher in co-research is to encourage solutions that allow reflection on multiple and intersectional positionalities and attend to plurality in identity work. Similarly, [Whitney-Mitchell and Evans \(2022, p. 6\)](#) have described the importance of creating an environment in which participants can openly identify each other’s differences and needs, instead of urging similarity based on a shared experience of a chronic illness. In the co-research in the Clubhouse community, one solution was to hold regular, facilitated work counselling for the entire co-research team, in which the co-researchers’ identity challenges and everyone’s strengths and vulnerabilities—including the professional researchers—could be openly expressed and discussed. This helped to ensure feelings of safety and lower the differences between and among professional and co-researchers alike.

Discussion

Co-research is a research orientation i.e. increasingly being adopted, particularly in research with people who belong to marginalised groups or face the threat of stigmatisation (e.g. [Spies et al., 2022](#); [Tanner, 2012](#)). Despite its increasing applications, engaging in co-research requires reflection on several methodological and ethical questions that have so far been underexplored in the methodological literature. In this article, we contributed to this literature by specifically focusing on issues of inclusion in the case of co-researchers who face the need to negotiate institutionally stigmatised positions. With examples from our research projects, we have focused on four themes that capture dynamics in the process of co-research that are crucial for moving towards inclusivity.

These were reflections on the researchers’ positionality, inclusive invitations, co-researchers’ motives and personalised projects, and the advantages and challenges of peerhood. We have illuminated the relevance of these dynamics using the concepts of positionality and positioning. These concepts enable attending to the marginalising effects of intersectional inequalities and the institutionalised force of stigmatisation that many co-researchers are forced to struggle with, on the one hand, and the co-researchers’ agency in resisting the identities forced on them and to adopt multiple and shifting identities on the other.

First, we discussed the importance of reflexivity and open discussion regarding the *researchers’ intersectional positionalities* in relation to the research topic, phenomena and groups of people whom the research concerns. We suggested that such reflexivity builds the grounds for reciprocal relationships and thus for enacting co-research in an ethically sustainable way. Traditionally, the positions of knowers and researchers tend to align with intersecting systems of privilege and oppression such as capitalism, gender, racialisation and ableism. This exclusionary pattern is informed by institutionalised categorisations that produce reductionist identities especially for marginalised people and thus may create obstacles to their participation as co-researchers instead of as objects of knowledge. On the other hand, we want to emphasise that professional researchers’ prerequisites for implementing co-research are not based only on academic competences but also on their lived experiences, social relations and positions within institutional systems. All of these affect the ways researchers use language, assign meanings and avoid the use of jargon in communication with co-researchers (cf. [Beresford, 2019, 38](#); see [Smith, 2005](#)). In sum, we suggest that it is imperative to mutually reflect on the positionalities of both the professional and co-researchers, specifically for the purpose of understanding the intersectional hierarchies that construct differences in their viewpoints and the positions that are available to them (also [Cotterell & Buffel, 2023](#); [Littlechild et al., 2015](#)).

Second, we discussed the importance of *inclusive invitations* and called for careful reflection on how participants are invited and how they may interpret the invitation to participate. We noted that the power of the institutions – both those with which co-researchers are affiliated and the institution of academic research – to either assist in or obstruct the recruitment of co-researchers needs to be recognised. Furthermore, as [Littlechild et al. \(2015\)](#); also [Gjermestad et al., 2023](#) have pointed out, it needs to be acknowledged that quite often, despite intentions to disrupt the inequalities that inform academic research, in practice the ones who end up becoming co-researchers are often privileged due to their intersecting positionalities both societally and within the institutions they are affiliated with, due to, for instance, their educational status or able-bodiedness. To enhance inclusivity in invitations, special attention needs to be given to accessibility in presenting the research and its aims, and in enabling various

forms of participation that are tailored to meet the needs of co-researchers with varying capacities (also [Strnadová et al., 2020](#)).

