Social Research Between Participation and Action. Theoretical Reflections and Practical Suggestions[*]

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Abstract

Participatory research (PR) has gained particular interest in recent times and has been used in a variety of contexts. As often occurs with terms that become commonly used (i.e. "mainstream"), they often lose their original meaning and their ability to indicate an unambiguous significance. To clarify how the concept of PR is interpreted in the author's objectives, the paper first discusses the term participation in social research, highlighting a taxonomy that allows us to identify different levels of participation in the research activity. The second step – based on Paulo Freire's reflection – is to discuss how and why PR shares with 'action research' the fact that it is performative, due to its characteristic of involving different stakeholders (practitioners and non-professionals), as the co-production of knowledge is not without consequences for people's everyday practices (Bergold & Thomas, 2012). Likewise, the paper emphasizes why PR can enable the contribution of different actors, i.e. the multiple types of stakeholders that could be involved and, particularly, marginalized groups, by allowing them to have a voice. Given the limited scope of the paper, the objective is to underscore the relevance of PR as a pertinent methodology to address the multifaceted challenges posed by a complex society, mainly when different reasons of contention emerge. For this reason, in the last section, it presents an internationally well-known case study, emphasizing the role of participation in the research process: the aim is to propose solutions for promoting social participation as a research methodology even in a conflictual situation.

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1.   Introduction

The relevance that participatory research (PR) has assumed in recent times relates to complex social phenomena, which are different but convergent: the crisis of the systems of representation in mature democracies, on the one hand, and the more macroscopic changes connected to globalization on the other. In this context, PR seems to respond to a twofold need: the first is that of scientific research in the strict sense, the second connects with the context of everyday social relations, to the experience of social life that people have in a hyper-connected and multicultural world.

As will be attempted to show in these pages, in fact, PR on the one hand consists of a set of research tools and methods that require, if properly understood, a change in the relationship between those conducting the research and those who are the 'object' of the research, e.g. the communities being studied. In this sense, PR constitutes a genuine cultural perspective that seeks to question the hierarchical relationship between knowledge and thus the very relationship between science and society.

As Giddens elucidates at the beginning of the century, trust in experts' knowledge is crucial, a knowledge neither neutral nor flawless, according to the science and technology studies (STS) on the relation between science and society. When abstract systems occupy the total extent of the knowledge space, there is a high probability of the erosion of lay knowledge, which is often embodied in traditional practices and beliefs. More recently, studying media interactions, Carpentier (2011) advanced the notion that *participation* is a key factor in comprehending relationships within society, thereby superseding the notion of *interaction* itself.

On the other hand, participation methodology responds more appropriately to the demands of a more complex social reality, in which new instances and needs are explicitly emerging: the pluralization of social subjectivities; the cultural differentiation; the feminist approach; the need to listen to communities, and thus to effectively take into account the other's point of view. As well as the issue of social justice and, more generally, the sustainability (environmental but also social) of policy choices that will have consequences on people's lives. We are thus witnessing a phenomenon in which the very traditional forms of representation in the democratic societies of late modernity are strongly challenged. The articulated and differentiated paradigm

of participatory democracy seeks, in this context, to respond to this crisis: a model in which citizens are called upon to take part in decision-making processes, particularly when fundamental functions such as the common good (commons; Ostrom, 2000) are at stake. A framework in which, according to Habermas (2006), it is possible to bring together the demands of civil society with those of the institutions.

These phenomena have been the subject of theoretical reflection, but they have also inspired a process of reform in decision-making processes (Bonazzi, 2007), aimed at bringing civil society closer to political institutions (Moro, 2009). In that case, the aim is therefore to develop intervention that is effective but also sustainable: this is no different from the purpose expressed in the "Social Labs" model. Whatever the case, these attempts must be regarded as being of major social interest, in that they increase the trust of citizens in political institutions.

The crisis of traditional models of participation is particularly evident in complex, multicultural and multi-ethnic societies, where the difficulty of taking a strictly rationalistic perspective in the conduct of decision-making is increasingly evident (Bertin, 2022).

Participatory research is therefore of twofold interest: to improve the ability of scientific research to understand complex social processes in depth, on the one hand, and as an attempt to address the new social cleavages, starting from recompositing of a connection between people's everyday lives (lifeworld) and institutional action, on the other (Bertin, 2022).

