

## **PARTICIPATORY COMMUNICATION AND CITIZEN SOCIAL SCIENCE LESSONS LEARNED AND NEW ETHICAL AND POLITICAL CHALLENGES**

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### **ABSTRACT**

This paper contributes to the discussion around the epistemic foundations of citizen social science (CSS) by drawing from participatory communication. We argue that the latter's long history reflecting on the ethical and political challenges that emerge from its dialogical perspective to empowerment and social change, could enhance the nascent CSS concept. In establishing that relation we also explore how CSS can further develop participatory communication. To that end we look into YouCount, an ongoing CSS project that, from its inception, has understood dialogical communication as inextricably linked to the research process. Our main findings are that: (i) old challenges related to the instrumental use of participatory communication are relevant

to CSS; (ii) CSS offers a space to transcend entrenched narratives around knowledge production and communication that hindered the participatory communication paradigm; and, (iii) CSS has the potential to expand participatory communication's scope through its use of information and communication technologies (ICTs) but faces important challenges related to research control of personal data and disclosure.

#### **KEYWORDS**

Citizen social science; participatory communication, science communication, ethics, ICT's, YouCount Projec

## **1. INTRODUCTION**

Citizen participation in scientific activities is not new and has in fact gone under different names that depend on the academic discipline, geopolitics, culture and modes of engagement (Eitzel et al., 2017). While the term 'citizen science' was coined in 1989 in an article published in the *MIT Technology Review* (Hacklay et al., 2021) the number of scientific articles using the 'citizen science' label have experienced a notable increase over the past 20 or so years particularly those presenting results from data collection and classification based on digital platforms and pertaining to the natural sciences (Kullenberg & Kasperowski, 2016). Indeed, the digital revolution has made it possible for citizens to contribute observations at a scale that would have been unthinkable before digital tools became widely available<sup>1</sup>. However, participation in scientific activities is not restricted to data-gathering activities, with citizen scientists increasingly involved in other stages of the research process (Resnik, et al., 2015) and the focus on participatory and co-creative methods has increased in recent years (Senabre et al., 2021). This has created new channels for communication between science and society which is why citizen science can be thought of as a form of science communication (Wagenknecht et al., 2021).

Citizen science has developed from different traditions, which are not mutually exclusive and can actually coexist for different purposes as is shown in this article. One such approach is based on the work developed by Bonney (1996) in the context of their work on ornithology. Here citizen science is a research method that enables large scale studies by engaging citizen scientists in mapping and monitoring activities. A different approach developed from the work of Irwin (1995) in the context of their studies on sustainable development. This tradition understands citizen science as a way of democratising social science through dialogue to serve the needs of society and empower citizens. A more recent approach sees citizen science as a form of activism, particularly around environmental issues (Kasperowski et al. 2023).

<sup>1</sup> Typical examples are bird watching for natural conservation or classifying galaxies. See Galaxy Zoo: <https://www.zooniverse.org/projects/zookeeperfor>

While citizen science has received wide attention and is well established in the natural sciences (Ballard et al., 2017; Frigeiro et al., 2021; McKinley et al., 2017; Merenlender et al., 2016; Sauermann et al., 2020), the numbers of studies are substantially less in social sciences, and there is little evidence of how citizen science in social science research might work in practice (Heiss & Matthes, 2017; Tauginienè et al., 2020). This may be due to the fact that social sciences already have a rich participatory tradition (Albert et al., 2021). Nevertheless, over the past years, citizen social science (CSS) has made its way into the academic discussion in Europe in part due to the availability of funding from the European Union (EU) to projects that explore citizen science in social sciences and the humanities (SSH). Funding often stems from the Science with and for Society Program (SwafS), which recognizes a heightened policy interest in engaging society, embraces ideal high-level aims of a participatory democracy and recognizes the need to assess the societal, democratic and economic costs and benefits of engagement (EC, 2016).

This paper builds on Albert et al. (2021) who explore the ways in which the roles of citizens and researchers play out in social sciences and identify Participatory Action Research (PAR) among the epistemic foundations of citizen social science. We add to what has already been said about the legacy of participatory approaches to CSS by drawing from a school that contributes a communication perspective: Participatory Communication (PC). This school of thought has its roots in the work of Latin American communication scholars and, like PAR, was influenced by Paulo Freire's notions of dialogic communication and praxis (Freire, 1996).

The difference between PAR and PC is that while the former emphasizes collaborative participation of trained researchers and local communities in producing knowledge directly relevant to the stakeholder community (Coghlan & Brydon-Miller, 2014), the latter understands participation as dialogue (Dagron, 2008) and focuses on how participants in collaborative research processes express and communicate their own knowledge (Cornish & Dunn, 2009). In other words in PC, communication, through dialogue is inextricably linked to the research process itself. PAR and PC are not opposites and share the values of promoting participation, empowerment, and social change and like Irwin's dialogical and democratic approach to citizen science draw from the participatory tradition that emerged in the Global South, and internationally, during the 1970's.

