# Youth Participatory Approaches and Health Equity:
## Conceptualization and Integrative Review

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## Abstract

There is an array of youth participatory approaches relevant for health equity efforts in community psychology, adolescent health, youth development, and education. While they share some commonalities, they also reflect important distinctions regarding key processes and intended level of impact. Here, we consider: (a) Youth-Led Participatory Action Research - YPAR, (b) youth organizing (YO), (c) youth-led planning, (d) human-centered design, (e) participatory arts, and (f) youth advisory boards. Informed by community psychology theories on empowerment and levels of change and social epidemiology frameworks that focus on the social determinants of health inequities, we aim to promote greater clarity in the conceptualization, implementation, and evaluation of youth participatory approaches; frame the "landscape" of youth participatory approaches and their similarities and differences; present an integrative review of the evidence regarding the impact of youth participatory approaches; and describe several illustrative cases so as to consider more deeply how some youth participatory approaches aim to influence the social determinants of health that lead to the physical embodiment of health inequities. We conclude by identifying areas of future policy- and practice-relevant research for advancing youth participation and health equity.

**Key Words:** youth participation; health equity; youth-led participatory action research; youth organizing; participatory arts

# Youth Participatory Approaches to Promote Health Equity:
## Conceptualization and Illustration

## Context for Youth Participatory Processes and Health Equity

Young people are a major force in fighting for equity on pressing health-related issues. For example, in the Arab uprisings, Black Lives Matter movement, 2018 U.S. gun control protests, and the 2019 international climate strikes, young people asserted their rights to survival, health, economic opportunities, political expression, and education. Aligned with these actions, there has been an upsurge of research, practice, and policy interest over the past two decades in the capacities and rights of youth[1] to have agentic roles in their own health and wellbeing, and address inequities in social conditions, systems, and services that shape their development (Patton et al. 2016; United Nations, 1989; WHO, 2014). Promoters of youth participation also grapple with what constitutes meaningful, ethical, and developmentally-appropriate approaches (Checkoway, 2011; Kearney & Cala, 2015; Villa-Torres & Svanemyr, 2015), especially as youth participation can carry social, political, career, and safety risks.

"Youth engagement" and "youth voice" are often used broadly, smoothing over key distinctions in approaches such as peer education, youth boards, youth-led participatory action research (YPAR), youth organizing, and qualitative research. Further clarity is needed to advance shared agendas among diverse research and practice communities. we aim to address this gap by offering researchers, community-based organizations (CBO's), policy-makers, and funders a) a conceptual frame on the variegated "landscape" of youth participation; b) an integrative review of the breadth and depth of research on the impact of youth participatory approaches on health promotion and equity efforts; and c) case examples to illustrate how youth participatory approaches can subvert the social and economic pathways of unequal power that shape health inequities (Marmot, 2017). There are multiple participation approaches relevant for health equity efforts in adolescent health, youth development, education, and public health. The approaches engage youth in agentic roles in which they have varying levels of power to make or influence decisions about research, program design, actions, and systems change. We consider:

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[1] Consistent with the World Health Organization (WHO), we refer to "adolescents" as young people between the ages of 10 and 19. The UN defines the term "youth" as referring to those within the age range of 15 to 24; here, we use the terms "youth" and "adolescent" as appropriate to the context of our reference and claim.

1) YPAR, 2) Youth Organizing (YO), 3) youth-led planning, 4) human-centered design, 5) participatory arts, and 6) youth advisory boards (YABs) and councils (YACs).

### Conceptual Frames for Linking Health Equity and Youth Participation

**Empowerment and levels of change**. Our analysis of youth participatory approaches to promote health equity is informed by core theoretical perspectives from public health and community psychology on empowerment (Rappaport, 1987; Zimmerman & Eisman, 2017) and levels of change (Robinson, Brown, Beasley, & Jason, 2017; Watzlawick, Weakland, & Fisch, 1974). Through an empowerment lens, youth participatory approaches can be critiqued with respect to how they create the conditions for empowering processes and outcomes at the individual-, organizational-, and community-levels (Zimmerman, 2000). For example, how do participatory processes promote young people's capacities to analyze the conditions underlying health inequities and gain power to act on those conditions? Which levels of change are emphasized in the youth participation literature (i.e., first-, second-, or third-order changes)[2]?