The paper therefore aims to present the constitutive and essential elements of participatory research, starting first with a theoretical reflection of a methodological nature. Initially, the essay defines the basic terms in which the authors describe the development of PR in the broader context of the evolution of social research and thus its socio-cultural origins but also its main fields of application (2). The following part proposes a comparison with the most relevant experiences of participatory research, showing their key factors, challenges and processes: from power relations, to the ethical dimension, from community empowerment, to social change as the ultimate goal (3, 4, 5). The last part focuses on the exploration of one of the fields of application of participatory research, the area of healthcare, with the aim of providing some practical guidance based on the analysis of an eminent PR case (6).

2.   What is participatory research

There is now a wide range of researchers using PR. In a 2020 article a not exhaustive list of 27 frameworks, approaches, and orientations that utilize PR

are identified (Vaughn & Jacquez, 2020). This indicates, on the one hand, a great dynamism associated with this research approach, but on the other hand, the difficulty of identifying processes, methods, and techniques within a rigidly defined and exhaustive framework.

In general, PR consists of processes in which knowledge construction arises from the collaboration between two "worlds": the world of scientific knowledge and the world of practical knowledge, the world of researchers and the world of people who are directly touched/affected by the object/phenomenon being studied (Campbell, 2002). It is defined as participatory, then, given that the research activity involves people who are "experts by experience" not only in the role of informants but as co-researchers. As pointed out by Fals-Borda (2006), one of the original precept of this research approach is "compiling with mutual respect the sum of knowledge from formal academic erudition, informal wisdom and popular experience" (p. 354). All subjects who make up the research team – social scientists and non-social scientists – are called upon to develop a process that leads them to abandon their familiar cognitive routines, interaction practices, and power relations to construct new interpretations of situations and imagine new strategies for coping with them: professional researchers and experts by experience help each other to bracket the already known, to give up on the priority of their own point of view in order to co-construct new knowledge.

The birth of the term "participatory research" can be traced back to North American and Scandinavian development practitioners who were engaged in two projects in Tanzania (Hall, 1975; 1992; 2005; Swantz, 1974)[1]. It is possible to attribute the PR to original theoretical references: the "Northern tradition" that is related to the work of Kurt Lewin (1948) and his proposal for a research cycle composed of inquiry, action, and ongoing evaluation carried out with and by (rather than on and for) marginal groups in society, and the "Southern" tradition, that refers to the work of Paulo Freire and his Pedagogy of the Oppressed whereby vulnerable people are "not as empty vessels and objects of inquiry, but full participants in inquiry, able to determine their own needs in order to improve their own lives" (Macaulay, 2017, p. 256). Feminist

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[1] Specifically, they were Budd L. Hall, who, after doing his doctorate at UCLA in International and Comparative Education with a dissertation on adult education and the development of socialism in Tanzania, was working at the Institute of Adult Education at the University of Dar Es Salaam and engaged in a research project on adult educational needs, and Marja Liisa Swantz, a researcher at the Bureau for Resource and Land Use Productivity at the same university, who was conducting research on women residing in coastal areas.

approaches have also often used a participatory approach, contributing to the spread of PR (see: Cancian, 1992; Mies, 1983).

At the heart of PR is the involvement of subjects that are not social researchers, and that often are part of disadvantaged social groups, in the production of knowledge through their involvement – as far as possible – in all stages of research. In this context the popular knowledge of community members is enhanced, local peoples analytic abilities are supported with the aim to empower communities to plan and undertake sustainable action (Campbell, 2002)[2]. As noted by Fals-Borda (1991): PAR is an "experiential methodology [which] implies the acquisition of serious and reliable knowledge upon which to construct power, or countervailing power, for the poor, oppressed and exploited groups and social classes – the grassroots – and for their authentic organizations and movement" (p. 3).

Originally, academic researchers, but also international organizations such as the World Bank and UNESCO and NGOs, have used PR to work with vulnerable communities and social groups with the aim of generating knowledge useful for transformative action in life contexts and "to force policy changes and to acquire much-needed funding" (Macaulay, 2017, p. 256). In the 1980s, PR spread particularly in the public health sector in North America, leading to the development also of thinking about the characteristics that a rigorous PR carried out with a community must have[3]: Recognizing community as a unit of identity; Building on strengths and resources within the community; Facilitating collaborative partnerships in all phases of the research; Integrating knowledge and action for mutual benefit of all partners; Promoting a co-learning and empowering process that attends to social inequalities; Involving a cyclical and iterative process; Disseminating findings and knowledge gained to all partners (Israel et al., 1998).

Over the years, however, the spread of PR and its use in many areas of society (from organizing in workplaces to community resilience, from education to justice, from urban planning to health, from severe marginality to agriculture, to name a few), not only with marginal and/or vulnerable subjects, led to less

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[2] In practice there are numerous research processes that refer to PR; as non-exhaustive examples we can mention: Participatory Action Research - PAR, (Kemmis & McTaggart, 2005), Cooperative Inquiry (Heron, 1996), Participatory Rural Appraisal - PRA (Chambers, 1994), Participatory Learning and Action (PLA), Participatory Learning Research (Chambers, 2007), Development Leadership Teams in Action - DELTA (Hope & Timmel, 2003), Theater for Development (Kaptani & Yuval-Davis, 2008).

