

Biomedicine, deliberative democracy and childhood: The limits of children and young people's involvement in health research

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ENG Abstract: In recent years, children and young people (CYP) have been increasingly included in patient and public involvement (PPI) in health research and innovation. Such initiatives intend to give a voice to CYP in such matters. Given that it is debated whether PPI in health care fosters the values of participation, public discussion and decision making put forward by deliberative democracy, this article examines three sets of challenges concerning the involvement of CYP by focusing on age biases. After describing some existing initiatives, the paper critically examines why CYP are involved, how the CYP group is constituted and then investigates the moral status of CYP in biomedical settings. It shows that the rationale for involving CYP in PPI is mainly top-down and adult-centric, thereby questioning the authentic participation in decision making. It also suggests that to ensure democratic inclusion, the CYP group should be constituted by considering both age and politics. Lastly, the article indicates that, despite the increasing recognition of child-specific rights, the sociocultural norms and power dynamics in pediatrics undermine their moral status and challenge political equality. These three sets of considerations offer a preliminary theoretical contribution toward improving democratic legitimacy and representation of CYP in health research and innovation.

Keywords: Public and patient involvement, Health research, Deliberative democracy, Childhood.

ENG **Biomedicina, democracia deliberativa e infancia: los límites de la participación de niños y jóvenes en la investigación sanitaria**

Resumen: En los últimos años, los niños/as y jóvenes (NYJ) han sido involucrados cada vez más en iniciativas de participación pública y del paciente (PPP) en investigación e innovación sanitarias. Tales iniciativas están pensadas para dar voz a los NYJ en estos asuntos. Dado que se debate si la intervención ciudadana en ámbito sanitario fomenta los valores de participación, debate público y toma de decisiones que propone la democracia deliberativa, este artículo examina tres conjuntos de retos relativos a la implicación de los niños y jóvenes centrándose en los prejuicios de edad. Tras describir algunas iniciativas existentes, este artículo examina críticamente por qué se involucran a los NYJ, cómo se constituye el grupo de NYJ y, a continuación, investiga el estatus moral de los NYJ en entornos biomédicos. En primer lugar, muestra que la justificación de la participación de los NYJ es principalmente descendente y adultocéntrica, por lo tanto, plantea cuestiones sobre la posibilidad de colaboración auténtica en la toma de decisiones. También sugiere que, para garantizar la inclusión democrática, el grupo de los NYJ debería constituirse teniendo en cuenta tanto la edad como las consideraciones políticas. Por último, indica que, a pesar del creciente reconocimiento de los derechos específicos de los niños, las normas socioculturales y la dinámica de poder en pediatría vulneran su estatus moral y desafían la igualdad política. Estos tres conjuntos de consideraciones ofrecen una contribución teórica preliminar para impulsar la legitimidad democrática y la representación de los NYJ en la investigación y la innovación sanitarias.

Palabras clave: Participación pública y del paciente, investigación sanitaria, democracia deliberativa, infancia

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Summary: Children and young people advisory groups in medical research and innovation. The rationale of patient and public involvement with children and young people in research and innovation. The constitution of the children and young people group. The moral status of children and young people in biomedical settings. Conclusion. References.