**Health equity**. Social epidemiology emphasizes institutional factors (i.e., economic, legal, educational policies/systems) that produce and maintain social inequity. Models such as Krieger's ecosocial theory of disease distribution emphasize the structural nature of institutional determinants, how they work together to impose hierarchies of power, and subsequently shape health inequity patterned by experiences of marginalization by race, class, gender, and sexuality, among others (Krieger, 2001; Link & Phelan, 1995). A central tenet of ecosocial theory: accountability/agency, examines the extent to which actors (e.g., institutions, researchers, youth) are empowered to produce knowledge and develop interventions related to health and health equity. Taken together, the empowerment and health equity literatures provide key dimensions for characterizing the range of youth participatory approaches currently in practice.

**Youth-adult partnerships**. Our consideration of youth participation is grounded in the peer-reviewed and practice literatures on youth-adult partnerships (Hart, 1992; Shier, 2001; Treseder, 1997; Wong, Zimmerman, & Parker, 2010), which have distinguished among levels of

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[2] First-order changes address a health issue or empower youth without attending to the underlying contextual factors that shape the health issue; second-order changes work on underlying inequitable social conditions to prevent health issues; third-order changes transform the culture and "social fabric" of the community, focusing on structure and process rather than a specific health problem (Bartunek & Moch, 1987; Robinson et al., 2017; Watzlawick et al., 1974)

participation and debated the level of control most beneficial for youth and for change efforts (Hart, 1992; Shier, 2001; Treseder, 1997). A new practice matrix for youth participatory evaluation is useful for our analysis, framing youth participation roles as consultants who provide insight and advice, collaborators who engage in parts of the process, partners who share work across the process, and leaders who may or may not engage adults as collaborators or consultants (Richards-Schuster & Plachta, 2019). Further, an under-explored role is youth as funders who develop capacity to independently engage in fundraising, allocation, and grant making [see the Young Feminist Fund (2019), HIV Young Leaders Fund (2019)].

**Participatory Approaches: Overview, Overlap, and Divergence**

In YPAR, a form of Community-Based Participatory Research (CBPR), youth train as researchers to study equity issues they want to influence and advocate for changes based on their findings (e.g., Cammarota & Fine, 2010; Fine, 2008; Kidd, Davidson, Frederick, & Kral, 2018; Mirra, Garcia, & Morrell, 2015; Ozer & Piatt, 2018; Rodríguez & Brown, 2009). YPAR is an orientation, rather than a method, that challenges dominant assumptions about who holds and creates knowledge. Youth are considered experts who generate valid knowledge about the conditions they seek to change while working to shift power structures and change inequitable systems, policies, and practices (Fine 2008). The research designs and methods used in YPAR are highly diverse, including surveys, interviews, observations, photovoice, GIS mapping, and artistic and narrative forms of expression. When YPAR evaluates a youth-serving program, service, or organization, it is sometimes referred to as Youth Participatory Evaluation (Flores, 2008). YPAR groups have tackled a range of health equity issues in the peer, family, school, community, and policy domains such as air pollution, gender-based dating violence, bullying, and unequal access to healthy food and physical activity opportunities (Garcia, Minkler, Cardenas, Grills, & Porter, 2014; Lindquist-Grantz & Abraczinskas, 2018; Ozer & Piatt, 2018). Extensive work across the public health, education, sexual and reproductive health, and international development fields has developed principles, processes, and curricula to support high-quality training of adult facilitators and implementation of YPAR (e.g., Ozer et al., 2010; Rodríguez & Brown, 2009; Rubin, Abu El-Haj, Graham, & Clay, 2016; Anderson, 2019).

Youth organizing is a rights- and youth development-focused form of community organizing in which adolescents activate to "claim power and make change for themselves"

(Christens & Kirshner, 2011). Examples cited earlier, such as international movements to address climate change, may be organized by young people without formal adult support. However, YO also takes the form of a programmatic youth development and social justice approach in which adult partners train youth organizers within existing organizations (Torres-Fleming, Valdes, & Pillai, 2010, p.2). Many YO projects specifically tackle issues related to health, such as food justice (McLean, 2019). YO efforts frequently target system-level determinants to disrupt their effects on inequitable health outcomes.