[3] The theme of "community" not only as a place to conduct PR, but as the subject of the research itself is a critical element that will be discussed later in this paper.

attention to methodological rigor. So much so that some researchers: "began to describe their projects as participatory – although in practice many were just talking with communities or running a few extra focus groups" (Macaulay, 2017, p. 257).

It is therefore necessary to provide clarity on what can be defined as PR. Biggs[4] (1989) proposes a taxonomy of participation in social research, ranging from the minimum level of participation to the maximum one. In the first level, which is defined as *contractual*, the involvement of the target population is extremely low, as they are considered only as subjects who can provide resources for the research. In the second one – named *consultative* model – the population is considered as informants, and therefore subjected to interviews at the beginning of the research and, treating Biggs of action-research, they are asked for a final evaluation of the strategies deployed: experts by experience and other stakeholders provide material to which the researcher will be able to attribute meaning. The third level – *collaborative* – involves continuous interaction between researchers and the target population (in the specific case of Biggs, farmers) to build a partnership relationship in the research. In general terms, in this model, researcher identifies, concerning a problem, which subjects are directly involved in it and bear specific interest and expertise (teachers in schools, social workers in social services, health personnel in hospitals, and so on) and involves them in the different stages of research. Lastly, the *collegial* mode provides for the inclusion in the research not only of particular population groups, but of the community itself (e.g., in a school not only teachers, but also students and their families, technical staff, educators, and so on) who share responsibility for the whole process. Probst and Hagmann (2003) produced the table below, in which, from Biggs' taxonomy, the following topic are clarified: the level of participation of actors, the relationship between professional researchers and other actors, and the division/sharing of power in making research decisions.

Thanks to the typology proposed by Biggs, it becomes possible to read all social research according to the interpretative key of "participation", placing different research strategies along a continuum from minimal to maximal participation, passing through intermediate levels. For example, research through biographical interviewing, i.e. that social interaction that: "allows the interviewee to explain himself/herself and to argue, to give, in words, meaning to his/her experience, to re-construct connections and patterns, to evaluate and

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[4] Biggs created this categorization starting from a clint-oriented research in national agricultural research system.

compare as a function of his/her social becoming" (Bichi, 2006, p. 143), presents a tension to give voice to the interviewees thanks to a profound conversion of the gaze by the sociologist (Bourdieu, 1993), which favours and supports the expression of the witnesses' representations. It, however, provides for their participation only at a specific stage of the research process and assigns – in most cases – to the scholar the task of returning their point of view[5].

Table 1. Different modes of participation in research and innovation processes.

Participation Mode	Characteristics in terms of actor involvement and control over the process
Contractual	One actor has sole decision-making power over most of the decisions taken in the process, and can be considered the "owner" of this process. Other actors participate in activities defined by this "owner" by being (formally or informally) "contracted" to provide services and support.
Consultative	Most of the key decisions are kept with one actor, but emphasis is put on consultation and gathering information from other actors, especially for identifying constraints and opportunities, priority setting, and/or evaluation
Collaborative	Different actors collaborate and are put on an equal footing, emphasizing links through an exchange of knowledge, different contributions, and a sharing of decision-making power during the process.
Collegiate	Different actors work together as colleagues or partners. "Ownership" and responsibility are equally distributed among the partners, and decisions are made by agreement or consensus among all actors.

Source: Probst and Hagmann (2003).

Quite the opposite, the characteristic of PR in its most rigorous form is the full collegiality in the entire research process. Co-researchers participate in the production not only of their own subjective knowledge, but together with the social scientists they participate in the definition of the research question (or its redefinition if one already exists posed by the researcher), in the choice of tools to collect information, in the work of reading and interpreting the corpus of material collected on the field, in the elaboration of the strategies of action that derive from the knowledge produced. Thanks this path they develop awareness not only of their own personal conditions of life but also of the social structures within which their biographies are articulated, of the micro-meso-macro linkages, of the possibilities for collective action to which they can give rise. Through a process of mutual cognitive support, people who are experts by experience and stakeholders stimulate the social scientist to step outside his or her already known and established territories, to develop – where necessary – new theoretical constructs and apply new interpretive categories to the phenomena studied. Reciprocally, social scientists support the empowerment of local people who become more aware of their condition and the links to

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[5] Except when backtalk is used (Lanzara, 1993), which is "a discussion of the collected text involving the social actors involved, narrator and researcher" (Bichi, 2000, p. 393).

social structures, and can take action to introduce transformative actions. Vaughn and Jacquez (2020) identify 5 levels of participation (inform, consult, involve, collaborate and empower): obviously, "research tools and methods can vary in the degree of participation" (p. 6).