However, we suggest that the legacy of PC is understudied in the literature on the emerging CSS concept and that the former's history reflecting on the ethical and political challenges that emerge from its dialogic perspective to empowerment and social change could enhance the latter. Moreover, if as mentioned earlier, citizen science can be thought of as a form of science communication (Wagenknecht et al., 2021) then CSS with its aim of empowering participants and producing social change can be thought of as a form of participatory communication. In suggesting this relation, we also aim to understand how CSS can further develop PC.

The paper is structured as follows. First, we present the PC concept through its core epistemology highlighting its similarities with CSS and how the former can enhance the latter. The section also identifies the ethical and political challenges that have emerged from the practice of PC that can be relevant to CSS. Second, we present an ongoing citizen social science project: “YouCount - Empowering youth and co-creating social innovations and policymaking through youth-focused citizen social science”. The authors of this paper participate in the project which is an interesting case to reflect on the link between PC and CSS because it reflects current trends in EU science policy and, because from its inception, participation in the project has been understood as dialogue. In a third section we discuss the YouCount project in the light of PC’s ethical and political challenges and identify new ones, specific to CSS. In the fifth section we present our main conclusions, highlighting the need for systemic change in the research ecosystems in which CSS develops in order for it to bring into play its full potential, for citizen empowerment and social change.

## 2. PARTICIPATORY COMMUNICATION

The participatory paradigm is closely linked to the work developed by Brazilian pedagogue Paulo Freire in the 1970’s (Huesca, 2008; Jacobson, 1993; Morris, 2003; Roman, 2005). Drawing from his experience with adult education programmes, Freire highlighted the power of education as a political tool for stimulating the consciousness of oppressed people’s situation and for organizing action to improve it. In *Pedagogy of the Oppressed* (1996<sup>2</sup>) Freire develops two key notions that underpin PC: Dialogical communication and praxis.

The notion of dialogical communication captures Freire’s criticism of the narrative character of teacher-student relationships in which students are treated as empty containers to be filled with information deposited by teachers: “...in the banking concept of education, knowledge is a gift bestowed by those who consider themselves knowledgeable upon those whom they consider to know nothing...[it] negates education and knowledge as a process of inquiry” (Freire, 1996, p. 53). Instead the Brazilian pedagogue called for a problem-posing education in which students become critical co-researchers in dialogue with teachers and are jointly responsible for a process in which all learn.

Freire (1996) attaches great importance to how educators approach dialogue arguing that educational or political plans fail because those who design them only consider their own reality without asking themselves if it connects with the reality of those who those plans are designed for. In his words: “It is not our role to speak to people about our own view of the world, nor to attempt to impose our view on

<sup>2</sup> The book was published in Portuguese in 1968 and in English in 1970. The 1996 edition was published by Penguin.

them, but rather to dialogue with people about their view and ours” (Freire, 1996, p. 77). Finally, for Freire (1996), dialogical communication results in transformation through the notion of praxis, based on what he identifies as the two parts of a word: reflection and action.

Freire’s work was published in the context of Cold War propaganda and the prevalence of quantitative, positivist social science, both of which permeated mass communication research and practice (Wahl-Jorgensen, 2013). Indeed, mass communication in that period was closely tied to the idea of ‘development’ and “assigned the role of disseminating the ‘right’ knowledge” (Waisbord, 2005, p. 83). The approach was based on a knowledge-deficit assumption addressed by massive injections of information (Dagron & Tufte, 2006). The mass media were seen as “magic multipliers able to accelerate and magnify the benefits of development” (Fair & Shah, 1997, p. 4); communication was sender and media centric and attached great importance to communication technology, using general marketing techniques (Servaes & Lie, 2014). Indeed, mass media campaigns were very often designed by advertising firms with no knowledge of health, agriculture or development problems in general (Dagron, 2011). Overall it was seen to impose the interests of dominant elites contributing to reinforce the status quo (Huesca, 2008).

Freire’s dialogical approach had an enormous influence on communication scholars from Latin America, where PC practices can be traced back to the early 20<sup>th</sup> Century but had not developed conceptually (Barranquero, 2017). The Latin American perspective turned away early on from positivist notions of objectivity and neutrality acknowledging that researchers’ values permeated their inquiry (Beltran, 1976, p. 125) and stressed the uniqueness of each community, arguing that while development processes may have universal characteristics, the solutions would always be local (Rifkin, 1996). The rejection of a communication model based on information transfer suggested that “human understanding was forged through intersubjective co-activity” (Dervin & Huesca, 1999, p. 174) that transformed both individual and common understanding and resulted in a re-constructed reality (Beltran, 1976). Communication was therefore the “permanent process in which people discover, elaborate reinvent and make knowledge theirs” (Kaplún, 1998, p. 50).

From this perspective, PC can be understood as a methodology, defined by Coghlan & Gaya (2014) as the philosophical approach to how knowledge is produced. Indeed, PC helped to include previously excluded knowledge in knowledge production and diffusion processes traditionally reserved for academics and universities, thereby setting the basis for integrating academia more directly with practice (Barranquero, 2011). It also outlined the intersection between communication and participatory methodologies, recognizing the importance of politics around knowledge production (Lewin & Patterson, 2012). This approach

sees a role for researchers as political actors, facilitators and communicators working in placed-based development processes that lead to change (Roman, 2005). Scholars working with PC understand communication as a process and as an end, where the end is community building (Dagron, 2011; Kaplún, 1998; Waisbord, 2015) and use information dissemination as tools or methods that are always part of a wider dialogue (Barranquero, 2006; Dagron, 2008; Dagron, 2011; Servaes, 2008; Servaes & Lie, 2014). The participative approach to communication has been analysed as a way to advance democratic participation (Deetz, 1999).