In youth-led planning, adolescents typically work on a specific planning problem identified by a defined client, such as a government agency (McKoy & Vincent, 2007; "Youth-Plan Learn Act Now," 2019); for example, how can public transportation routes or parks best serve youth to promote health and wellbeing? Youth who engage in human-centered design (HCD; also "design thinking or "user-centered design") contribute the "user experience" perspective to adults' design of programs or products; in the health realm, this can take diverse forms such as informing the development of health related "apps" for smart phones, or youth-informed design of health-related services intended to serve youth.

Participatory arts refer to adolescents making and sharing various forms of art (e.g. theatre, poetry, photography) to express themselves. Often, these methods are used only as an additional aspect of data collection, but without (or with little) youth agentic roles. Here, we use the term emancipatory participatory arts to refer to the use of participatory arts in projects that provide agentic roles for youth to raise the visibility and critical consciousness of health-related issues and promote action. Participatory arts often explore topics that may be difficult to vocalize (Coemans & Hannes, 2017; Wang et al., 2017, p.11). Photovoice is the most common participatory visual arts method using photography to facilitate a reflective inquiry process (e.g., Wang & Burris, 1997; Zarobe & Bungay, 2017).  In photovoice, participants document their realities, partake in critical dialogue, and advocate to policymakers for change (Wang, 2006). Participatory theatre (or popular theatre, forum theatre, process drama), an outgrowth of Freire's popular education movement and Boal's theatre of the oppressed (Conrad, 2004b; Sloman, 2011), is a common performance-based participatory art. These theatre methods encourage 'participants to develop a critical consciousness, question their social and historical realities' (Grewe et al., 2015, p.304), and take emancipatory action (Wernick, Kulick, & Woodford, 2014).

While photography or video can be used as method or data source in YPAR, we consider participatory arts on its own because its approaches also occur outside of YPAR.

Youth advisory boards and councils provide sustained opportunities for youth to express ideas and provide their perspectives to guide policies and practices of adult-led organizations. Youth boards take diverse forms in the global governmental, NGO, and health practice and policy spheres (He, 2018; Newman et al., 2011; YouthPower, 2020). U.S. academic institutions have developed youth advisory boards, in which youth provide consultation and feedback on adolescent health projects, while sometimes engaging in hands-on training, service-learning, and advocacy (Northwestern University Center for Community Health, 2016; UCLA Center for Prevention Research, 2019, Johns Hopkins Center for Adolescent Health, n.d.).

**Shared features aligned with health equity promotion.** All of these participatory approaches share the assumption that youth have unique expertise that is needed for understanding and addressing key issues affecting their health, development, and wellbeing. When implemented with integrity, these approaches also share core components including: a) inclusion of adolescents as intended "agents" and beneficiaries; b) adult support that amplifies rather than replaces adolescent perspectives; c) an action component, that may be informed by research-based inquiry; d) physical and/or virtual supportive/safe spaces; and e) promotion of conditions for youth to develop agency, positive social identity, and empowerment (Ozer, 2017; Patton et al., 2016; Suleiman, Ballard, Hoyt, & Ozer, 2019). YPAR, YO, and emancipatory participatory arts emphasize youth-generated knowledge and action as crucial for transforming systems and conditions that lead to health inequities, targeting second-order changes.

**Distinctive features**. Figure 1 is a conceptual diagram of the overlapping and distinct features of youth participation approaches, organized around data-based inquiry and power. It is intended to encourage consideration of the relative "fit" of these distinct approaches, depending on the goals and audience (i.e., research, practice, and policy). It also differentiates youth participatory approaches from adult-led research that elicits data from youth.

First, youth participation approaches differ in their emphasis on conducting data-based inquiry to generate evidence for action. For example, YO sometimes begins with data-based inquiry to contextualize the issue but is focused primarily on action rather than also on generating research evidence. HCD focuses on conducting sufficient formative research with users to empathize with their experience and inform the design of prototypes but does not focus

on youth-generated evidence. In contrast, YPAR focuses on data-based inquiry and evidence generation grounded in deep understanding of the problem to inform solutions that challenge power structures and promote second-order change and health equity. High-quality implementation of YPAR takes more time than rapid-response types of organizing. Emancipatory participatory arts emphasize inquiry in distinctive ways, using art at multiple phases of the inquiry process including question identification, data collection and analysis, and results dissemination (Wang, Coemans, Siegesmund, & Hannes, 2017; Wernick et al., 2014).