Third, we discussed co-researchers' *motivations* for participating in the research and the importance of allowing them to create their personalised projects (cf. [James & Buffel, 2022](#); [Mubeen & Tokola, 2021](#)). The examples above illustrate the variety of motives that can drive participation, even within the same co-research project. These may range from a desire to express gratitude to being based on an activist position geared towards enacting change in oppressive and stigmatising institutions. Cultivating such variety is crucial for moving towards inclusivity. Therefore, co-researchers should be invited to consider and reflect on their interests, experience-based knowledge and the positionalities these are linked with. Furthermore, the co-researchers' efforts to reposition (cf. [Fine et al., 2021](#); [Tanner, 2012](#)) themselves within the research process in ways that challenge reductionist and stigmatising assumptions of their positionalities and identities need to be recognised and supported. Viewing the social constitution of identities through the concept of positioning enables this because it is based on the assumption of people's relative agency in negotiating their identities in constantly evolving social practices. These identities are formed in dialogue with, but not submerged to, the restraining impact of intersectional forms of oppression and privilege that co-research with marginalised people often aims to disrupt (cf. [Fine et al., 2021](#)).

Finally, we addressed the *ambivalences connected with peerhood*, that is, relations among co-researchers and between co-researchers and other research participants. We concluded that peerhood is a complex issue, which again requires careful reflection that is sensitive to diversity within presumably homogeneous groups. For instance, co-researchers' attempts at (re)positioning to escape stigmatisation may create a sense of detachment from the groups that they have been presumed to represent and thus challenge the idea of peerhood. To remain sensitive to and support co-researchers' self-determination ([Fine et al., 2021](#)) and the potential shifts in their positionings during the research process, grounding co-research on 'imagined communities' ([Littlechild et al., 2015](#); [Roy, 2012](#)) that overlooks complexities in co-researchers' identities needs to be avoided. However, if the goals of co-research are defined in a manner that avoids assuming the existence of a coherent group ([Desmond, 2014](#), p. 551), but rather enables a plurality of goals and sub-projects, positions are afforded for co-researchers that enable them to be seen as active actors and subjects in a more multidimensional way. This might open up positionings for them that have previously remained unavailable and to reach out and articulate worlds of experience that are otherwise easily overlooked in research. This in turn, promotes the dissolution of traditional power structures and hierarchies between professionals and co-researchers. At the same time, it makes room for the diversity of peer relations between co-investigators and prevents

competition between them. Despite the differences in experiences and identities of co-researchers, it is possible to create a solidarity, which does not assume that everyone's struggles are the same struggles, as noted by [Ahmed \(2004, p. 189\)](#). Instead, solidarity involves commitment, and work, as well as the recognition that even if we do not have the same feelings, or the same lives, or the same bodies, we do live on common ground and can have a common goal that unites various subgoals ([Whitney-Mitchell & Evans, 2022](#), p. 7; also [Beresford, 2013](#), p. 31).

Inclusivity and accessibility at the stage of inviting co-researchers therefore have implications for the whole process, since it sets the stage for the inclusive integration of multiple motives and personalised projects as well as multiple forms of peerhood. This is a prerequisite for power-sharing in co-research and, at its best, it can create a process that is led by co-researchers and their interests. The Living Life to the Fullest Co-research Project (see e.g. [Liddiard et al., 2022](#)) is an inspiring example from the field of critical disability studies of co-research which made space for disabled young people to take control of the research agenda and methods and to define their own roles in the project and finally to co-lead to project ([Liddiard & Watts, 2022](#), p. 29; see also for more details [Whitney-Mitchell & Evans, 2022](#), pp. 6–8). On the other hand, [Gjermestad et al. \(2023\)](#) have problematised the ideal of co-participants exerting control over the research process by noting that especially for people with profound and multiple learning disabilities, this may not be possible. They suggest that inclusive research should instead prioritise the creation of dialogical, close relationships based on trust between co- and professional researchers.⁵ We suggest that the solutions to this dilemma need to be based on careful case-by-case reflection and, when possible, on mutual discussion.

Conclusion

We wish to highlight the importance of reflexivity which focuses on the issues of identity and inclusion from the perspectives of both intersectional positionality and positioning, and which informs all stages of co-research and thus constitutes one of its core practices. Such reflexivity is crucial from the very beginning, as the lack of it in the initial stages has implications throughout the research process: whose voice we speak with and whose motives guide our gaze and fingers on our keyboards ([Hietala et al., 2023](#)).

