CHAPTER 1

Health Research with Adolescents

> [S]haring power . . . is particularly vital in working with youth who are subordinated in multiple realms of their lives.
>
> L. Rodriguez and T. Brown, 'From voice to agency: Guiding principles for participatory action research with youth'

Chapter Highlights

1. Adolescence is a complex and multifaceted concept as biology, age, psychology, culture, content and time have an impact on this definition.
2. Adolescents should be included in health research and service development, but there are still significant barriers to their participation.
3. Participation is a multidimensional concept.
4. Participatory methods is an umbrella term encompassing several epistemological approaches and methods.

This chapter is focused on understanding crucial concepts including adolescents, participatory research and health research and technology, and how and why these concepts can be related to each other. The chapter begins by providing a definition of adolescence. Why? Because depending on your culture and your background, this might mean something different to you. Participatory research is also an umbrella term for a series of methods which share commonalities but also important variations. These methods serve different purposes and uses. Some are more suitable to answer specific research questions than others. Therefore, a guide to this variety of methods – together with examples, facilitators and challenges – is given in this chapter.

1.1 What Is Adolescence?

The term adolescence originated from the Latin term *adolescere* which means 'to grow maturity' (Banati & Lansford, 2018). It is important to acknowledge that adolescence is a social construction, defined by specific communities and cultures (Sawyer & Patton, 2018). Historically, adolescence begins with the onset of puberty (biological) and ends with social role transitions into adulthood (social), for example, employment, financial independence and parenting (Sawyer & Patton, 2018). The definition of adolescence, however, varies by country and cultural context (Patton et al., 2016), as well as historical time and location (Wulf-Andersen et al., 2021a).

Adolescence has been defined as a transitional phase of life between the two more stable stages of childhood and adulthood (Wulf-Andersen et al., 2021a). There are also biological changes that characterise this developmental stage (Patton et al., 2016). Adolescence is characterised by brain development and interaction with the social environment shaping the capabilities adolescents will bring to their adult life (Patton et al., 2016). The physical, psychological and cultural expressions of adolescence can appear at different times in a person's life (Banati & Lansford, 2018). Adolescents should not be understood as a specific age cohort (Wulf-Andersen et al., 2021a). Adolescents in this stage acquire the physical, cognitive, emotional and economic resources that are the foundation for health and well-being later in life (Patton et al., 2016).

Adolescence has also been explained by theories of adolescent development. For example, Erik Erikson proposed an eight-stage model. The identity versus role confusion stage covers 12–18 years of age, with people of this age typically described as adolescents. In this stage adolescents affirm their ideals, values and sense of self, as well as experience rejection, which may lead to insecurity and confusion. Another classical theory of development is that of Jean Piaget. Adolescence corresponds to the fourth and last stage of his theory, the formal operational stage. This is a stage of the establishment of reasoning about tangible, hypothetical and abstract objects and manipulating mental representations. These classic models of development are informative; however, research has identified that not all children and adolescents follow these developmental trends. Determining adult–child communication solely by developmental ages and stages can be misleading, as this may underestimate or overestimate children's and adolescents' abilities (Alderson et al., 2006), particularly those who have experienced illness or disability from a young age.

Wulf-Andersen et al. (2021a) defined adolescence as 'a life stage in which social positions and processes shape young people's ability to make choice, and their life chances, in particular historical and societal contexts' (p. 12). Therefore, research and methods must be capable of dividing up and capturing the commonalities and differences between adolescents. Adolescents and researchers are not a homogeneous group and therefore specific research activities may impact young people and researchers differently (Wulf-Andersen et al., 2021b). Research must not privilege the views and perspectives of specific groups of children and adolescents over others. According to Hampshire et al. (2012) differences in age, gender, class, wealth, disability, family situations and personality are bound up in complex power relations that ultimately shape the research carried out with these children and adolescents.

Even though adolescence should not be defined exclusively by age, sometimes this is needed to define the samples or populations that will be included or excluded from a research study. This has a practical justification; for example, the research resources and capacities for inclusion and other developmental markers of a specific culture or group where there is an agreement of adolescents as a group. Considering the limitations of this generalisation, defining a group by age may be justified. And, if so, the next challenge is to define the age boundaries of adolescence, on which there is no consensus either.