Cancian (1993) points out that PR is characterized by the presence of four elements: 1. participation in the research by members of the community under study; 2. awareness raising and training of participants; 3. inclusion of popular knowledge; and 4. political action. However, it is noticeable that many PRs fail to achieve this full form of collaboration throughout the research process, for various reasons, such as lack of time, conditions of co-researchers that do not always allow their full inclusion (for example, people with intellectual disabilities or those placed in the penal circuit), constraints related to the context, and so on.

PR represents, more than an actual methodology, "an orientation to inquiry" (Reason & Bradbury, 2008), in which more or less wide space in knowledge production is given to people expert by experience and stakeholders.

PR is also embodied in research practices that are not necessarily new compared to traditional and established techniques. But that use (also) the latter in a new way: "the difference between participatory and conventional methodologies lies not so much in the theories that inform these methodological frameworks or even in the methods they use, but in who defines the research problems and who generates, analyzes, represents, owns, and acts on the information sought" (Cornwall & Jewkes, 1995, p. 1668).

3. The keywords of participatory research

One of the main issues related to PR is that of power. This peculiar approach, in fact, by involving as much as possible in the different stages of research those who are usually considered the population under study (moreover, in many cases, belonging to groups lacking power because they are marginal and disadvantaged) challenges inequality within the research process, as well as in the wider society (Cancian, 1993, p. 94). As underlined by Gutiérrez (2016) "emancipation is a process which can only be achieved from within, by the active participation of the oppressed in the very process of developing the intellectual resources to inform their practice in order to overcome domination" (p. 61).

PR identifies two agents of change in society: those belonging to exploited groups and researchers from outside. Recognizing the power relations within which research activity is situated (Bourdieu, 1993), PR tries to activate a process in which the conventional subject/object relationship is challenged and

rebalanced. Different actors, each with their own knowledge, techniques, and experience, starting from a position of power dissimilarity, collaborate to produce new forms of knowledge, but also new relationships. The heart of PR lies "on how and by whom is the research question formulated and by and for whom are research findings used" (Cornwall & Jewkes, 1995, p. 1668).

Indeed, the concept of "conscientization" coined by Freire (1967) appears central to PR. Education as a practice of freedom entails in fact a pedagogy of the oppressed people, that is, not a pedagogy for them, but of them, directed toward activating a permanent reflection, capable of producing self-awareness and an awareness of the relationship with the world in a transformative perspective of the world itself. PR has strong political overtones, in that it is directed at cultivating a critical awareness on the part of those involved, directed toward social change.

According to Maguire (1987), PR produces social change at three levels: individual, community, and societal. At the individual level, it develops confidence and critical consciousness. PR produces change in the local community as it strengthens relationships among the stakeholders involved and improves living conditions. Finally, it is transformative for society as a whole in that it is not geared toward adapting people to oppressive power structures (Brown & Tandon, 1983), but intends to accompany social change through the modification of power structures: "some scholars argue that 'real' participatory research must include actions that radically reduce inequality and produce 'social transformation' " (Cancian, 1993, p. 94). Although some scholars theorize this structural transformative dimension as necessary in PR, it should be emphasized that it is not always possible to achieve this goal, and thus a PR can be considered successful when it has fostered at least individual and community empowerment (Park, 1978).

In general, Selener (1997) states that the effectiveness of PR should be assessed by the extent to which members of a group increase their options for concrete actions, their autonomy in using these options, and their ability to deliberate on action choices.

The emphasis on action could lead to confusing PR with Action Research. Although they are very close and often use similar paths, PR emphasizes the collaborative dimension throughout the whole research, of which action is only a part. Action research, moreover, is not necessarily based on a collaborative approach. As Kemmis and McTaggart (2005, p. 563) point out: "not all theorists of action research place this emphasis on collaboration". Moreover, although Whyte (1991) contributed to the popularization of the term "Participative Action Research", it should be noted that his work has been concentrated in organizational settings, where an asymmetry of role is maintained between the professional researcher, who usually works as a consultant, and the workers,