Second, youth participation approaches differ in their focus on youth having power to identify the problem or research question versus youth as "consultants" to explore a question posed by adults. In youth participatory planning, evaluation, and HCD approaches, a question is usually defined by adult stakeholders, such as government or NGO leadership. For example, they may seek youth input in the design of a resource (e.g. park, transit routes, school) that will affect young people as constituents or users. In contrast, YPAR, YO, and participatory arts typically start with youth identifying the problem, usually with strategic advising by adults (Conrad, 2004a; Ozer, Newlan, Douglas, & Hubbard, 2013; Wernick et al., 2014). A potential benefit of client-centered approaches, such as youth-led planning or HCD, is a clear stakeholder audience who presumably have power to enact the youths' recommendations (assuming those align with adult interests). A potential downside is if the problem frame posed by adults is not of interest to youth, does not center their lived experiences, or address core equity issues (Fine et al. 2008).

Third, the relative power adults have over decision making differs across approaches. Some YO and participatory arts projects—explicitly focused on second-order change to influence power structures and inequitable conditions—are fully initiated and run by youth (Watzlawick et al., 1974; Wong et al., 2010; Christens & Kirshner, 2011; Robinson et al., 2017; "Student Volunteer Army," 2018; Yee & Blinder, 2018). In contrast, some youth advisory boards invite youth to inform adult understandings absent decision-making power, suggesting forms of "symbolic power" in which youth express views while adults have control (Wong et al., 2010; Richards-Schuster & Plachta, 2019).

The fourth distinction is the participatory approaches' relative emphasis on disrupting social contexts that create and maintain health inequity (i.e., "fundamental causes") versus efforts to promote individual behavior change within those social contexts (Link & Phelan, 1995). For example, HCD approaches may have youth inform the design of an application or

program, but do not seek to change systemic conditions that shape health inequity. In contrast to HCD, YO is explicit about changing social contexts to equalize power. Further, YO, emancipatory participatory arts, and YPAR engage youth in mapping power and ecological influences related to their identified problem, and promote critical consciousness through reflection and action (Kirshner & Ginwright, 2012; Watts, Diemer, & Voight, 2011).

**Youth Participatory Approaches: Consideration of Literature and Illustrative Cases**

Below, we summarize the nature and scope of empirical inquiry for each participatory approach, in terms of best practices and impact on health outcomes and health-relevant systems including health care, government, education, and social services. We are mindful of the complexity of the participatory and health equity domains in which this scholarship is grounded. First, some but not all youth participatory approaches that focus on health articulate health equity as a goal. Our broad consideration of these literatures with our health equity lens is inclusive of efforts that (a) focus on health outcomes and/or b) seek to influence social, educational, political, and economic conditions that shape trajectories of health and wellbeing across the lifespan. Second, consistent with the spirit of participatory research, this analysis considers multiple types and sources of evidence as legitimate (Fine, 2008). We recognize that gaps in peer-reviewed attention should not be interpreted as indicating null findings or lack of importance. Third, a systematic review of all youth participation literatures is beyond the scope of our analysis given our wide "landscape" lens on many forms of youth participation; further, several approaches considered here provide important models for audiences concerned with promoting health equity but have received little empirical attention. Thus, we provide an integrative review of reviews based on a purposive and intensive—but not systematic—search strategy, as detailed below.

**Search strategy**. We conducted a search of two selected databases in English most relevant for health (PsycINFO, Pub Med) and Google Scholar up to October 2019 to identify review articles conducted for the six youth participation approaches considered here. We queried combinations of participation type (YPAR, CBPR, organizing, participatory arts, boards, advocacy, planning, user-centered design, human centered design), youth (e.g., adolescents, teens), and review type (systematic review, scoping review, landscape analysis, narrative review). These reviews were then read by the second author, who documented review type, search terms, purpose, theories, and exemplars. The first and second authors then compared and synthesized across reviews. This yielded 17 relevant systematic and non-systematic reviews with

variable scope and emphasis. As there were few reviews for some participation approaches (i.e., youth board, HCD), we expanded the search to include combinations of participation type, youth, and the terms "best practices," "guidelines," "practice-based evidence," "theoretical model," and "framework." We excluded reviews that focused only on adults or on community-based approaches that were not participatory (e.g., collecting focus group data, culturally tailoring interventions). Our final yield consisted of 24 review articles. While we did not include single empirical studies, we do reference examples below to broadly characterize the nature and focus of the literature for youth participatory approaches for which there were no reviews.