Under the United Nations Convention of the Rights of the Child (UNCRC), a child is defined as anybody under the age of 18. The World Health Organization defines adolescents as aged between 10 and 19 years of age, whereas youth is between 10 and 24 years of age (King et al., 2022). Different definitions can also be found in published research studies; however, these use different groupings and terminology. For example, youth (15–24 years) (Patton et al., 2016), young people (10–24 years) (Patton et al., 2016), youth and teenagers (13–18 years) (Hart, 1992) and young people is the umbrella term to refer to both groups (Hart, 1992). Overall, the terminology used is complex and often differs across countries and social contexts (Gibbs et al., 2020).

Age Categories

For reporting age disaggregated data in adolescent research, Patton et al. (2016) provided the following age categories:

1. Early adolescence: 10–14 years
2. Late adolescence: 15–19 years
3. Young adulthood: 20–24 years

1.2 Participatory Health Research with Adolescents

Investing in adolescent health and well-being is beneficial today but the impact lasts over decades and into the next generation (Patton et al., 2016). Adolescent morbidity has an obvious consequence but also a cost for society. It is necessary to consider public accountability of money invested in adolescent programmes to reduce risk and improve adolescent health if these programmes are ineffective (Rogers et al., 1994). Adolescence is a time when individuals make increasingly complex decisions affecting their health and wellness (Flicker & Guta, 2008). Adolescents' healthy development involves making informed decisions, managing risks and negotiating options regarding their health (Flicker & Guta, 2008). There are major knowledge gaps in adolescent health needs and, therefore, there is a lack of evidence base for action, civil structures for advocacy and the systems to ensure intersectoral action (Patton et al., 2016). Additionally, participation of adolescents in healthcare may be more viable in some countries than others. In some jurisdictions their involvement is compulsory. For example, the Medical Treatment Agreements Act (WGBO, 1995) is a Dutch Act where adolescents between 12 and 15 years can co-decide with their parents about their treatment. Adolescents over 16 years of age can make treatment decisions on their own. According to Van Staa et al. (2009) these opportunities are limited in primary care. Particularly relevant to participatory methods, adolescents are often excluded from research that is necessary to improve their health and inform health policy (Society for Adolescent Medicine, 2003).

Research has a significant role in ensuring healthcare is sustainable, effective, efficient, safe and appropriate; however, society and health systems are not currently getting the maximum benefits from research findings (Jull et al., 2017). Adolescent research is also disproportionately focused on adolescents in high-income Western contexts and is mostly published in English (Banati & Lansford, 2018). Effective adolescent health programmes need adolescents' involvement in designing programme objectives, policy development and allocation of resources (Ballonoff et al., 2006). Health disparities that adolescents experience will continue until they are fully engaged as partners and leaders in addressing social inequalities and health issues as well as planning and evaluating health programmes targeted at them (Ballonoff et al., 2006). Younger adolescents are usually missing from the data, which mostly focuses on those aged 15 years or over (Patton et al., 2016). Effective planning responses require data that is timely, developmentally appropriate and locally relevant. Ideally, data should be longitudinal and global, enabling analysis of differences between countries over time (Patton et al., 2016). Currently, low- and middle-income countries are dependent on global surveys for their own health policy and planning (Patton et al., 2016).

On a positive note, research with children and adolescents is increasingly using participatory approaches to inform health resources and interventions (Freire et al., 2022). Participatory health research is based on the premise that children and adolescents should be involved in decision-making processes about their health as this is a way to enhance and promote their self-esteem and positive self-regard, which can subsequently enhance their well-being (Coyne, 2006). Including adolescents in health-care agendas is an acknowledgement that they are important consumers of healthcare, individually and collectively (Coad & Shaw, 2008). Giving citizens choice about services can improve standards, efficiency and increase patient-centred care (Coad & Shaw, 2008). Children and adolescents can express their views on living with chronic illness and disability, as well as communicate their needs and provide ideas on how to improve the quality of healthcare services (Van Staa et al., 2009). Coyne (2006) asked children about being involved in decision-making and they expressed a need for consultation and information to help them understand their illness, prepare themselves for procedures and take actions towards ‘getting well’. The study found, however, that opinions were often underused, with some expressing a lack of consultation about bed allocation, food preferences, waking time and sleeping time.