who play a marginal role in the different stages of the research process. As already highlighted, PR instead requires the real, active, and empowering participation of individuals belonging to the community (whether physical, a community of practice, etc.) that is both the object and the subject of the study, as evidenced by the diverse forms that this approach assumes in fieldwork (Refer to Boyd (2014) for an overview of the different forms that Participatory Research can take).A second fundamental concept, closely related to power, is, of course, that of participation. It has already been pointed out that it can be present in different intensities and at different moments of the research: what PR requires, however, is the enhancement of the knowledge of the people on whom the research is carried out. Undoubtedly there is a collaborative aspect to PR, which makes it very close, though not completely overlapping, with collaborative research (Reason, 1988; Heron, 1996), a path in which a group of co-researchers interested in a certain topic use their experience to produce knowledge by activating a process of constant dialectic between experience and reflection on it. The fundamental difference between the two modes of research is that PR involves democratization of the research method, in that – in its most rigorous form – all decisions about the research process must be made by the group consisting of researchers and co-researchers, whereas collaborative research involves democratization of the content, which is achieved cooperatively through a defined process (constant referral between practice and reflection on it)[6].

In PR practice, it is possible to find different intensities of participation at different stages of the process: it may be the case that at the beginning people with whom the social scientists intend to collaborate have little or no confidence in their own implicit knowledge and expect the researcher to guide them. The latter can then support participants in activities that promote their reflexivity and/or technical/methodological skills, to activate them in increasingly collegial processes of mutual learning and consciously shared choice-making. In this perspective, professional researchers assume the role of facilitators of processes of empowerment of co-researchers, who become active and purposeful subjects in research (Chambers, 1992). "Ideally, academic-community partnerships will work together to make choices that will best meet the needs of both the research and those involved in the research. These choices might lead to highly participatory strategies for some steps in the research process, and more researcher-driven strategies at others" (Vaughn & Jacquez, 2020, p. 5)

PR requires working with "community": this concept, however, is extremely complex both in theoretical terms and in its practical expression. It is often assumed that the community exists as a distinct, cohesive entity with clear

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[6] Practice research, for example, moves in this direction (Uggerhøj, 2011).

boundaries in which there is sharing with respect to the definition of problems and needs (Schwartz, 1981). In actual experience, however, when approaching a community this homogeneity is rarely present. Often we are faced with groups of people with different interests when not at odds or in conflict, with defined and established power relations, sometimes with problems or absence of communication between groups. In this context, several questions arise for the researcher: who to involve as co-researchers, how to manage power differences, and what strategies to use to ensure that all voices are recognized and valued. Obviously, the choices made will affect the PR results. It can argued that in some cases the "community", rather than a subject to work with, is one of the goals of the PR, particularly when it is embedded in community development projects.

4. Some challenges

The first challenge to be faced in carrying out a PR is the involvement of co-researchers: it cannot be assumed, in fact, that people who are experts by experience are strongly interested in participating, or that they have the possibilities and the time to do it. Indeed, it should not be forgotten that PR requires a long time and intense and constant commitment, which finds justification in engagement with the topic or in the prospect of benefits to the community or group of which one is a part (Stone, 1992). "Unless a definite political commitment to working with the powerless is part of the process, those who are relatively inaccessible, unorganized and fragmented can easily be left out" (Cornwall & Jewkes, 1995, p. 1673).

It should also be borne in mind that the idea of democracy invoked by researchers to stimulate participation might not be shared by those they wish to involve: it can happen that the need of participation is a desire of the researcher rather than of the eventual participants. In addition, participation may be limited to a consultative or collaborative dimension, especially within research projects that already have a well-defined structure, within institutions or "vertical programs" that limit the freedom (and therefore indeterminacy) that instead characterizes collegial participation.

An important question concerns which groups to involve in the research: different groups have in fact developed different knowledge and understanding with respect to the topic under study. Simplifying, one could distinguish at least two types of knowledge concerning a topic: the "professional" types (e.g., in a PR on homelessness the knowledge of social workers, educators, street workers, volunteers, and so on) and the knowledge of those who experience firsthand the condition (for example, the homeless). How to involve groups that are

extremely marginalized or have difficulty expressing themselves? If the decision is made to involve everyone, how to create symmetry in the relationships between subjects who in their daily lives are service providers (sometimes subjects who act simultaneously aid and control) and the users of these same services? How do we ensure the retention of all subjects throughout the whole research? What happens, at the end of the research, to the relationship that was formed between the participants and the researcher(s), how to manage the conclusion of the relationship with the most vulnerable subjects?