In sum, PC in research means that “research participants, local citizens, or those traditionally referred to as ‘the researched’ are able to participate in creating and expressing their own knowledge and, in so doing, empower themselves to effect social, political, economic, and cultural change that is appropriate to them” (Cornish & Dunn, 2009, p. 666). This shows a connection with the democratic tradition in citizen science developed from the work of Irwin. It also fits with the broad definition of citizen social science as an approach using participatory methods to address social concerns (Albert, 2021). Moreover, PC’s understanding of dialogue as a process where reality is transformed through inter-subjectivity is particularly relevant for citizen social science’s aim of producing social change. In contrast with citizen science approaches that have reflected on the roles played by citizen scientists (Eitzel et al., 2017) PC problematizes the role of researchers in dialogical process (facilitators, communicators, translators...); their positionality in the research process and their relation to non-academic participants (i.e. Freire’s teacher-student relationships). Moreover, PC’s pedagogical essence connects with the science education component of CSS projects.

Over the years, scholars working with PC approaches have captured important ethical and political challenges that, for the purpose of this paper, we group around three sub-headings: (i) instrumental uses of PC; (ii) beyond entrenched narratives; and (iii) the challenge of scope.

#### *(i) Instrumental uses of PC*

When PC is used in too instrumental terms its ultimate objective of empowerment and social change is lost and can tarnish the expectations created among participants when they realise that there is a gap between discourse and practice. This happens when certain concepts are used in policy without facilitating their implementation. From the 1980’s onward, international organisations like the World Bank and many governments had incorporated participation and dialogue into their language and agendas without a change in practice. When PC was institutionalised, it became just a set of techniques (Leal, 2007) divested of its philosophical approach to knowledge creation and communication. This challenge around the politics of knowledge production is nicely captured by Rogers (2005) when he argues that when PC is used as a mere technique without considering its

epistemological and ontological assumptions, contradictions emerge leading to “participatory diffusion” or semantic confusion.

Indeed, despite the rhetoric, in practice governments and funding organisations were not really supportive of participatory approaches since a true commitment to civic participation would have meant a serious reconsideration of the way funding was organised, how bureaucracies’ function and their distrust and impatience with participatory approaches (Waisbord, 2005). This because by PC is, by definition, a slow process that often does not have predetermined outcomes but rather goals that are negotiated in dialogue with stakeholders continuously (Lennie & Tachi, 2013). PC is about long-term processes that need time to build trust among participants and are at odds with the results-oriented approaches required by funding bodies where researchers need to evidence impact within the project’s time frame (Cornish & Dunn, 2009; Lewin & Patterson, 2012). Furthermore, success in participatory communication is likely to be in the subjective intentional order since it will more often be judged by the protagonists of the research process itself (White, 1999).

### *(ii) Beyond entrenched narratives*

The historical context in which PC emerged, namely the Cold War era and the use of the mass media to impose the interests and world view of the United States in Latin America (Huesca, 2008; Servaes, 1999), led to the development of entrenched narratives where mass communication was related to the powerful and participatory communication to the powerless; the former the evil, the latter the good (Barranquero, 2015). Clemencia Rodriguez (2001) moved beyond the entrenched narrative drawing from radical democracy theory to coin the ‘citizens media’ concept. Citizens media redirects the focus of analysis from a comparison between community or alternative media with the mass media, to the more complex cultural and social processes behind citizen’s re-appropriation of the media that tell the stories about and shape their local communities. This approach, that breaks the passive acceptance of identities (the powerless) imposed by others (the powerful) has important ethical implications in that it recognizes agency in the ‘powerless’ and offers a more nuanced understanding of power relations. Indeed Rodriguez (2009) describes them as not monolithic but constantly shifting and changing at the community and individual levels.

In terms of research approaches, a study of projects funded by the World Bank (Inagaki, 2007), found that the epistemological assumptions of researchers tend to spill over to the methodological approach used, with a clear association between quantitative methods and mass communication strategies and qualitative methods and dialogical communication strategies. Hence, Lennie & Tacchi (2013) highlighted the need for an appropriate combination of qualitative and quantitative techniques, complementary approaches and triangulation, and above all, recognition that different approaches are suitable for different issues and purposes.