Adolescence is the developmental stage where specific health problems emerge due to the beginning of sexual activity, emotional control and risky behaviour (Patton et al., 2016). Adolescence is also a time of academic disengagement and emerging psychopathology (Ozer et al., 2010). Globally, adolescents can experience health issues as a consequence of unhealthy lifestyles, unemployment, lack of family stability, environmental issues, armed conflict and mass migration (Patton et al., 2016). Adolescents have several unmet needs in their healthcare, and they may experience barriers due to inexperience and lack of knowledge about how to access it; they can also experience confidentiality breaches (Patton et al., 2016), which could lead to a loss of confidence in the system overall. Adolescents should have accurate knowledge about local services and they should know where to turn to if they need help and advise their peers about where to find the help they need as well (Oppong-Odiseng & Heycock, 1997). Over time, physical health in adolescents has improved; however, mental health issues have increased (Department of Health, 2003). Mental health issues are significant in adolescents as it is the age when mental health outcomes persist and can even worsen over time, even for adolescents in clinical care (Cheng et al., 2018). A significant challenge is that research on adolescent health lacks indicators on topics such as mental health, substance disorders, obesity, physical activity and fruit and vegetable intake (Patton et al., 2016). Adolescence, however, is also the stage where opportunities for good health are created for adulthood (Whitehouse et al., 2013).

Overall, the way to achieve a fairer and healthier society is to improve health and overcome health inequalities early in life (Department of Health, 2003). Almost all the countries in the world have ratified the UN Convention on the Rights of the Child; however, there are vast differences in legal frameworks which underpin adolescent health. Additionally, in some countries customary or religious laws take precedence over adolescent rights (Patton et al., 2016). At a practical level, some hospital policies support child-centred services, for example. This means children and adolescents should be partners in decision-making and exercise choice about their health and care (Coyne, 2008). Despite this, children and young people are rarely involved in consultations and decision-making regarding their healthcare. Coyne (2008) identified some of the reasons for this as:

1. not knowing health professionals
2. not wanting to hear bad news
3. fear of asking questions and causing trouble
4. being ignored
5. not being believed
6. experiencing difficulties contacting health professionals
7. not being listened to
8. difficulty understanding medical terms.

Healthcare professionals and parents have a significant role in enabling adolescent participation (Coyne, 2008). Healthcare professionals usually direct conversations mostly to parents, and children and adolescents become accustomed to playing a passive role or may assume this role to avoid censorship from adults (Coyne, 2008). The situation can be more difficult for specific groups of adolescents, as they experience added exclusion and vulnerability; for example, the needs of ethnic minorities, LGBTQ+ people, those with disabilities and those who are homeless or in juvenile detention are usually invisible (Patton et al., 2016). Seldom are children and adolescents with disability and chronic illnesses involved in health service development (Sloper & Lightfoot, 2003; Watson et al., 2006). Adolescent involvement is possible and can generate benefits for them. There is currently, however, a gap in children's and adolescents' own views of their experiences in service development (Sloper & Lightfoot, 2003). There is a lack of evaluative research to determine if adolescents' decisions and choices are acted upon and if healthcare providers are responsive to their needs (Coad & Shaw, 2008). Hallström and Elander (2004), for example, explored decision-making of parents and children aged 5 months to 18 years during hospitalisation and identified that children and parents made few decisions themselves and, if they disagreed with a decision, on very few occasions was that reconsidered. The authors argue that children and adolescents may not have the knowledge to make decisions about medical interventions but that they can participate when decisions are made.

When including adolescents in research and service development, methodology is fundamental. Stafford et al. (2003) suggested that there is an increasing tendency in research with children and adolescents to use a combination of methods, as this can help overcome the limitations of a single method. It has been established that a single method cannot capture the fullness of the experience of participants and therefore the use of multiple methods can also help active engagement (Stafford et al., 2003). According to Larsson et al. (2018), methodology can convert a traditional top-down research paradigm into a more egalitarian one, increase credibility and reduce biases by triangulating different data sources. Methods that enable participants to actively express themselves – including drawing, painting, storytelling, software, digital tools and mapmaking – achieve higher levels of participation (Larsson et al., 2018). These methods are not a guarantee of a participatory approach, but they can promote a sense of control in participants that may lead to more active participation (Larsson et al., 2018).