PR often engages individuals from fragile, marginal, oppressed groups as co-researchers: therefore, there is a need to ensure a safe environment in which they can feel comfortable and protected in expressing their ideas and confronting each other. "It is not a question of creating a conflict-free space, but rather of ensuring that the conflicts that are revealed can be jointly discussed; that they can either be solved or, at least, accepted as different positions; and that a certain level of conflict tolerance is achieved" (Bergold & Thomas, 2012, p. 196). Moreover, the research group can only function if a relationship of trust is created among the members: this requires an effort on everyone's part to get to know and accommodate diversity and the investment of some time. Emotional aspects are very important, and those who accompany PR processes must not only have the sensitivity to grasp them, but also skills to handle them constructively.

The path of PR is by definition open-ended: the research team must therefore be able to manage indeterminacy, but together also expectations that may be different among participants and may change during the process, sometimes leading to conflict situations and/or exits from the research group.

Co-researchers are then asked to acquire some skills about the research methodology that they do not have: "for example, linguistic competencies, the ability to proceed systematically in the research process, communicative skills in dealing with groups, etc. Professional researchers should offer training courses and workshops on these thematic areas and impart these skills in their everyday dealings with the co-researchers" (Bergold & Thomas, 2012, p. 204). In this sense, PR also becomes an opportunity for capacity building for experts by experience.

Throughout the PR process, reflexivity[7] must be activated: it is required that each member of the group activates it with respect to his or her own life experience and the interpretative schemes he or she uses to attribute meaning

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[7] Reflexivity refers to "The regular exercise of the mental ability, shared by all (normal) people, to consider themselves in relation to their (social) contexts and vice versa" (Archer, 2007, p. 4).

to it, but also concerning the signifying processes of others and the possibility of co-constructing shared meanings.

An important challenge of PR refers to the management of power: as explained, PR is based on the assumption that co-researchers are experts in their own lives and therefore able to cooperate in the production of knowledge, (Campbell, 2002; David, 2002; Wahab, 2003) thus eliminating the relationship of power dissymmetry with respect to the researcher. However, it is appropriate to bring the issue of power to the forefront, asking who decides where to carry out a PR, who selects the participants and based on what criteria, how and how much researchers actually make their knowledge (both methodological and with respect to the subject matter) available for the empowerment of groups, whether there is an effective transfer of power from the researcher to the co-researchers and not rather from the researcher to their leaders (David, 2002; Pain & Francis, 2003). It should be kept in mind that "power is not unidirectional or hierarchical but dynamic, complex and a process of negotiation" (Bourke, 2009, p. 468).

PR has seen a steady growth in interest and use in recent years to the extent that it has become a kind of catch-all concept, and this presents a major challenge, as PR methods can also be used "to secure funding, to co-opt local people into the agendas of others or to justify short-cut research within a top-down process" (Cornwall & Jewkes, 1995, p. 1668), to support some special interests within the community, or to guide its choices. To avoid distortions, it is necessary to keep in mind what the underlying characteristic of PR is, namely, the co-building of the research process through a partnership between researchers and members of a community, stakeholders, and experts by experience (Jagosh et al., 2012), with a capacitating and emancipatory purpose.

Through the transparency of the research process and the explication of the choices made, the researcher will make visible the actual level and spaces of participation guaranteed in the specific research.

5. The PR process

Although PR presents itself as indeterminate in its making, as it is always subject to co-design and consequently to greater factors of instability, it is possible to identify a process model (Ripamonti & Boniforti, 2020) as a guide to the implementation of collaborative-based research that is divided into six stages.

In the first one, the purpose of the PR needs to be clearly spelled out: that is, it is necessary to be explicit and transparent with respect to the purposes for which that particular type of action is put in place. Since carrying out a PR does

not mean (only) using participatory techniques, but activating a long and arduous process of co-design and co-realization, it needs to be made very clear that the cognitive and action goals will be pursued with a sufficiently long time frame and that it is only possible to indicate a direction concerning the results, which nevertheless remain undefined.

The second phase involves the identification and involvement of stakeholders, that is, people who, because they are interested in the issue/problem on which the PR intends to act, will be able to collaborate as co-researchers. Among the various techniques that have been tested, one that can be employed at this stage is the Synergy Model (Brush et al., 2011).

PR has proven its effectiveness predominantly in local contexts, in bounded communities: it is, therefore, necessary to define in the research team (thus formed by professional researchers and co-researchers) the boundaries within which PR and the resulting transformative action can move. Extent and sustainability are crucial in this type of research, to avoid negative effects such as disillusionment and anger.