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Patient and public involvement (PPI) refers to the active involvement of lay people and/or patients in health-care-related matters (e.g., biomedical research, health policy and healthcare management). Despite the increasing international implementation of PPI initiatives, the concept and practices of PPI generate certain confusion and are questioned from an ethical standpoint due to their vagueness and heterogeneity (Ives et al., 2011; McCoy et al., 2019; Rose, 2014; Warsh, 2014a). Moreover, the exact meaning and reasons for adopting PPI vary from context to context and have changed over time (Barello et al., 2014). For instance, PPI can refer to the government's concern in educating patients so they can take an informed and active role in improving care, or it can emphasize the participants' desire to improve trust relationships and patient empowerment in their health journey (Barello et al., 2014; Dresser, 2016). In the United Kingdom, a clear distinction is made between PPI, 'patient engagement' and 'participation' in health research. Engagement relates to raising awareness and sharing knowledge with the public, PPI is understood as active collaboration and co-creation, and participation refers to people taking part in research as volunteers (Warsh, 2014a; NIHR, 2022). Issues regarding patients' rights are strictly regulated in most Western countries. In compliance with the Oviedo Convention (1997), most national laws on patient autonomy specify rights and obligations regarding the informed consent procedure (e.g., French Law 2002-303, of March 4th, 2002, on Patients' Rights and the Quality of the Health System; Spanish Law 41/2002, of November 14th, 2002, regulating patient autonomy and the rights and obligations regarding clinical information and documentation). Legislation concerning PPI, however, refers to the right to participate in health policy but does not provide guidance on actual forms of implementation (e.g., the aforementioned French Law 2002-303 refers to '*démocratie sanitaire*' [health democracy], while Spanish Law 33/2011 of October 4th, refers to '*derecho a la participación*' [the right to participate]).

The scientific and grey literature provide two main reasons for justifying the implementation of PPI: to enhance the quality, relevance, or effectiveness of services; and to provide democratic legitimacy and representation in health care (Warsh, 2014a). Since 2000, children and young people (CYP) have been increasingly involved in PPI initiatives. The main reason given for involving CYP has been the desire to give them a voice in health care, clinical trials and research and thereby address their underrepresentation (Gaillard et al., 2018; Tsang et al., 2020). Given that it has been questioned whether PPI in general fosters the democratic values of participation, public discussion and decision making put forward by deliberative democracy (Warsh, 2014a), this article examines three sets of challenges concerning CYP involvement by focusing on age biases. CYP involvement requires special attention because one of the defining concepts of deliberative democracy is the citizens' ability to participate freely and equally in decision making (Elster, 1998). However, the common conception of childhood presents it as different, if not inferior, to adulthood in terms of autonomy and rationality. After describing a number of the existing initiatives, I critically examine the reasons for involving CYP and the constitution of CYP groups and then investigate the moral status of CYP in biomedical settings.

Children and young people advisory groups in medical research and innovation

Among the various initiatives introduced to involve CYP in health care (Sellars et al., 2021), Kids Impacting Disease Through Science (KIDS) and Young People's Advisory Groups (YPAGs) are particularly well-known internationally. Although they have somewhat different scopes (KIDS is essentially a scientific council on medical innovation and YPAGs specializes in health research), they often have double designations and share the same scopes. The first YPAG, which has since merged into the GenerationR Alliance national network, was created in 2006 in the UK by the National Institute for Health Research and was followed by the Scottish Children's Research Network in 2008; by the KidsCan Vancouver, Canada, in 2013; and by Kids Barcelona and Kids France, in 2015¹. There are currently approximately 30 groups in various European and African countries, the United States, Canada and Japan². A number of the YPAGs concentrate on

¹ See: GenerationR YPAG (<http://generationr.org.uk>), Scottish Clinical Research Network (<https://generationr.org.uk/scotcrn-ypag/>), KidsCan (<https://www.micyrn.ca/ypag>), Kids Barcelona (<https://www.kidsbarcelona.org/en/kids-barcelona>), Kids France (<https://ripps-pediatrics.org/kids-france/>) [Retrieved March 19, 2024].

² For more detailed information on the different groups, or chapters, see: <https://www.icanresearch.org/kids-chapters> [Retrieved March 19, 2024].

particular medical specialties such as ophthalmology and mental health³. The global collaboration known as the International Children's Advisory Network was established in 2014, sponsored by pharmaceutical companies, government initiatives, non-profit organizations and research institutions, among others⁴. More recently, the European Medicines Agency promoted the European Young Persons Advisory Group Network⁵. YPAG/KIDS groups are affiliated or collaborate in various ways with organizations such as Conect4Children, the Pediatric Clinical Research Infrastructure Network and the European Network of Excellence for Paediatric Research and Rare Diseases Europe⁶.