Setting is another important element to consider when carrying out participatory health research. For example, Sartain et al. (2000) showed that episodes of illness and unfamiliar environments (e.g. hospital settings) may have an effect on the cognitive and behavioural activities of children. This may also have an impact on research and data collection and the answers participants provide as a result of a crisis or a specific situation, which may not have been their answer in different and more familiar circumstances.

Sommer et al. (2021) suggest that it is essential to use creative approaches that have rigorous designs, capture the richness of the data and empower adolescents to capture their perceptions, desires, experiences and recommendations. Additionally, Sommer et al. (2021) suggest that data triangulation can be very useful to gather in-depth sensitive data such as that regarding adolescent alcohol consumption and sex life. Triangulation can combine, for example, participatory and more traditional methods such as in-depth interviews.

Table 1.1 *Methodologies by research objective*

Research Purpose	Suggested Methodologies
1. You want to understand what adolescents perceive as a problem, the context of adolescents' lives and where there is potential for most impact.	Surveys Co-design workshops Focus groups Interviews Online discussions Facebook polling
2.The area of focus, impact and outcomes are already defined. You want to use these methods to understand how the issues/topics should be positioned in a meaningful and engaging format which will lead to developing concepts and strategies relevant for adolescents.	Focus groups Brand testing Friendship interviews Online discussions Card sorting Co-design workshops Crowdsourcing
3.You have concepts, prototypes, products and services. You want to know if these are engaging for adolescents and how to improve them.	Co-design workshops Prototypes Usability testing Pilot testing Mobile diaries

Hagen et al. (2012) provided useful suggestions for adequate methodologies by research purpose or objective, as shown in Table 1.1.

There is also no 'right method' as different methods will suit different adolescents; every method will suit a different research purpose, so the 'fit' should be carefully considered (Lightfoot & Sloper, 2002). The skills and experience of the research team are therefore crucial to select the most suitable method or combination of methods according to the research aims, objectives and resources available.

Incorporating adolescents with special needs and characteristics is a challenge. Working with adolescents with a chronic illness or disability requires serious consideration regarding their needs. For example, Lightfoot and Sloper (2003) experienced challenges with data collection with adolescents as they wanted to carry out group interviews but participants with cystic fibrosis, for example, were at a high risk of cross-infection in group situations. This shows that researchers should consider the specific diagnoses of potential participants when designing studies. Additionally, children with chronic illnesses should not be treated as a homogenous group, but their abilities, diversities and specific illness needs should be taken into consideration (Sartain et al., 2000). B. Young et al. (2003) identified that managing communication with adolescents who have a life-threatening chronic illness can be complex, as parents have an important role in communication, and they can both facilitate and constrain that communication. Health professionals, as well as researchers, need to be aware of the executive roles parents have when professionals seek a relationship with adolescents (B. Young et al., 2003). This may explain why participation of adolescents with chronic conditions in medical decision-making and service evaluation is limited (Van Staa et al., 2009).

Burstein et al. (2005) carried out a study with adolescents with special health needs using a participatory action research (PAR) approach. Adolescent diagnoses included spina bifida, cerebral palsy, traumatic brain injury, spinal cord injury, epilepsy and errors of metabolism. The research study was carried out by the researchers and three adolescents with special needs themselves. It is important to note that these adolescents had specific characteristics and experiences that made them suitable for this role. Two adolescents had taken part in the pilot study and another adolescent had previous experience working with adults with acquired disability and was a community advocate (Burstein et al., 2005). Burstein et al. (2005) used different technology to support data collection; however, alternative methods were also available to cater for the different needs of participants, therefore maximising active participation. The *Youth Individualized Planner* consisted of emergency medical information, medical records and a daily planner. It also included data collection sheets, weekly and monthly summaries of health status, social events and records of research goals. The *Personal Digital Assistant* recorded participants' personal data digitally and this information could be downloaded for tracking, analysis and graphing. This tool was particularly suitable for those adolescents that struggled to write (Burstein et al., 2005). Burstein et al. (2005) argue that PAR is ideal to work with adolescents with disabilities, as it is empowering and focused on identifying solutions for participant problems.

1.3 Adolescents, Technology and Health

Technology is becoming and will continue to be the driving force of economic growth and social development; however, investment in digital education is low (Banati & Lansford, 2018). Contemporary life is saturated with technology and media and these drive and transform society, culture and individuals (Moyer, 2023). It is therefore important to ask how adolescents navigate their identity and perceptions within this heavily mediated society in which they live (Moyer, 2023).