It is important to recognise that participation in co-research does not dissolve intersectional patterns of privilege and oppression but rather is shaped by it. Nevertheless, co-research can destabilise intersectional hierarchies that are reproduced both societally and within research processes, and thereby make room for positionings that enable gaining of a sense of inclusion. Recognising possibilities for positionings that challenge marginalisation is the first step in creating conducive conditions for this. Therefore, in line with observations made in previous literature (e.g. [Goodley et al., 2022](#);

Littlechild et al., 2015), we maintain that instead of idealising co-research, researchers working with the approach should commit to the constant, reflexive development of research practices that aim to take co-research closer to the ideal of inclusivity.

In addition to the internal power imbalances, there are obviously many inbuilt external structural constraints in academia, which do not ease our efforts to practise inclusion. In our own academic context, these constraints include, for instance, externalised research funding systems, which for several reasons do not easily allow the involvement of co-researchers in the planning stages of the research. In addition, formal ethical review processes do not always recognise the evolving and transformative nature of co-research as a process. Third, the academic publishing business seldom acknowledges the kinds of research outputs that would be more intrinsic deliverables of the co-research projects than peer-reviewed journal articles.⁶ In sum, even if all power asymmetries cannot be demolished or structural constraints overcome, we nevertheless maintain that, for the sake of knowing better together, it is worth taking the steps towards inevitably imperfect inclusion.

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Notes

1. Alongside being a trend in research, the strive towards ‘inclusion’ and ‘citizen participation’ has, during the last decade, served as a wider political project to enhance participatory democracy globally (see WHO, 2008) and in the local Finnish context of our enquiry (see SHM, 2022). However, in research, as in decision-making, service design, and the like, one needs to be aware of the risk of illusory and slogan-like participation in which citizens fulfil their participation duties without an actual contribution (cf. Meriluoto, 2018, pp. 98–99).
2. Dr. Meri Kulmala has led two separate but interrelated research projects, which engaged in co-research with young adults who

were transitioning from different forms of foster care to their independent living. One of these projects “A Child’s Right to a Family: Deinstitutionalization of Child Welfare in Putin’s Russia’ (2016–2020)” was funded by the Academy of Finland (No. 295554), University of Helsinki (ref. 412/51/2015) and Kone Foundation (cd276a and df3277). The other focused on youth wellbeing in the Arctic: ‘Live, Work or Leave? Youth—wellbeing and the viability of (post) extractive Arctic industrial cities in Finland and Russia (2018–2020)’ and was funded by the Academy of Finland and Russian Academy of Science (AKA No. 314471, RFBR No. 1859–11001). See for more details about the research focus and design in for example Kulmala et al., 2021; Kulmala & Fomina, 2022. Kulmala is also involved in a co-research project which engages young adults as co-researchers in the context of peer support, mental health and social media (see <https://sites.utu.fi/tubedu/en/>), funded by the Finnish Research Council (Decision number: 348521).

3. Dr. Outi Hietala worked as the project manager in the Finnish Clubhouse Coalition’s Community “Inclusion & Individual Transitions (OSSI, 2020–2022)” project which applied a co-research design (see <https://suomenklubitalot.fi/the-co-research-project-ossi-and-its-results/>). The project was funded Finnish Funding Centre for Social Welfare and Health Organizations (STEA) (Case number: C7354). The Finnish Clubhouse Model is an evidence-based, recovery-oriented program for adults living with mental health challenges (see <https://suomenklubitalot.fi/finnish-clubhouse-coalition/>). See also Footnote 2 about Kulmala’s mental health related co-research project TUBEDU.
4. Dr. Karoliina Nikula is involved in the “Empowering People Towards Socially Inclusive Society” project, which engages in co-research in the context of marginalisation with trained experts-by-experience (2022–2024). Nikula is involved in particular in the co-research with experts-by-experience with a history of crime (see e.g. Lindström & Toikko, 2021). The project is funded by the Finnish Ministry of Education and Culture (Decision number: OKM/106/523/2021).
5. Guidelines for practical implementation of inclusive research with people with disabilities can be found for example here: <https://commonslibrary.org/what-is-inclusive-research/>.
6. Earlier-referred ‘Living Life to the Fullest’ is, however, an inspiring example of a co-research project which was planned already before funding together with co-researchers and the findings of which have been extensively co-published with co-researchers (see Liddiard et al., 2022).

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