*(iii) The challenge of scope*

The explosion of smartphones and the social media signalled a new momentum for PC, through large scale movements using them for dissent like the Arab Spring or the Yosoy132 movement in Mexico (Barranquero, 2015; Hemer & Tufte, 2016) and raising new questions around what the blurring of boundaries between small and mass media mean for PC's traditionally narrower scope (Waisbord, 2005). Indeed, the Internet and social media have broken the confines of the physical space for engaging in dialogical communication. Virtual communities offer a new space for participant-driven production and communication of research (Thompson, 2008) and can lead to new knowledge co-creation (Canto-Farachala & Larrea, 2022). They have been shown to host reflection processes (Kantanen, Manninen, & Kontkanen, 2014); create social capital (Daniel et al., 2003) and provoke social change (Fernández-Sánchez & Valverde-Berrocoso, 2014). Moreover, when combined with in-person communication they can bring research communities working in different contexts closer (Canto-Farachala & Estensoro, 2020). On the downside dialogical communication in virtual environments needs to be facilitated (Canto-Farachala, 2021); ICT's have become a gold mine for researchers looking for big data (Rodriguez et al., 2014) and that they can perpetuate exclusion through the digital divide (Cullen, 2001).

**3. THE YOUCOUNT PROJECT**

The YouCount project (hereinafter also referred to as YouCount) is funded under the Horizon 2020 SwafS programme and runs from 2021 to 2023. It involves 11 partners across 9 European countries working on 10 different case studies that include young people (aged 13-29 years) as young citizen scientists (YCS), some of whom are experiencing situations that put them at risk of social exclusion.

YouCount's objective is to generate new knowledge and innovations that empower and increase social inclusion of youth across Europe through youth citizen social science (Y-CSS). The project includes four main interlinked sub-studies that have the following aims: (i) to develop a conceptual and methodological framework for Y-CSS; (ii) try out this framework through a multiple case study consisting of ten local case projects in nine countries across Europe; (iii) use the multiple case study to evaluate the process and outcomes of Y-CSS and to assess the costs, benefits and impact of the Y-CSS activities; and (v) maximise social and scientific impact through widespread scaling up and continuity. In order to develop new knowledge and innovations, each sub-study comprises a convergent parallel design, utilising a mixed-methods design (see Figure 1).



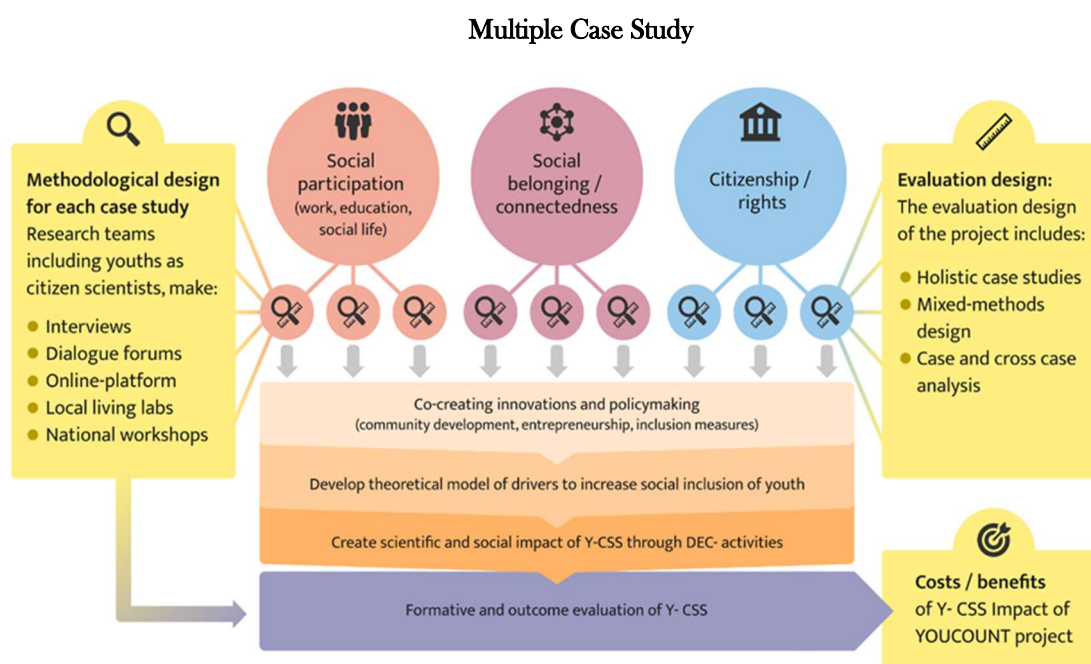


Figure 1. YouCount: Multiple Case Study Design. Source: Adapted from YouCount's Document of Action.

In the project, 'social inclusion' is considered as a broad, multi-dimensional and multi-level concept, and as both a process and goal. Overall, social inclusion refers to "citizens' chances to access the same opportunities and resources to participate in economic, social, political, and cultural life within a given society" (Butkeviciene et al., 2021, p12). The 10 cases highlight three dimensions of social inclusion: (i) social participation (including employability); (ii) social belonging and connectedness; and (iii) citizenship and civic participation. YouCount seeks to explore meanings of 'social inclusion' and its positive drivers from young people's perspectives by working co-creatively with them (Ridley et al., 2022). As mentioned earlier, while the project addresses the circumstances of youths who are most at risk of social exclusion, it also engages a broad range of young people from local areas and university settings. This is meant to avoid stigmatising particular groups by labelling them as 'disadvantaged youths' and to stimulate dialogue and social networking across groups of young people. In doing so, the project acknowledges that young people are a diverse group of citizens, and many possess important social resources for peer support and local innovation and development.