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**Empirical Landscape of Youth Participation**

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We found several recent reviews on youth participation across disciplines including community psychology, social work, nursing, education, and public health; the majority of the 24 reviews identified in our search (asterisked in the reference section) were published between 2017 and 2019. We discuss in detail those that constituted systematic empirical reviews of youth participation (Anyon, Bender, Kennedy, & Dechants, 2018; Jacquez et al., 2013; Kennedy, DeChants, Bender, & Anyon, 2019; Shamrova & Cummings, 2017; Vaughn et al., 2013), weaving in findings from others as relevant. The systematic reviews varied in aims, scope (e.g. inclusion of international work, types of participatory approaches), and level of outcomes (individual and/or environmental). Although none focused specifically on health equity, they provide context for considering the empirical literature on youth participation and health equity.

Initial reviews (Jacquez et al., 2013; Vaughn et al., 2013) used CBPR as the primary search term to understand youth participation in studies claiming that approach. For example, Vaughn et al. (2013) included 34 multi-method CBPR studies focused on children and health. They found a clear emphasis on health domains (e.g., diabetes, asthma, lead poisoning, child abuse, violence prevention, health literacy) and noted a range of ages among those involved in participatory approaches with varying levels of engagement. Specifically, high school students were more deeply engaged in data collection and research design, middle school students in advocacy, and elementary-aged children had less involvement. Jacquez et al. (2013) provided a deep examination of youths' roles in 56 CBPR studies—inclusive of but not limited to health domains—according to five phases of potential engagement outlined by Israel and colleagues (2005): 1) giving early input, 2) identifying research questions, priorities, and goals, 3) designing and conducting research, 4) conducting or contributing to data analysis and/or interpreting and

summarizing findings, and 5) translation and/or dissemination (Israel et al., 2005). Overall, they found less engagement in later rather than earlier phases of CBPR.

Shamrova and Cummings (2017) expanded the scope, including international research and a wider range of search terms (i.e., CBPR, YPAR, participatory research). Building on Checkoway (2011) and Gal's ecological model, the authors found evidence for effects at youth, organizational, and community levels that we characterize as likely to strengthen health equity, including organizational shifts in sexual education policies, anti-discrimination policies to protect LGBTQ students, and stricter tobacco access. They also identified community changes that addressed health risks and inequities related to water quality, post-disaster school reconstruction, gender-neutral bathrooms, and accessible transport.

Anyon et al (2018) conducted the broadest review of youth participation to-date in the U.S., using PRISMA systematic review guidelines to identify multi-method peer-reviewed research studies published through to 2016 in the health, social services, education, and psychological literature. The authors included studies with diverse forms of youth inquiry (e.g., YPAR, YO, and youth councils), based on criteria for defining YPAR developed by Rodriguez & Brown (2009). They analyzed 63 studies that included youth up to age 25, and found that the most common youth inquiry topics were education (50%), social inequality (40%), health (32%), and violence/safety (25%). Among those that examined health topics, particular indicators included substance use, access to healthy foods and physical activity, asthma, birth control availability, and sexual harassment. In a follow-up study, Kennedy et al. (2019) used the same search strategy but focused on systems outcomes. They found 36 studies that reported impact on outcomes such as practitioner growth, peer norms, research quality, program improvement, and policies. All of the policy outcomes cited were health-related and relevant to health equity promotion given a focus on health domains across which structural marginalization consistently shapes outcomes (e.g., access to high quality food, targeted marketing of tobacco). Neither systematic review conducted a meta-analysis of effect sizes.

Beyond the inclusion of YO in systematic reviews on youth inquiry (Anyon et al. 2018; Kennedy et al. 2019), the peer-reviewed literature on YO consists primarily of theoretical papers, illustrative case examples, and a small number of multi-method empirical studies. Although there is no comprehensive review of YO impact, a "field scan" provided descriptive information on 160 YO organizations and detailed the types of projects, youth ages, location, and impacts on

communities (Torres-Fleming et al., 2010). YO empirical work primarily characterizes how YO affects youth development, indicating that it strengthens sense of efficacy (Gambone & Connell, 2004); can re-engage youth in school (Cammarota & Romero, 2009; Rogers & Terriquez, 2016), build civic, political, and leadership skills (Christens & Dolan, 2011; Gambone, Yu, Lewis-Charp, Sipe, & Lacoe, 2006); and promote civic and political involvement (Rogers & Terriquez, 2016; Terriquez, 2015). These outcomes are dimensions of psychological and political empowerment (Zimmerman & Eisman, 2017) and can be seen as indicators and predictors of wellbeing and positive youth development. Other studies document how YO has affected programs and policies regarding transportation vouchers (Moore, 2011) and school quality (e.g. Christens & Kirshner, 2011; Mediratta, Shah, & McAlister, 2009).