The next phase requires reaching a common definition of the research object, which takes into account the different perspectives, and a design of the research in the field. Training actions are often envisaged in this phase to provide non-professionals in social research with the methodological knowledge that allows them to make informed choices. In this phase, traditional or innovative and creative tools can be used. Several innovative techniques can support participant engagement at this stage of Participatory Research, such as: Forum Theatre (Brandt & Grunnet, 2000), Fictional Inquiry (Dindler & Iversen, 2007) and Storytelling Group (Kankainen et al., 2011)

The shared analysis of what was collected through the field phase will lead to shared knowledge about the object and the making of transformative action choices. There is also a wide range of experiences and techniques documented in the literature concerning the participatory and collaborative analysis of collected materials (data and narratives). By way of example, one can cite the five-phase process described by Jackson (2008) for analyzing qualitative data, used in three projects involving marginalized women in Ontario, Canada, as well as the three-step analysis process employed by Vasquez Guzman and Heintzman (2024) within the framework of the Cervical Cancer Project

However, it is important to underline that, for the participants, participation in the PR project itself is transformative, as through it they acquire new knowledge, activate a process of individual and relational reflexivity, and if they are marginal (or stigmatized) subjects they are recognized in a new role, with new skills at the service of the common good.

6. Participatory research in health: suggestions from the experience

One of the eminent fields of application of participatory research is health services. The reason for this interest lies, on the one hand, in the complexity of dimensions that are involved in the concept of health and wellbeing (multidimensionality); on the other hand, in the need to take into account a plurality of actors and stakeholders who take part in the construction of health processes.

Since the 1970s, in fact, various participatory instruments have developed that, as pointed out by Giarelli et al. (2020), have concerned all the actors of the care process citizens (as users of services and/or patients); health professionals, with their different internal articulations (doctors, specialists, nursing professions, social workers...) and the related health organizations; finally, the extended social contest (with specific reference to the issues of tight public budgets, but also to the issues of systemic and epistemic violence, to which some marginalized social groups are subjected; Spivak, 1988; Fricker 2007).

The need to consider all types of social actors and their contexts implies that it is essential to refer to different dimensions: the *micro* level (the patient and his engagement in the care process by the health professional); the *meso* level (the health and representative organizations); the *macro* level (the extended social context). The most remarkable experiences of participation in healthcare involve both the engagement of the patient's knowledge, with the aim of empowerment (patient engagement); and more complex processes of co-production of care processes. In this field, a model developed by Trisha Greenhalgh and colleagues among others, Community-Based Participatory Research (CBPR) (Greenhalgh et al., 2016), which constitutes a participatory research process with the result of profoundly changing the relationship between actors, has become established.

One of the most significant cases concerns what happened in Australia, concerning a general practice facility run by the University of Queensland and the local health authority (Queensland Health). Thus, a small group of academics and health leaders were charged with saving the service, which, among other things, provided health care to a vulnerable and disadvantaged community. The service was going through a deep crisis, making huge financial losses (about $800,000 per year), so much so that it was destined for closure. The damage would have been manifold for the local community, which was losing an essential service, and for the academic institution, which was seeing the failure of a project it had provided for many years, resulting in further reputational damage.

The initial working group opted for an innovative approach of value co-creation, intended to generate benefits for all end users of the service. The

objective was therefore not the traditional target of 'quality improvement', which according to the proponents was too narrowly focused on 'customer satisfaction' alone, but rather on the generation of shared well-being. This value co-creation approach, therefore, did not foresee defining a goal and then later involving the stakeholders to achieve it. However, to define the objectives together with the stakeholders (co-construction/ co-creation approach), putting the patients' experience at the centre and not the resources and constraints of the healthcare organization with the aim of finding shared solutions (Ramaswamy & Ozcan, 2014).

The first step, therefore, was to identify and then invite all stakeholders (service users, primary and secondary care providers, funders, politicians and administrative staff) to participate in the proposal co-creation process. A sub-group of stakeholders selected for their vision and organizational flexibility was then tasked with putting forward a proposal to be submitted to the funders. This initial step, therefore, although concretely proposed by a small group, was shared with all participants: all had the opportunity to indicate objectives, priorities and possible operational solutions. The main objectives identified were: to extend and integrate local general medicine, specialist and other primary care services and to restore financial equilibrium within three years.

The proposed model (defined as 'Primary Care 'Beacon' Practice') envisaged the creation of a new entity: a non-profit organization with management autonomy with a board of directors made up of representatives of the two promoting institutions (University and Queensland Health), but also a local MP (who collected community input), an administrative director and an independent chairperson with expertise in primary care reform. The board was, at this point joined by two other technical bodies (one strictly for health and one for research to evaluate the project as it progressed). A number of working groups were then organized with representatives of the various interests, with the aim of seeking innovative solutions (on topics such as chronic diseases, co-morbidity, transport, freedom of access, etc.). The solutions identified by the individual working group were not proposed to the other groups until a consensus had been reached.