Each YPAG/KIDS group was established by following different strategies. They work mainly on projects of local interest while receiving international recognition from regulators and pharmaceutical companies. YPAG/KIDS groups are composed of 10 to 30 members, generally aged 8 to 19 years, although certain groups include older young adults up to the age of 21 years, whereas others start inclusion at 12 years of age. Members might have chronic conditions or disabilities, experience with clinical research or just a general interest in research and science. Certain groups organize training of varying length and content, whereas others do not (Tsang et al., 2020). The groups meet regularly at times when CYP are more easily available, namely on weekends, evenings and school holidays. CYP are involved in age-adapted projects, including through games, videos and quizzes. Although concerns have been raised about the "lack of academic literature to guide researchers on how to set up, run and evaluate the impact of such groups" (Pavarini et al. 2019, p. 743), recent studies have begun to fill this gap (Chan et al., 2020) and provide information to produce globally standardized training protocols (Tsang et al., 2020). Guidelines and toolkits are also available on some of the groups' websites⁷.

These groups' methodologies, conditions and rationale for involvement vary considerably. Three main models are taken as standard: the consultative, the collaborative, and the child-led. In the consultative model, CYP are consulted on specific issues to improve services, policy and product development –e.g., a website–. In the collaborative model, CYP can participate in decision-making. In the child-led approach, CYP lead, organize and conduct specific tasks; for example, focus groups and interviews, with the help of adults (Chan et al., 2020). Existing initiatives do not necessarily follow these models strictly. For example, CYP are involved to a greater or lesser extent depending on the specific case, according to the assigned activities. On a case-by-case basis, CYP might act as consultants in revising the informed consent, shape research methodology, and even coauthor papers; however, there is generally no discussion in the literature on why CYP take certain roles rather than others and the implications of assuming different roles (Chan et al., 2020).

The rationale of patient and public involvement with children and young people in research and innovation

Unlike the history and organization modes of PPI initiatives with adults, CYP are included in PPI mainly due to top-down initiatives. YPAGs and KIDS, for example, are initiated and organized by adults *for* CYP and not *with* them. Carnevale et al. (2015) indicated that although the biomedical approach focuses on issues such as the best interest standard, parental authority, family interest and children's rights (e.g., Dekeuwer, 2017; Diekema et al., 2011; Garrett, 2018), it does not ensure considerations of CYP's own agency.

Adult PPI in healthcare has a rich history, written by activists and critical thinkers, as well as by governments and other stakeholders. The first patient initiatives, such as Alcoholics Anonymous, appeared in the early 20th century. They were followed in the 1960s by the civil rights movements, and in the 1970s and 1980s by a wave of criticism of medicine and its subfields –such as psychiatry– (Basaglia, 1968; Illich, 1975; Zola, 1972) and a defending of the rights of specific disadvantaged groups such as women and people with disabilities (Boston Women's Health Book Collective, 1970; Oliver and Barnes, 2012). The inability to treat certain diseases such as HIV, along with scandals related to healthcare injustice and harm to specific patient populations –e.g., the transmission of Creutzfeldt-Jakob disease to children treated with growth hormones–, further encouraged the formation of patient associations and organizations (Barbot & Didier, 2010; Dalgalarondo, 2004). Under the slogan "nothing about us without us", grassroots movements demanded respect for patient rights, promotion of patient autonomy and empowerment, and the abandonment of medical paternalism (Charlton, 1988). These movements were backed by government initiatives and public policies aimed at improving healthcare outcomes and reducing costs. Over the last 20 years, an increasing number of funding bodies in Western countries either demand or strongly encourage the pursuit of PPI (McCoy et al., 2019).

³ See: EYE-YPAG (<https://generationr.org.uk/eye-ypag/>) and NeurOX YPAG (<https://oxfordhealthbrc.nihr.ac.uk/patient-and-public-involvement/young-peoples-involvement/>) [Retrieved March 19, 2024].

⁴ International Children's Advisory Network (<https://www.icanresearch.org/>) [Retrieved March 19, 2024].

⁵ European Young Persons Advisory Group Network (<https://eypagnet.eu/about-eypagnet/>) [Retrieved March 19, 2024].