**Overview of other youth participation approaches and health equity**. A bibliography of youth using art in CBPR (Primeau, Giddings, & Cheeseman, 2019) was recently published. A scoping review of digital storytelling for sexual health among migrant/refugee populations highlighted its use as a form of social activism (Botfield, Newman, Lenette, Albury, & Zwi, 2018). A narrative review of 10 photovoice studies found that it enabled young people to raise awareness and advocate, as well as enhanced parent-youth relationships (Wang et al., 2010). A broad review that included photovoice research across age groups found positive impacts on individual empowerment, enhanced understanding of community needs, and increased action and advocacy (Catalani & Minkler, 2010).

Although there are important youth-led planning practice-based health examples (i.e., adolescent safety, physical activity), there has been little formal evaluation beyond the Youth–Plan Lead Act Now (Y-PLAN) model (McKoy & Vincent, 2007; "Youth-Plan Learn Act Now," 2019). For HCD, we identified a small number of papers on adolescent input in the development of prevention messaging such as prevention of child marriage (Bakker, Handayani, Minnick, & Syafitri, 2018). We identified one systematic review of young people's involvement in the design of technology-based applications to promote mental health and wellbeing (Orlowski et al., 2015), which reported that participation was limited to mainly "consultative and consumerist" engagement in design and usability/pilot testing (Orlowski et al., 2015).

While youth boards and advisory councils serve as a mechanism for adolescents to vocalize their health-related concerns and needs in the global governmental, NGO, and international adolescent health practice and policy spheres, we found little empirical research on

youth boards. A recent brief from the US AID-funded YouthPower Network (2020) summarizes best practices and resources for Youth Advisory Councils (YAC's), noting the need for further systematic research. We did identify a rich area of the literature on foster youth participation in advisory boards concerning aging-out of foster care (e.g., Forenza & Happonen, 2016) and one field scan focused on youth informing policy decisions (Jenkins et al., 2019). The international sexual and reproductive health justice field includes numerous examples of innovative board models, some representing intersectional feminist approaches to working with youth such as India-based Hidden Pockets and the international RESURJ. USOther examples of boards with a research emphasis include ALPHA (2019), a trained group aged 14-25 who advise U.K. researchers on health topics and planned research, and multiple U.S. academic institutions with youth advisory boards who provide consultation on adolescent health projects, sometimes engaging in hands-on training, service-learning, and advocacy (e.g. Newman et al., 2011; UCLA Center for Prevention Research, 2019; Johns Hopkins Center for Adolescent Health, n.d.).

### Illustrative Examples of Youth Participation for Health Equity Promotion

Having summarized the landscape of research on youth participation, we consider four examples of youth participatory approaches that illustrate potential impact on health equity. These include two YPAR (one at the local level and another at the national level) and two YO examples (one local, one national). We note that the YPAR efforts targeted health domains, whereas YO sought to address broader political and educational factors that shape health equity.

**Dream Teens.**  Dream Teens, initiated in 2014, is a Portuguese national network of youth researchers to promote health, wellbeing, education, and civic participation (Frasquilho et al., 2018; Ozer et al., 2016). With support from university teams, youth recruited via municipal youth councils and mass media advertisements studied a range of health-related topics in online collaborations and consulted with peers via Skype, email, and social media. Youth researched topics such as health and physical activity; mental health and quality of life; and social capital. Fifty adolescents attended the first Dream Teens Meeting where they exchanged ideas, built relationships, received research feedback, and identified themes of addiction, social capital, civic participation, personal resources/wellbeing, lifestyles, and love/sexuality relevant to adolescents' lives. They developed recommendations, which they presented to the Secretary of State for Health and other cabinet ministers to promote health equity. Long-term impacts include changes to the Ministry of Education funding requirements that now mandate youth participation and the

replicating of Dream Teens at the local and national levels (M. Gaspar de Matos, personal communication, March 7, 2020).