Technology is a seamless part of how adolescents conduct their lives (Flicker et al., 2008). New media and technology are now a central part of adolescents' lives, resulting in new forms of communication, identity formation and social relations (Mallan & Singh, 2010). Adolescents are having to adopt technologies at a faster rate (Moyer, 2023). Adolescents tend to embrace new technologies, currently representing an estimated one in three users worldwide (Gibbs et al., 2020).

Technology and new digital media provide opportunities for adolescents to nurture skills, connect with others and engage in meaningful play. They also offer skills that can support their future careers, civic engagement and contribute to overall good (James et al., 2009). Adolescents can engage with new digital media in many ways and therefore can assume a variety of different roles (James et al., 2009) including the ones shown in Table 1.2.

One of the challenges of involving technology in research with adolescents is the fact that there is still an uneven access, due to several factors including geographical and economic inequalities. These differences shape the ways in which adolescents use and interact with technology in their daily lives (Mallan & Singh, 2010). It is therefore necessary as researchers to reflect on how your study will approach these inequalities. Will the research continue to reinforce the existing inequalities? For example, by including those who currently have access or to instead take a more democratic approach and include those who have traditionally been excluded or have had limited access. This, of course, is determined by

Table 1.2 *Adolescent roles in digital media*

1.Self-expression and identity experimentation	Adolescents can engage in creative activities such as creating avatars, role playing, games, virtual worlds, creating content, sharing content through blogs, music sharing sites and social media.
2.Social networking	Adolescents can engage with friends, reach out to people with similar interests and find social support.
3.Gaming	Adolescents can engage in single- and multiple-player games and role-playing games.
4.Consumption and entertainment	Adolescents can do online shopping, download music and watch videos.
5.Education	Adolescents can engage in teaching, mentoring and learning from their peers through online communities, programmes and other informal learning environments.
6.Knowledge building	Adolescents can engage in different activities such as research, schoolwork, following news and using other ways of gathering information like Wikipedia, Google and online news.
7.Dialogue and civic engagement	Adolescents can engage in public discourse, promoting social change and political, social and cultural critique.

many factors such as local access to resources such as internet access and funding. How much of the research funding can support democratisation of technology? For example, by providing adolescents with hardware to increase their access or software to be involved in a study. At the very least, research studies should be transparent and explicit about how these inequalities were given careful consideration and a description of the efforts made to reduce them. They should also include the reasons why these inequalities (geographical, economical, structural) were not dealt with if this were the case.

Researchers working with adolescents and technology should not assume that all adolescents are interested in technology, that they are all tech-savvy and have the skills and knowledge to work with technology successfully. The reality is they may not be. Research with technology should also be transparent and admit that studies using technology will probably include a sector of adolescents who are interested and possibly confident in the use of technology. As Mallan and Singh (2010) suggested, the social realities and lived experiences of adolescents are different; there is no ‘one best’ approach to researching their experiences.

Rapid advances in technology can provide opportunities for adolescents to influence health policy and practice (Gibbs et al., 2020). ‘Adolescents are not passive technology users but active agents capable of widespread social change’ (Gibbs et al., 2020, p. S15). Technology can be an opportunity to appeal to adolescents and engage them in health promotion (Flicker et al., 2008). For example, health intervention with adolescents has been traditionally delivered face-to-face in individual or group sessions. This means sessions rely on factors such as ability to travel, time commitment and financial capacity of participants (Malloy et al., 2023). The digitalisation of healthcare can contribute to facilitating reach and access to health services (Malloy et al., 2023). Adolescents who are active technology users may be suitable to produce adequate content that is attractive to their peers (Oridota et al., 2023). Social media can provide a ‘voice’ for adolescents to engage with peers and communities (Patton et al., 2016). Digital media has the potential to improve the sharing and presentation of data, generate new data, improve the quality of data and enable data sharing with a wider audience (Patton et al., 2016). New media is an opportunity to extend adolescents’ social networks and engage with new ideas and like-minded peers despite cultural and geographical differences (Patton et al., 2016). Technology, therefore, offers a possibility of having the healthiest generation of adolescents ever (Patton et al., 2016).