⁶ Conect4Children is a European network that aims to facilitate the development of drugs and therapies for the pediatric population (see: <https://conect4children.org/>). Pediatric Clinical Research Infrastructure Network is a European project that aims to develop capacity for the management of multinational pediatric non-commercial trials (see: <https://ecrin.org/projects/pedcrin>). The European Network of Excellence for Paediatric Research facilitates the integration of pharmacological research activities, contributes to the promotion of medicines and health policies and raises social awareness on the importance of pediatric medicines (see: www.teddynet.net). Rare Diseases Europe is a non-profit alliance of various patient organizations on rare diseases that aims to foster the patient community and shape research policies and patient services (see: <https://www.eurordis.org/it/>) [Retrieved March 19, 2024].

⁷ See, for example, the Generation R website (<https://generationr.org.uk/about/>) [Retrieved August 19, 2022].

CYP involvement, in contrast, is not driven by representative grassroots movements –such as Youth for Climate, an international movement conceived, organized and proposed by students–. Instead, regulatory and funding bodies, from public and private institutions alike, are increasingly demanding CYP involvement in health research (Chan et al., 2020; Tsang et al., 2020; Sellars et al., 2021). Moreover, YPAGs and KIDS are run and managed by adults who are mainly healthcare professionals, in collaboration with the pharmaceutical industry. In published articles, organizers of YPAGs and KIDS justify these initiatives listing actual and potential benefits for CYP and adult actors. Among the benefits mentioned for CYP are the feeling of empowerment and access to their right to participate; the fact that they undergo training in clinical research, developing specialized skills and improving their CV; socialization with others and the development of personal confidence and self-esteem; and the opportunity for them and their family to have a say on matters that concern them (Gaillard et al., 2018). These benefits reflect an adult-centric and medical agenda that is accompanied by a list of benefits provided to researchers. First, these groups allow them to improve the quality of the research, its acceptability and feasibility, and increase its relevance and the impact of its findings. Second, collaborating with CYP allows professionals to acquire innovative skills and develop sensitivity toward CYP perspectives. Third, CYP participation enhances inclusion and compliance with research, increases public trust and improves society-science interactions (Gaillard et al., 2018; Sellars et al., 2021).

This agenda inevitably leads to various biases. For example, published papers on these groups are oriented toward organizational matters, corroborative evidence and standardization of practices, to the detriment of fundamental ethical, political and epistemological questions, such as: what are the social and political assumptions, presuppositions, and power dynamics of these groups; what understandings of childhood are reflected and enacted in these initiatives and how do they shape participants' relationships and communication; what room is left for deliberation and decision making; to what extent is democratic accountability granted; and what are the implications for stakeholders, medicine and society?

By way of example, one of the main points on the YPAGs and KIDS agenda is to bring CYP closer to science, in the sense of allowing them to have a say in it, to have their needs better addressed, and to receive education to better understand the purpose of the research and its methods. Most YPAGs and KIDS highlight their role in training CYP in biomedicine and biomedical research before taking part in the various activities proposed. What is not examined, however, is how to ensure that the biomedical education of future generations does not become the central aim of YPAGs and KIDS at the expense of democratic deliberation on issues that presently concern them. If the primary aim of YPAGs and KIDS is to foster a society in which medicine and science have a crucial role, the democratic legitimacy of these initiatives is undermined because it puts biomedical progress first. Although the involvement of healthcare professionals in these initiatives ensures a high degree of detail and information on scientific aspects, can their knowledge and skills really be separated from their political culture and leadership? To what extent are CYP free to express alternative views, interests and objectives in such constructed spaces?

In terms of rationale for involving CYP, sometimes the ideas that adults have about what is good for society as a whole do not correspond with what children think is best for them. Preciado (2019) mentions the example of adults joining demonstrations to defend children's rights against gay marriage and the use of medically assisted reproduction technology by gay couples. Preciado argues that, in these cases, people defend the values that they want to promote rather than being concerned for the children themselves. What really matters to them is not so much how children feel but the affirmation of values that they believe to be crucial for the common good. Although they seemingly are demonstrating to ensure children's rights, they are actually interested in maintaining the heteronormative order of relationships. Critically examining the ethical, political and epistemological rationale for including CYP in PPI would help prevent the uncritical validation of the adult-centric and biomedical perspective, *de facto* enforcing new forms of medical paternalism.