The project is currently in its last phase of the implementation period and has started the data analysis (broadly understood) together with dissemination activities. To what extent and how the project manages to realise its aspirations is yet to be analysed and will be described in future scientific publications. We will hereby thus

focus on the project’s visions and design to illustrate how it integrates principles of participatory communication even if under the CSS name.

YouCount reflects the policy turn in the EU mentioned earlier, that sees CS as a pathway to democratise science and a potential promising scientific approach for involving citizens to develop new knowledge and new or improved solutions to increase social inclusion (Reiersen, 2022). PC is reflected in the project’s vision<sup>3</sup> “to strengthen the transformative and participatory aspects of citizen science and social science, by enabling citizen participation in all facets, reaching out for a more egalitarian way of conducting science...” YouCount also incorporates the principles of Open Science and Responsible Research and Innovation (RRI) aiming for scientific practices that are open to the world, diverse, inclusive, flexible, and reflexive (EC, 2016). This brings participatory communication forward from the start of the project through Responsible Research Communication (RRC), a dialogical approach that combines RRI and PC principles (Canto-Farachala, 2019). Moreover, PC is also reflected in the societal vision of the project that aims to “contribute to create inclusive and innovative societies for European youths and to empower them in promoting active citizenship and a just and equitable future, particularly for youths with disadvantages.”

Furthermore, YouCount incorporates a participatory approach to science communication by defining co-creative Y-CSS as: “...a form of participatory social research that involves youths as citizens working together with social scientists creating and communicating new knowledge...it means striving for youth participation and involvement in all aspects of the research design, data collection, data analysis, writing up and scientific communication”. Yet, the project also combines several participation levels (Hakley, 2018; Richardson, 2014) where this co-creative approach is combined with lower levels of participation, where a larger group of youths in the community or targeted organisations participate in local dialogue forums and/or in YouCount App study, which we will elaborate on below. An important implication of this approach is that the project does not include a moral view on participation where co-creation is inevitably regarded as the highest standard.

This approach is visible in YouCount’s communication plan (DEC Plan) where dialogical communication is conceived of as an inextricable part of the research process and its outcomes (Canto-Farachala et al., 2021). Three spaces are identified: a micro space where dialogical communication develops in the local cases; a meso space where dialogical communication gains scale through hybrid approaches supported by ITCs; and a mass space where only one-way communication is possible. Potential indicators are shown in the column on the right (Figure 2).

<sup>3</sup> Quotes in this section are from See <https://www.youcountproject.eu/about-the-project/about-the-youcount-project/concept-and-methodology>

### The Overall Approach to Maximising Impact in YouCount

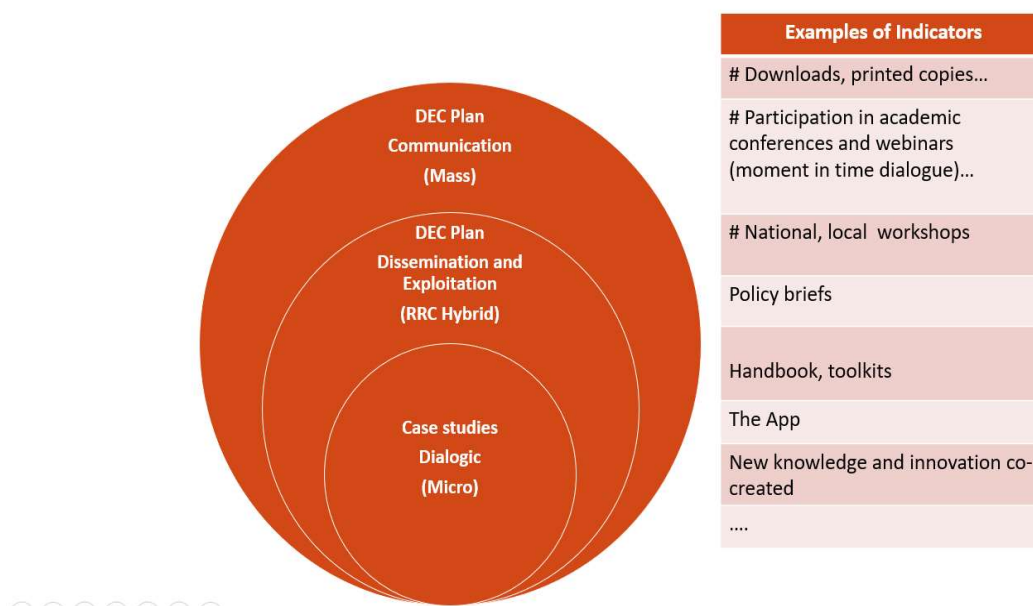


Figure 2. YouCount: Communication Approach. Source: Adapted from Canto-Farachala et al. (2021)

The case studies work in a flexible way at the local level with youths and stakeholders in so-called living labs, defined as dialogical agoras where democratic dialogue is connected to practice that can be changed through dialogue (Gustavsen, 2008). The dialogical agoras use different kinds of qualitative methods such as ethnography, interviews and creative methods and also aim to engage youths that are further away from science in dialogue to gather rich, in-depth knowledge about social inclusion experiences from young people's perspectives (Ridley et al., 2022). These dialogical agoras or living labs are pragmatically used as an umbrella term for innovation forums, using data and insights provided by the participating young citizen scientists to co-create policymaking and innovations that lead to social change.