Recommendations for Participatory Action Research (PAR) Authors

The following are recommendations for PAR authors on how to report their research (Shamrova & Cummings, 2017):

1. Include participants' age.
2. Describe in depth the involvement of adolescents and their roles in the research.
3. Be explicit about the distribution of power between adults and participants and the nature of the relationship (e.g. who initiated the research, description of the cultural context in which adult–participant relationships take place).
4. Describe the PAR methodology used in detail as well as any challenges experienced.

1.4 Participation

Participation is defined by Hart (1992) as the 'process of sharing decisions which affect one's life and the life of the community in which one lives' (p. 5). It is described as a fundamental right of citizenship; according to Hart (1992) participation is the standard by which democracies should be measured. This definition, however, excludes children and adolescents who do not live in a democratic regime or culture which means their participation is already limited by the context they live in, and research may reinforce this. Participation becomes particularly relevant for children who live in disadvantage, as this is an opportunity to learn about their capacity and ability to fight for their rights in equality and solidarity with others and also to exert their rights (Hart, 1992).

Participation as a democratic exercise requires confidence and competence; according to Hart (1992) these must be acquired gradually through practice. Participation also requires motivation from adolescents. Adolescents can manage complex projects if they have a sense of ownership (Hart, 1992). In research, this means involving adolescents in designing project aims, for example (Hart, 1992).

Participation is a multidimensional concept. According to Sinclair (2004) it is made up of four components:

1. Level of participation. The level of participation can be determined using different models of participation, for example Hart's ladder of participation; however, there are several models that are described in more detail in Chapter 10. The ideal level of participation may be different depending on the activity, the project or the organisation.

2. Focus of the decision-making. The focus of decision-making may vary depending on the target, whether it is service planning, service development, policy, or decisions targeted at a specific organisation only. Private refers to decision-making within the family context or between people. Public refers to public services. Additionally, decisions may also relate to the child individually and others may affect the whole group.
3. Nature of the participatory activity. Participation activities can have many different forms, for example one-off consultations, involvement in governance or adolescent-led initiatives.
4. Children and adolescents involved. Children in this case are defined as those under 18 years of age (UNCRC definition). This, however, includes a very diverse group with different personal circumstances (age, sex, ethnicity, culture, disability, social and economic circumstances), interests and capacities, which also change over time as children grow. Therefore, there should be an array of forms of engagement and dialogue that 'start from the position of the child' (Sinclair, 2004, p. 109), independent of their age or ability.

Specifically, regarding different levels of participation, adolescents may have various roles in research, which are described by Checkoway and Richards-Schuster (2003) in Table 1.3.

Table 1.3 *Adolescent levels of participation*

Adolescents as subjects	Adolescents are observed, tested, measured, enumerated and analysed by researchers. Participants are usually unaware of how the research was designed, how the data was gathered or how the findings were disseminated, even if these are included in subsequent publication that may benefit adolescents.
Adolescents as consultants	A study is initiated by an adult in consultation with adolescents to make the study more effective. This consultation may include advice on the age or cultural appropriateness of interview questions. Adolescents' knowledge about themselves is recognised.
Adolescents as partners	Adults initiate a project and involve adolescents as partners with both an equal and unequal level of participation. For example, young people may be trained in research methods and actively engage in the research, for example involving students in surveys with younger classmates.
Adolescents as directors	Adolescents organise their own research project to work on solutions needed in their communities. The underlying motivation is to take action and not to develop knowledge.

1.4.1 Theoretical Underpinning of Participation

Gibbs et al. (2020) provide some of the theoretical underpinnings of participatory research. This includes a rights-based, an instrumental and an empirical approach. Ozer et al. (2018) consider these frameworks should be complementary instead of dichotomous.

1.4.1.1 Rights-Based Approach

Adolescent participation in health-related research, specifically in relation to services and systems that affect them, is a fundamental right (Gibbs et al., 2020). International policy has been very significant in the development of participatory research, for example the UNCRC. The United Nations (UN) held a special session at the UN General Assembly on Children in 2002 where the document 'A World Fit for Children' was supported by the UN, UNICEF, UN agencies, governments, civil society organisations and non-governmental organisations. This document states that:

> Children, including adolescents, must be enabled to exercise their right to express their views freely, according to their evolving capacity, and build self-esteem, acquire knowledge and skills, such as those for conflict resolution, decision-making and communication, to meet the challenges of life. The right of children, including adolescents, to express themselves freely must be respected and promoted and their views taken into account in all matters affecting them, the views of the child being given due weight in accordance with the age and maturity of the child. (United Nations General Assembly, 2002, p. 7, cited in Coyne, 2008)

1.4.1.2 Instrumental and Epistemological

Adolescents can provide a unique 'insider's' expertise that increases the validity of adolescent-generated research knowledge on health and well-being, which can lead to better and more effective design of service and systems for adolescents (Gibbs et al., 2020).