The constitution of the children and young people groups

The literature on PPI stresses that it is important to define *who* is involved in PPI, because it also tells *how* and *why* they contribute. This is evident in the case of the distinction between the involvement of patients *and* public (or citizens). These two groups of people have different interests and expertise, reasons for which they can provide different contributions, and they are generally involved for different purposes –for example, either on matters of one's own care or on health services and policies to benefit the community– (Williamson, 2014; Warsh, 2014b; Fredriksson & Tritter, 2016; McCoy et al., 2019). This section examines how the CYP group is constituted and suggests some aspects that should be considered.

In YPAGs and KIDS, the defining inclusion criterion, besides their specific medical condition, is age. YPAGs might include individuals aged 8-21 years; however, the age criterion makes them highly heterogeneous groups; there are major differences between the involvement of an 8-year-old and a 21-year-old. Failing to acknowledge the heterogeneity of the pediatric population has been criticized as one of the drawbacks of the European regulation on medicinal products for pediatric use (Regulation (EC) No 1901/2006). Although this regulation has succeeded in its intent of increasing the number of studies conducted on minors in recent years, it has failed –critics argue– to consider the difference between administrative and biological aspects. According to Klaus Rose (2021), this is the main reason why the regulation does not reflect the physiological needs of differing pediatric subgroups. The age limit of 18 years is justified from a legal and administrative standpoint; however, adolescents are physiologically more like adults than infants. Requiring them to be prescribed drugs with the pediatric label restricts their access to superior and effective treatment and unnecessarily includes them in clinical trials targeted to younger people (Rose, 2021).

YPAG and KIDS organizations would also benefit from explicitly stating how the age inclusion criterion affects the political rights of CYP. This is particularly important because the testimonies of CYP, their forms of communication and the interpretative framework might suffer from epistemic injustice (Carel & Györfy, 2014). The philosopher Miranda Fricker (2007) defines epistemic injustice as “a wrong done to someone specifically in their capacity as a knower” (p.1). She distinguishes two forms of injustice. (i) Testimonial injustice has to do with the level of credibility that is attributed to the speaker. CYP's preferences might be dismissed, for instance, because of the traditional understanding of children as less autonomous and less rational than adults. (ii) Hermeneutical injustice refers to “a gap in collective interpretative resources [which] puts someone at an unfair disadvantage when it comes to making sense of their social experience” (Fricker, 2007, p.1). Professionals involved in YPAGs and KIDS might not be aware or might not have incorporated the difference between the age criterion and the political relevance of the CYP group. Adults in charge of PPI initiatives with CYP are therefore confronted with extra challenges; they need to have (as in any citizen involvement initiative) specific knowledge and skills to interact with people and willingness and time to dedicate to building trust relationships (Lowry & Stepenuck, 2021). Moreover, they must be careful not to reproduce childhood-specific forms of exclusion or injustice by emptying the political relevance of their participation.

The formal inclusion of people of a certain age does not in itself ensure actual inclusion. Iris Marion Young (2000) formulated the concept of ‘internal exclusion’ to designate the phenomenon according to which those who hold social and economic power might –often unconsciously– neglect, disregard or patronize the opinions of individuals who had been previously excluded from officially participating in democratic practices. It is important to highlight that exclusion mechanisms are often unconscious. Susan Stokes (1998) examined cases of unsuccessful democratic deliberation, in which lobbies intentionally manipulate the public with various strategies. In her examples, people with individual self-interest intentionally induce stakeholders to endorse an idea or a cause, even though they satisfy the needs of only a single person or a small group and do not serve the common good. It is not that PPI initiatives are intentionally created for these purposes. However, extra efforts should be made to establish important criteria for defining the CYP group that should be included in certain YPAGs or KIDS initiatives. What relevant political difference can be made between including an 18-year-old or a 21-year-old? What is their specific contribution compared with that of adults? Should they be selected to represent the interests of the group as consumers, as citizens or as patients? What is the contribution that is sought with their inclusion: a generational outlook on specific matters, or rather the situated and contextual individual’s opinion?