**U.S. physical activity promotion**. YPAR using photovoice methods was implemented alongside physical activity programming in a middle school after-school program in the southeastern U.S. (Lindquist-Grantz & Abraczinskas, 2018), with the goal of promoting physical activity for all students. The physical activity focus was pre-determined due to grant funding; within the topic, participants chose any area of physical activity to change at their school or after-school program. Girls advocated for an after-school dance team, telling adult stakeholders that boys but not girls had choices for activities that they liked. Another group identified that only higher achieving students were receiving needed breaks at school. Student research teams presented to school administrators, parents, and program staff. After the presentations, the assistant principal and program director agreed to the proposed changes. Students from a local university volunteered to lead a dance team, and the principal created a recess period at the end of the school day for all students. The participatory efforts developed a feedback loop in which students offer guidance and propose additional program/school changes. The feedback loop and changes within the school/program are examples of second order change, as they transformed the social regularities of the setting with potential implications for health equity.

**Youth and the Arab Uprising.** The Arab Uprisings in Tunisia and Egypt are examples of impactful youth organizing efforts focused on creating second order change targeting underlying social, educational, and economic conditions that contribute to unequal distribution of wealth and health. Factors underlying the unrest in the Arab world in 2010 are complex but many have argued that youth were a driving force. Typical of many YO efforts (Kirshner & Ginwright, 2012), youth channeled their frustration with the lack of economic opportunities and institutional factors into protest and organizing efforts across Arab countries (Mulderig, 2013). In Egypt, youth-led protests started as decentralized and grassroots activism, and became more organized over time, culminating in a coalition, Coalition of January 25 Youth, with specific demands for their government (Halaseh, 2012). While many youth were not already part of political organizations, scholars suggest that many developed relevant skills and networks through participation in other civic organizations that they translated into political organizing (Abdou & Skalli, 2017; Halaseh, 2012; Kirshner & Ginwright, 2012). In line with ecosocial theory, young people held those in power accountable for economic and political demands.

**Philadelphia Student Union.** As education is a social determinant of health (McGill, 2016), youth organizing efforts aimed at creating more equitable education systems may provide important levers for health equity (Cohen & Syme, 2013). The Philadelphia Student Union (PSU) was started by students in 1995 to address educational inequities and build individual and collective efficacy for community change (Terriquez, 2015). Diverse student members across Philadelphia middle and high schools have access to PSU training via city-wide meetings, summer programs, and school-based chapter meetings. Paid adult staff serve as key keepers of PSU "institutional memory" (Terriquez, 2015), given the turnover in youth participants. PSU has led and collaborated on many education reform campaigns in Philadelphia and is currently focused on pressuring district leaders to shift from exclusionary discipline practices such as expulsion to a focus on prevention and restorative practices. PSU has influenced local policy processes by insisting on accountability from leaders and elevating student voice (Conner, 2012; Terriquez, 2015), reflecting a long-term approach for youth to promote second order changes in the institutional conditions can impact their health and developmental trajectories.

## Discussion:  Gaps and Next Steps

There is growing recognition of the capacities and rights of youth to influence the social conditions, programs, policies and systems that shape their development and health. Our conceptual and integrative empirical review focuses on advancing understanding of youth participatory approaches for health equity by identifying the core components and distinctions of an array of participatory approaches in practice, their relevance and relative strengths for promoting health equity, and the extant nature and scope of empirical study devoted to each.

The uniquely broad scope of our analytical lens is aimed to generate understanding and inquiry regarding "fit" and trade-offs, rather than a one-size-fits-all approach to youth participation. Inherent in our goal is recognition of the potential value of intentional and high-quality implementation of diverse youth participatory approaches for the promotion of health equity, while emphasizing that some approaches are more oriented towards and likely to promote second- and third-order changes than others. We submit that all approaches considered here offer potential value contingent on (a) the capacities and resources to do them well and (b) intentionality and transparency in roles and power-sharing for youth participants as well as in reporting to the field. Our language regarding fit and trade-offs is hypothetical as there are no reviews (or studies to our knowledge) that provide empirical investigation of the relative

strengths of distinctive participatory processes—or relative quality and intensity of implementation—on health equity-related domains of impact. Even for YPAR, the approach with the most empirical study, there are no empirical data to guide practitioners or policymakers in choosing one approach versus others for a particular outcome at the individual or systems level. Still, systematic reviews on YPAR discussed earlier (Anyon et al., 2018; Jacquez et al., 2013; Kennedy et al., 2019; Shamrova & Cummings, 2017; Vaughn et al., 2013) lay important groundwork for field-building by summarizing topics, outcomes, and samples.