Young citizen scientists are involved in both the design and use of qualitative and quantitative methods, for example surveys and in developing creative methods for sharing and communicating the project with local stakeholders. They have also been involved in the development, pilot, use and evaluation of an application for smartphones and computer (PC) – named the YouCount App Toolkit (hereinafter the YouCount App or the App). Their participation is an important aspect of the dialogical processes integrated in the research process. Although the App is but one among other methods and tools actively involving young citizen scientists, in this paper we focus our attention on the process of obtaining its approval by the ethics

committees and data protection authorities. This because of its relevance to the overall discussion around old and new ethical and political challenges, namely the potential that CSS offers to expand the scope of participation -understood as dialogue- through ICTs.

Indeed, the piloting of the App was approved by the supervisory authorities as part of co-design process with a smaller group of young citizen scientists in the research teams. Yet, when the time came to launch the App to young people in general, the supervisory authorities in Norway requested a Data Protection Impact Assessment (DPIA). The App includes data collection opportunities of relevance for the ethics and policy discussion below: GIS data (place based - interactive map); Quantitative (spots, survey data); Qualitative (commentary text fields); Images (e.g., pictures); Actions (own /others, e.g., participation in activities); and Interactions (e.g., comments/reactions to each other/networking. Participants were informed that their home address should not be spotted. The App differs from ordinary social media platforms by not allowing hidden personal messages or use of negative emojis (only hearts). The App has been used locally in the cases since June 2021 and will be running until the project ends (Ridley., et al., 2022).

In practice, the supervisory ethics committees, and data protection authorities relatively easily accepted the use of the qualitative and quantitative methods as these are common research practices. However, the use of the App created many challenges in the institutional domains of data protection and ethics. These challenges were to a large extent related to the ambitions of open CSS which challenged the traditional supervisory institutions' interpretation and practices with respect to General Data Protection Regulations (GDPR) and research ethics. The approval process was also complicated and delayed by lack of competence and guidelines on local and national levels concerning CS and the use of such open digital tools, and enforced by the researcher team's struggles to provide sufficient and targeted information that suited the logic and needs of the supervisory institutions due to the novelty of such research.

The request for a Data Protection Impact Assessment (DPIA)<sup>4</sup>, unveiled the challenges related to open CSS due to its research focus and more personal character. For instance, the Norwegian supervisory authorities assessed that “the planned processing of personal data will involve a relatively high risk to the rights and freedoms of the data subjects”. The concerns were related to: Processing special categories of personal data (sensitive information), or information of a more personal character; Processing of personal data on a large scale, both in terms of sample size, amount of information (variables), duration and regularity; Combining data sets (e.g., different purposes and/or different data controllers) in a way that exceeds the data subject's reasonable expectations; Processing of personal data about vulnerable individuals, and partly minors.

<sup>4</sup> General Data Protection Regulation art. 35 nr. 1.

The DPIA was approved after two months with the following consequences for the project: (i) a long, formal, and extensive written consent form integrated in the app; (ii), limitation in the use of the App to local case participants; (iii), a system for parental consent for minors or exclusion of opportunities to participate for those under 16/18 years when parental consent was too difficult to achieve (iv) extended guidelines to require use of pseudonyms, no identifiable pictures of self or others and (v) procedures for safe data transfer/storage and use of an App moderator group to prevent possible personal or improper content (already planned for, but more underlined).

While the DPIA to some extent contributed to strengthen data protection considerations and technical/organisations measures to safeguard participants, the consequences described above resulted in the tendency of excluding the youngest participants from the study, and to reduced possibilities for open personal engagement in science through digital tools, compared to CS in natural sciences. Moreover, the GDPR assessment process displayed that several data related to youths' observations of social inclusion opportunities were 'automatically' considered as sensitive data (for example, spots or comments related to religious meeting places as important for social belonging). Social data was thus often regarded as more personal and riskier, especially the open commentary fields in the app and the interactive functions. The need for control and disclosure curtailed its use for open dialogical communication. The innovative purposes of the project were also regarded as out of the scope for the formal assessments, keeping a strict distinction between research and innovation, which conflicts with EU science policy and funding for the YouCount project

Another tension was between the ideal of citizen-generated data in CSS and the project's focus on young citizen scientists as equal partners or contributions/active agents in co-creative processes versus the traditional focus on participants as 'objects for science' and request for high research control of the data from the researchers. More overarching policy and ethical considerations concerning the underlining understanding of youth, sensitive data or vulnerability as more nuanced individual traits or power relations, were regarded as outside the scope for the DPIA assessment because the university contract with the supervisory authorities only included legal data protection issues and not ethical considerations. This institutional separation of data protection and ethics approval assessments, especially related to CSS (as social sciences and not health research) hampered the possibility of finding a good balance between the needs for disclosure and risk mitigation strategies with current policy aiming to provide youth and marginalised citizens to have a say in policy and science.