Relying on age criteria only is also problematic if the CYP group is defined in relation to the adult group. Consider a relational definition of the group: “In a relational conceptualization, what constitutes a social group is not internal to the attributes and self-understanding of its members. Rather, what makes the group a group is the relation in which it stands to others” (Young, 1997, p. 389). Contemporary philosophers have examined the profound implications of modern phenomena related to population aging and generational differences. For instance, the extension of life expectancy has prompted individuals to reconfigure their life path and experiences. New life experiences, such as ‘extended adolescence’ and mid-life crisis, as well as novel relational dynamics between different generations, challenge the boundaries of what should be considered adulthood (Deschavanne & Tavillot, 2007; Bodei, 2009). Moreover, researchers in the New Sociology of Childhood have deconstructed certain traditional epistemological assumptions about childhood that are based on dichotomies –e.g. being/becoming, competent/incompetent– (Prout, 2011). Accordingly, CYP should not be compared with adult capabilities and stages of life, but should rather be considered by their own specificities, which might vary widely at the individual and group level. Further examination is needed on how these specificities can be described and set as inclusion criteria in PPI initiatives.

The moral status of children and young people in biomedical settings

Most YPAGs and KIDS justify their work on the basis of the United Nations Convention on the Rights of the Child (1989). Article 12 establishes that children should be granted the right to express their views freely “in all matters” affecting them. The consideration that is due to them, depends on their “age and maturity.” They also have the right to “be heard in any judicial and administrative proceedings.” What YPAGs and KIDS generally do not mention is that ‘public participation’ is a human right recognized by international and national laws. Article 21 of the Universal Declaration of Human Rights (1948), for instance, claims the right for everybody to participate in the affairs of one’s country, either directly or by representation. CYP therefore enjoy certain rights, and although some are the same as those of adults, differences remain.

Historically, legal provisions in Western countries have been characterized by a certain ambiguity or even tension between the desire to protect children because of their vulnerability and the one to promote their autonomy as subjects of a right (Thèry, 1994). Over the last century, major efforts have been made to claim children-specific rights. Those related to medical care have been reaffirmed and strengthened by international recommendations, such as the 1986 European Charter on the Rights of Children in Hospital, the 1997 Oviedo Convention, and the 1964–2013 Declaration of Helsinki. In the last 20 years, a series of ethical guidelines and initiatives have gone a step further and encouraged active CYP involvement as co-researchers in health research –e.g., Nuffield Council on Bioethics, 2015–. The double designation of CYP as intrinsically vulnerable subjects to active co-researchers still coexist in health research (Murano, 2024).

Given this regulatory framework, the question arises as to the moral status of CYP in PPI. The moral status of a person is a condition of value that confers moral consideration and possibly rights (Zuolo, 2016). Moral status differs from moral value in that it does not depend on the person’s actions; it is

attributed to someone on the basis of properties or relationships that are independent of their will. Moral status has both an evaluative function and a prescriptive function. Acknowledging a certain moral status to a person defines not only how we should view and consider them but also how they should be treated (Zuolo, 2016). The way in which minors are understood and treated in PPI is certainly informed by national and international laws; however, practices are also influenced and nurtured by sociocultural norms and power relationships in pediatrics.

Since the second half of the 20th century, science and technology studies and feminist technoscience, among other fields, have highlighted that not only is science socially constructed but it also creates new subjectivities (Latour & Woolgar, 1979; Blanco & Iranzo, 2000; Johnson, 2017). Clarke et al. (2003) suggested that a major cultural shift occurred in the 1980s due to the increasing technoscientific opportunities offered by medicine to shape bodies for differing purposes as well as individual and collective identities. Medicine currently allows us not just to treat disease and normalize atypical physical traits but also to assess risks and transform and customize bodies. To indicate this transformation of the nature and goals of medicine, Clarke et al. (2003) speak in terms of biomedicine. This understanding of biomedicine implies that people rely on medicine not simply to prevent and cure but to improve their lives. Along these lines, biomedicine has allowed people to control reproduction, which increases the pressure to build a personal or joint “child project” (Charrier & Clavandier, 2013).