It should be emphasised at in this regard that the practice of sharing (co-construction and consensus) enabled the individual participants to develop skills that were not necessarily already present or had remained unexpressed in previous governance contexts: interpersonal skills, leadership (making themselves promoters of solutions in their communities of origin), diversity, the centrality of the person, and the propensity to change. In other words, the participatory approach made it possible to shift the cultural setting of stakeholders in depth, allowing the effect on individual communities (doctors, chronic patients, the elderly, the funders themselves) to be multiplied.

The participatory practice through regular meetings was not without its moments of conflict, but all participants were explicitly required to find a consensual solution.

To support the working group meetings, it was important that the supporting group of university researchers provided data, even in real time, for decision-making: clinical statistics, specialist scientific literature, budgets, previous staff and patient satisfaction surveys. This method made it possible to make decisions, to propose and select proposals based on evidence, rather than on participants' prior knowledge.

In the end, the different groups put forward an operational proposal centered on the different distribution of primary care tasks throughout the local community, which was the subject of an ongoing evaluation by the university research team. It is important to emphasize that the evaluation tools were also discussed and aimed at the shared objectives of the project.

By the end of three years, the practice was no longer at a financial loss, but more significantly, several improvements had been recorded: in particular, a new capacity to deal with patients with complex illnesses had developed, thanks to an integrated healthcare approach between different specialties and skills. The success was so remarkable that the state of Queensland decided to extend the model ('beacon') to its entire territory. It should also be noted that the issues on which the model has focused most are related, for example, to the health of refugees, but also to maternity care, i.e. new practices but also more traditional medical specialties.

The analysis of the project results, as described in the literature (Greenhalgh et al., 2016), does not conceal the many difficulties encountered in the process. There were several authentic conflicts mainly related to traditional governance roles and processes, economic resources, and professional cultures. However, conflict has not generated impasses, rather it has been an engine of change, helping to achieve some decisive consensus-building outcomes (the creation of a common vision; the orientation towards value creation for each partner; flexible and results-focused leadership; recognition of different stakeholder cultures).

7. Conclusions

The multifaceted nature of participatory social research, as outlined in this article and exemplified in sociological research in the field of health, has the potential to reveal numerous avenues for investigation and a wealth of insights, particularly if the concept of participation is expanded to encompass all knowledge production processes, whether scientific or practical.

The following discussion will commence with a review of the literature's terminology used to describe, as far as possible, the interweaving of relationships existing from epistemological foundations to the practice of research and action. These relationships are to be found between those who coordinate, manage, facilitate or conduct the research (the scientist, observer, expert or professional researcher) and those who are considered witnesses, experts or competent members (the case, object or co-researcher). As has been demonstrated, a classification of forms of PR can be constructed from the level of inclusion of the members of the populations involved in the research process: whether they are communities, collectivity or samples of a larger population, from individual members or groups of them. It is evident that when an inclusive process is considered, the involvement of 'others' in the process determines the primacy of one party over the other. However, as previously noted, PR constitutes a perspective that in fact questions the hierarchical relationship between different forms of knowledge. This is evident in a variety of contexts, including the decision-making processes within a community, the development of scientific theories, and the pursuit of social transformation or the cultivation of critical consciousness among the involved parties. The construction of knowledge is predicated on a plurality of subjects who, to varying degrees and with different statuses attributed to them, contribute procedurally to the result.

Furthermore, the contribution of each party is almost necessarily recoverable in its entirety only ex post, and therefore not projectable ex ante, except in its broad outlines. Indeed, the relationships cultivated *in itinere* serve to direct the ongoing trajectory of the research process and the progression of the research endeavours. Indeed, the power relations and ethical implications discussed here are applicable to all parties throughout the entire research process, necessitating continuous adjustment in connection with the relational balances established in the situation. In order to surmount the more evident issues of power differential that were manifest in the situation, there are numerous strategies that may be employed. One such strategy is the practice of peer research, which was conceptualised as a means of compensating for existing inequalities. However, it should be noted that this approach was also regarded as a multifaceted strategy. The primary objectives of this strategy included gaining access to voices that were otherwise marginalised, activating a process of participant empowerment, leveraging the added value of lived experience, collecting more accurate data, and activating communities. This strategy also had the potential to benefit peer researchers.

In conclusion, this paper establishes a foundation for future research by distinguishing between the various trending levels of balancing of the status attributed to the various parties involved. It further differentiates between

'participatory research' and 'participate research', indicating the latter as the expression used to denote the tendency towards recognised equivalence of status between the parties involved. This equivalence can be demonstrated through the mutual recognition of the various forms of knowledge.

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