These reviews also highlighted numerous gaps including a) less research with children and younger adolescents b) fewer studies in low and middle income countries, c) need for more consistent reporting standards including the type and phases of youth engagement and power-sharing, age of youth, adult roles, and outcomes measured to enable stronger syntheses and comparisons across studies; and d) further strengthening the evidence base via the use of experimental and quasi-experimental (QE) designs with systematic process and outcome assessment. Experimental and QE designs (e.g. Berg, Coman, & Schensul, 2009; Ozer & Douglas, 2013, Voight & Velez, 2018), would likely be facilitated via Research-Practice Partnerships (RPPs; William T. Grant Foundation, 2018) or other sustained collaborations among scholars, organizations, and youth, capitalizing on opportunities to embed and study the effects of intentional variation in the types and intensity of youth participation.

Measurement and reporting of implementation processes is underdeveloped (Ozer & Douglas, 2015), limiting the field's ability to determine which (and what intensity) of components may be linked to stronger positive or negative impact on health equity outcomes. For example, systematic U.S.-based reviews (Anyon et al. 2018; Kennedy et al. 2019) could not reliably code and analyze the type of youth participation approach used (e.g. YPAR vs. YO) due to insufficient process reporting in the original studies. We note that YO, which had no systematic reviews, has distinct modalities including (i) adult-led YO that recruit youth and provide infrastructure for YO, (ii) youth-led movements without infrastructure (e.g., Arab Uprising), and (iii) youth-led movements that evolve to a formal structure, such as the PSU. These distinctions will be important to characterize in future reviews of YO and health equity.

Despite the varied youth participatory approaches considered here, there are common cross-cutting gaps, including concerns regarding sufficient assessment of core implementation aspects (e.g., roles and power sharing between adults and youth); the type and intensity of

inquiry; and the participation of a 'select' profile of youth, who are more likely to be older, from high income countries, and live in urban areas. While youth from the global south are less visible in the research literature, significant lessons can be learned from youth participation in these regions. Importantly, there is a need to address policy and practice-relevant questions regarding the structural and organizational barriers to sustained and meaningful adolescent participation (Shier, 2001), with a focus on the most marginalized youth locally and globally (Bradbury-Jones, Isham, & Taylor, 2018) to avoid engaging only more privileged youth.

Youth participation approaches, such as YO and YPAR, that promote youth power to address inequities in health and other domains can involve conflict and confer risk for participants – particularly among those who experience structural marginalization. Future research should identify supports for youth organizers and researchers, including trauma-informed practices as relevant (Bulanda & Johnson, 2016). It is important to support the professional career and economic opportunities for youth leaders to transition into paid jobs as adults. Future investigation should also assess the ages and developmental stages of youth participants, and ways to strengthen the developmental fit of participatory approaches (Suleiman et al. 2019; Torres-Fleming et al., 2010). Last, there is a need to assess the impact of the evidence and actions generated by youth at the organizational and systems levels. Overall, creative and partnered research on youth participatory approaches is needed to bring together the expertise of youth and youth-serving organizations, with academic scholars, to investigate research and evaluation questions of relevance for advancing health equity.

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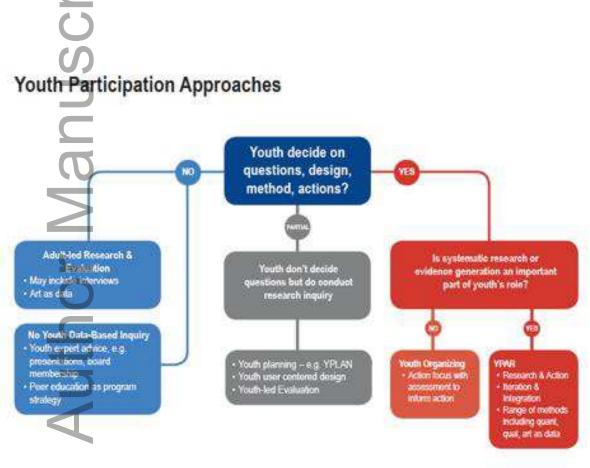
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Figure 1. Decision tree for the range of youth participation approaches



Youth Participation Approaches