Since the 1950s, a general trend of medicalization has occurred in various aspects concerning pregnancy, birth and child rearing (Gonzales, 2006; Massó Guijarro, 2017; Odent, 2009). Medicalization is a sociocultural process in which non-medical conditions are viewed as medical problems, therefore expanding the political sphere of medical influence (Conrad, 1992; Foucault, 1988; Murano, 2018). This process is not only driven by healthcare professionals but also involves the active participation of parents willing to improve their children's health and quality of life. In such medicalized context, parents embrace increasing opportunities to intervene in several aspects of children's lives by favoring a culture of enhancement with the aim of ameliorating their cognitive, physical or even moral characteristics (Douglas, 2014; Parens, 2007; Wickström, 2016).

In pediatrics, the distinction between therapy and research (curing the patient versus finding a new treatment for rare or life-threatening diseases (Blake & Kodish, 2011). Therefore, clinical research can sometimes have a therapeutic effect or can provide greater benefits than the currently available treatment. CYP participation in biomedical research can provide early access to drugs that are not yet approved (and therefore not proven to be effective) that sometimes represent the only hope to treat a condition (Reboul Salze, 2010). This type of research can create the risk of unrealistic expectations on the part of participants and families who anticipate therapeutic outcomes that are not envisioned by the research. These expectations also push certain parent groups to act as lobby groups to pressure policy makers to fund research into their children's condition (Rose & Novas, 2005; Rose, 2014).

The question of the moral status of CYP in pediatric care and research, therefore, is complex, involving deep emotions, high expectations and multifold power relations and dynamics. These relations involve several groups of individuals: the child, their relatives or legal representatives and the healthcare team. These multiple relationships involve asymmetries in power—doctor-patient, parent-child, expert-sick person—and different relational dynamics—within the family, between the family and the doctor, between the family and society; as well as potential generational power dynamics— (Mitchell et al., 2019). In this context charged with sociocultural norms and power dynamics, what moral status is attributed to children? What role can they play and how are they treated? What room is left for them to dissent and criticize? Given that CYP are involved mainly to narrow the divide between them and science and scientific institutions, how is the growing distrust of lay people toward health research addressed in PPI initiatives? The literature does not specify how contested issues are presented to CYP and treated in the work of YPAGs and KIDS. Three examples of the most commonly disputed territories are 1) the epistemological and methodological flows of research methods, as well as structural problems, such as biases, fraud and conflict of interest in healthcare (Moynhan & Cassels, 2005; Stegenga, 2018, 2022; Hauray et al., 2021); 2) the criticism of the predominant epistemological “(bio)medical model,” such as disability studies' vindication to the understanding of disability as a social rather than a medical condition (Oliver & Barnes, 2012); and 3) the inadequacy of diagnostic tools because of epistemological flaws that sometimes exclude disadvantaged populations (Slatman, 2011; Murano et al., 2020; Moalem, 2020). Including considerations on how to deal with controversial subjects would be a first step toward attributing CYP the moral status of adults, and to therefore foster political equality in PPI initiatives.

Conclusion

This paper offers a critical analysis of three points of reflection that need to be further analyzed to improve the democratic involvement of CYP in healthcare and health research. It shows that the rationale for involving CYP in PPI is mainly top-down and adult-centric, thereby questioning the authentic participation in decision making. It also suggests that to ensure democratic inclusion, the CYP group should be constituted by considering both age and politics. Lastly, the article indicates that, despite the increasing recognition of child-specific rights, the sociocultural norms and power dynamics in pediatrics undermine their moral status and challenge political equality. These three sets of considerations offer a preliminary theoretical contribution toward improving democratic legitimacy and representation of CYP in health research and innovation, which require further examination.

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