The challenges of more nuanced considerations of responsible citizen engagement were also enforced by a tendency to "automatically" frame youths as 'children' (and not adolescents) or as 'vulnerable' instead of being adult participants.

While the researchers found the written consent letter as too long and bureaucratic for the participating youth groups, this could not be changed as they required some standard formalities concerning GDPR. Broader and common ethics concerns and considerations were thus disconnected from GDPR, and the ethical epistemology behind GDPR legislation was left out. This GDPR logic also seemed to reinforce a paternalistic ethics where the user- involvement perspectives were downplayed to a larger extent than before. The many different and multi-level actors following the new GDPR in combination with the novelty of the App tool, also complicated the process, increased workload and delayed the processes which reduced the possibilities of using the App during the implementation period.

#### 4. DISCUSSION

The experiences in the YouCount project reflect both old challenges in participatory communication and new ones, given its novel character and its combination of different traditions and approaches to citizen science. In what follows we discuss two sets of ethical and political challenges that resonate with the challenges faced by participatory communication (the science policy environment and integrating different methodological approaches) and highlight one that we identify as emerging specifically in CSS (the use of open ICTs to expand the participation scope).

##### *The science policy environment*

If the discourse around CSS is not accompanied by a change in practice, CSS runs the risk of being used in instrumental terms like participatory communication before it, without delivering social change or empowering those who agree to contribute their time, efforts and hopes to engage in co-creative processes aimed at addressing a social challenge that directly affects them. Indeed, citizen science has been launched in a specific science policy context by research funding institutions (i.e. of EU or national research councils) as an important open science strategy and as a way to support participatory democracy and enhance science- society collaboration in research and innovation. These trends are reflected in the frequent use of the terms “co-creative research”, citizen or user-involved or generated science, “inclusive science” or “participatory research” as positive research and innovation qualities.

However, the conditions that are necessary for CSS to develop are still not fully incorporated in institutional structures and cultures in research funding organisations. Indeed, building trusting relationships that enable co-creative practices takes time and resources. An important message from the participating youths in the YouCount project is that trust and safety are core elements for

inclusive science and real participatory or co-creative research and innovation (Norvoll, Plassnig & Brattbakk, 2022). However, the time needed to build safe spaces does not often fit with the timing of traditional funding approaches nor are the resources necessary to adequately facilitate communication with different publics at different levels and in different spaces fully recognized in the budget.

Moreover, we can see from the first experiences in YouCount that facilitating inclusive science and co-creation and participation on European/project level with youth with disadvantages can be challenging due to language barriers and more. Even if this does not apply to all youths, participation doesn't come easy for those often further away from science and for those with most social participation challenges. To succeed with the ambition of inclusive science, there is a need among others: for extra resources to organise and facilitate meetings, follow up and support the youths in finding a social voice for their experiences and more. There is also a need to secure a budget for travel and participation in meetings as well as safety needs. In sum, CSS needs to be planned and allocated enough resources to succeed. If CSS is to contribute to strengthen participatory democracy, the aforementioned considerations need to be recognised, structured and funded adequately by policymakers and research funding institutions.

Finally, while the EU is promoting the need for more inclusive science and finding ways to involve a broader scope of citizens in science and innovations, the possibilities, and necessary rewards or regulations for this kind of research, are not sufficiently reflected in current legal regulations. While the risks of open science and use of open ICT tools must be acknowledged and safeguarded, there are nonetheless many bureaucratic obstacles that make it easier for researchers to leave out social groups further away from science to avoid work overload and challenges with progression in time-restricted projects. Indeed, there is a one-sided focus on vulnerability that runs counter to the voices for underrepresented groups who get left out of emancipatory /democratic representation. The challenge of CSS being used in instrument terms like participatory communication before it remains relevant.

### *Integrating different methodological approaches*

As discussed in the previous section, YouCount uses a mixed-methods design in the case studies in line with Lennie & Tacchi (2013) who call for an appropriate combination of qualitative and quantitative techniques in communication projects stressing that different approaches are suitable for different issues and purposes in development. Moreover, while participatory processes are meant to draw from the practical expertise of non-academic participants, professional researchers may also have scientific or topic expertise that is of interest or can benefit them. These different epistemological worlds or knowledge bases do not necessarily need to conflict (even if they may) or serve as instrumental communication. They can

combine in a positive way in CSS. Similarly, enhancing knowledge and learning from the researchers' expertise is not necessarily enforcing negative power balances. This connects with the finding by Rodriguez (2021) that power relations are not monolithic but fluid and changing.

Indeed, an important prerequisite for participation as described by the youth citizen scientists in the YouCount project is for example to receive sufficient information about the project and to be given enough time to learn about the topic. This is crucial for being able to participate in meaningful and empowering ways. Instead of thinking that professional researchers are there to fill a knowledge gap, more nuanced and interactive approaches to democratic processes can be possible. While trying to avoid instrumental approaches, there is a need to acknowledge that knowledge exchange unfolds in mutual and complex ways. This complexity should also be integrated in CSS. While avoiding the knowledge deficit approach prevalent in traditional science communication and citizen science, the overarching ambitions of science contributing to society through its scientific and expert knowledge may also be integrated and used in and CSS to a greater extent without trading its democratic ideals.