1.4.1.3 Impact on Development

Youth-led participatory action research (YLPAR) can positively impact on adolescents' development by enabling leadership opportunities for them, shifting the perspective of practitioners in recognising the value of adolescent input in key decisions (Gibbs et al., 2020). Involvement in YLPAR can be particularly beneficial for adolescents who experience disadvantages and challenges to their agency (Gibbs et al., 2020).

1.4.1.4 Empirical Rationales

Empirical rationales are focused on the potential to enhance the effectiveness and impact of programmes and policies designed with adolescents as 'active partners rather than passive recipients' (Ozer et al., 2018, p. 671). Empirical rationales perceived adolescents as 'experts', therefore capable of generating valid knowledge (Ozer et al., 2018).

1.4.2 Developmental Considerations of Participation

Development is one of the underpinning theoretical principles of participation. This section describes in more detail the developmental principles in participation. Development can be defined as a process of 'mutual interaction between the individual and their environment', which, according to de Winter et al. (1999, p. 16), consists of family participation, social and emotional development, perspective of others and gender. These are explained below.

1.4.2.1 Family Participation

Adolescents, in most cases, will probably have a family, or a unit they perceive and describe as family. An adolescent's rearing and attitudes towards their participation may not include providing or enabling them to have a voice. According to Hart (1992), this can be particularly relevant for children who live in disadvantaged countries or in low-income contexts, as parents (or the adults who fulfil this role) may perceive that they themselves have no voice or authority. Adolescents' participation may mean and involve whole family participation. Adolescents could be the instigators and their parents/families should at least be aware of the process (Hart, 1992). Working with families may start a move towards creating a more democratic society with equal rights for all (Hart, 1992).

1.4.2.2 Social and Emotional Development

According to Hart (1992), self-esteem is a critical variable affecting children's and adolescents' participation. The value judgement children and young people make based on their sense of competence in doing things has an impact on their participation and can also improve their self-esteem (Hart, 1992). Children and adolescents with low self-esteem may have distorted communication and difficulties expressing themselves and this might negatively impact their participation (Hart, 1992).

1.4.2.3 Perspective of Others

The ability to participate also depends on children's and adolescents' capacity to take the perspective of others. This ability develops over time from an early age to adolescence (Hart, 1992). Having the capacity of 'mutual perspective taking' is crucial when being part of democratic groups (Hart, 1992). Adolescents, developmentally, can imagine multiple mutual perspectives including social, legal and moral ones that all individuals can share (Hart, 1992).

1.4.2.4 Gender

Participation opportunities for girls and boys are unequal. Girls and boys are treated differently in different cultures and societies (Hart, 1992). Research studies and programmes should include boys' and girls' participation equally and this can have special significance for girls who can experience barriers to effective participation in family, school and community (Hart, 1992).

There is significant growth in participation activity (Sinclair, 2004); however, the challenge remains around the clarity of who is involved and who is not. Some groups of children are less likely to be included, for example young children, children with communication difficulties and those who in general have limited involvement in local agencies. Information is needed to monitor the extent to which children are being provided opportunities for participation (Sinclair, 2004). According to Stafford et al. (2003), girls are more likely to volunteer for consultative research than boys and they tend to have more verbal skills to express themselves assertively in group discussions. The reasons for these differences were not described; however, it seems to be important to create safe and appropriate environments where adolescents from both genders feel comfortable and happy to express their views.

1.5 Participatory Research

Defining participation is challenging; therefore, defining participatory research is challenging, as different authors have overlapping principles, but add or focus on different aspects. Some authors emphasise participants' creation of knowledge as the ultimate characteristics of participatory methods. For example, Foster-Fishman et al. (2005) highlighted that the role of the researcher is to facilitate knowledge creation and support participants to discover their own understandings to facilitate them in creating change. Participatory methods promote participant control over what knowledge is generated and how it is used, and they foster learning through action and reflection (Foster-Fishman et al., 2005). Participatory research is ‘carried out with and by the research subjects rather than on them’ (Van Staa et al., 2009, p. 96).