#### *The use of ICTs to expand the participation scope*

ICTs are an important tool in citizen science and in CSS they offer the potential of expanding the traditional scope of participatory approaches by enabling large-scale studies of social phenomena like social inclusion. YouCount pursued the development of an App to be used by YCS for three main reasons: (i) as a way of gaining more knowledge of young peoples' s' views and experiences with social inclusion through their mapping and monitoring of their social world; (ii) to develop more knowledge of suitable and inclusive ICT tools and how to use them in data collection with youths with disadvantages and from multicultural backgrounds; and (iii) to explore the possibilities of expanding the scope of participatory approaches that normally take place in small groups or use so-called small media providing opportunities for new knowledge creation through its interactive function. The first point is related to the CS tradition that uses digital tools for mapping and monitoring purposes (Bonney, 1996); the second addresses the challenge of increasing the digital divide (Cullen, 2001) and the third one follows Heiss & Matthes (2017) who highlight the potential for knowledge production by working collaboratively with citizens to enable access to both large-scale data and "hidden" data collected in situ.

The full experience with the App is yet to be analysed and described. However, the development and approval process show that collecting data in the natural sciences and collecting data in the social sciences has different implications. Indeed, the authorization processes with the supervisory data protection authorities show that the use of an open CSS app is experienced as riskier compared to traditional research and more unpredictable since the researchers are less in control of the data



collection process and the data are openly visible for others. It reveals limited and insufficient legislation and ethical guidelines for this kind of open interactive CSS research. Therefore a key institutional barrier for the use of ITC's in CSS emerges, calling for further development of data protection legislation and research ethics, and a stronger integration of data protection and ethics assessments on institutional level.

While digital technologies can offer new possibilities for social sciences, their use and design may be more difficult due to the complexity of recording social observations and ethical issues, not least when it comes to studies of vulnerable populations. Overall, more knowledge is needed to explore the actual risks /danger by using such open devices for sharing of comments and interactions. These challenges became evident in the approval processes of the YouCount App which demonstrate the need for more competence, guidelines and institutional changes in policy and supervisory institutions concerning CSS and use of open digital tools as elaborated on in the next section.

While recognising the variety and complexity of these issues, the DPIA processes revealed some interesting challenges related to open Y-CSS and communication. Indeed, more knowledge is needed to explore the actual risks /danger by using such open devices for sharing of comments and interactions and on how to facilitate safe and trusting dialogues about social challenges in app devices. This seems also to be enforced by the new GDPR and ethical approval structures. First, the processes displayed the challenges of finding a good balance in practise between the EU open science policy of "as open as possible and as closed as necessary" in CSS, and tensions between the EU policy of open science and GDPR, not at least concerning young people.

## 5. CONCLUSIONS

This paper builds on Albert et al., (2021) who identify PAR among the epistemic foundations of CSS by drawing from PC, an understudied approach in CSS's emerging literature. Our aim was to identify lessons on ethical and political challenges and identify new ones. To that end we analysed YouCount, an ongoing CSS project funded by the Horizon 2020 programme that, from its design draws from participatory communication to incorporate a dialogical approach to research.

From our analysis we find that some key ethical and political challenges identified by scholars working in participatory communication are still relevant and others are new. For instance, the ideal high level aims of participatory democracy without a change in practice, can end up providing nothing really valuable or meaningful for participants and can even encourage situations of exploitation. In this context, the clash between the needs of a truly participatory citizen social science project and the conditions attached to funding in terms of budget and time frames that do not allow

enough time for building trust or safe spaces for participating citizens needs to be addressed. Without this, CSS is prey to instrumental uses like participatory communication before it with negative consequences for the high ideals of a strengthened participatory democracy.

In terms of the entrenched narratives that characterised the history of participatory communication, we find through YouCount that while this challenge remains true, CSS can actually integrate and combine different approaches in all stages of the research process to address a societal challenge that is jointly perceived as important for researchers, funding institutions, public administrations and citizens themselves. However, since the project is still ongoing it is difficult to determine whether it will lead to significant changes in terms of social inclusion for the young citizen scientists involved.

However, one dimension that does emerge as a novel challenge is the use of ICT devices to expand the scope of participation due to their implications for research control of personal data and disclosure. Indeed, traditional institutions like the supervisory data protection authorities and ethics committees experience these devices as more risky which unveils a gap between the science policy environment and institutional structures, cultures and competences and raises the question of how to balance the principle of “as open as possible and disclosed as necessary” in open CSS promoted by the EU. There is a need to strengthen citizen based and inclusive science through a stronger institutional integration of data protection and ethics, and more competence and guidelines for the use of such CSS devices. More research in this regard is necessary and many questions remain unanswered like: Is it possible to facilitate open communication about social issues with the public in an open interactive app in a safe, dialogical and meaningful way? Does a strong focus on technological devices downplay broader dialogical processes and relationships? Are ICT tools really able to foster engagement, science- society relations and emancipatory processes? How can this be done and combined with other methods in the best ways?

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