Knowledge produced in participatory research is used to guide and achieve collective change in communities, organisations, programmes and research participant themselves (Powers & Tiffany, 2006). Additionally, knowledge generated through participation is culturally relevant and connected to the lived experience of participants, therefore it is more readily converted into action compared with academic theory and knowledge generated by outsiders (Wridt, 2018).

Participatory research ‘can fall between the crack that separates intention from action’ (Mallan & Singh, 2010, p. 269). There are several factors that can lead to this fall including institutional, generational and ideological ones. Institutional ones may include funding timelines and expectations. According to Mallan and Singh (2010) there is an inevitable mismatch between the world views of researchers and participants. Practical reasons may include negotiating spaces for adolescents that can meet the ethical expectations from schools, parents and universities (Mallan & Singh, 2010).

Participatory approaches have shown promise in increasing participation with adolescents that have been historically underrepresented in research, for example adolescents of colour and immigrants (Valdez et al., 2021). Geppert (2023) chose a participatory design in a research study with adolescents who were marginalised by race, class, ethnicity, gender and sexuality.

1.6 Adolescent Participation

Adolescent participation approaches is an umbrella term which encompasses a variety of ways in which adolescents can provide their expertise, from informal sharing in adult-led environments to more formal advisory boards and councils, and systematic youth-generated research as well as structured planning and design processes (Ozer et al., 2018). Participatory approaches share the principle that young people have the expertise to address issues that have an impact on them; however, they differ in their emphasis on research and equity (Ozer, 2016).

Adolescent participation is the process of sharing decision-making on issues that affect adolescents and their communities (de Winter & Noom, 2003; Shamrova & Cummings, 2017). Participatory research involves adolescents not as ‘the problem’ but as ‘subjects of knowledge’ who can identify, understand and find solutions for social problems (Wulf-Andersen et al., 2021a, p. 6). Not listening to the views of children and young people on matters that affect them is wrong, as it is a breach of their human rights (Lundy, 2018). Also, not seeking their views on the basis that it would be tokenistic is also wrong (Lundy, 2018). This means it is also wrong of adults to encourage participation if adolescent views are not given due weight (Lundy, 2018). Providing participants with the results of the research study is important; however, it is more important to also provide feedback on how their views are taken seriously (Lundy, 2018). This is described by Lundy (2018) as the necessary minimum, but researchers should encourage adults to engage in more meaningful ways.

Adolescent participation is therefore recommended practice; however, this has challenges, both logistical and ethical (Schelbe et al., 2014). Participation requires effort, resources and time, ensuring participants have access to information, understand the research topic and support provision (Lundy, 2018). Adolescent participation is uneven; some participate with fervour and others may express interest but may be unsure about how to deal with the research process (Checkoway & Richards-Schuster, 2003). Others may participate but lack support from adults or face obstacles to their participation (Checkoway & Richards-Schuster, 2003). Participation is always imperfect (Lundy, 2018). This is not bad; this is the validation that ‘real world research’ is challenging and there is no expectation of perfection, which is not the same as ethical and good practice, which should be the goal.

Participation quality is not measured by the quantity of adolescents who are involved in the research; it is measured by its effectiveness when adolescents influence the process, how they have an impact on decisions or how their involvement leads to a favourable outcome (Checkoway & Richards-Schuster, 2003). Additionally, participants may have not perceived or understood the process as participatory for themselves (Holland et al., 2010), even it was intended as participatory research design.

Adolescent participation can have several benefits and provide significant skills for adolescents. Benefits of participation can have a long-term impact. For example, de Winter and Noom (2003) used the participatory method in their research project as a model that could be adapted and used by agencies and institutions dealing with adolescents to enhance their dialogue and quality of care over time. Some of the benefits of adolescent participation are enumerated below:

1. Social action. Participation can be a way to develop knowledge for social action. Adolescents want to act, improve their communities and

provide credible information for action-taking (Checkoway & Richards-Schuster, 2003).

2. Political rights. Participation can enable adolescents to exercise their political rights (Checkoway & Richards-Schuster, 2003).
3. Democratisation of knowledge. Adolescents can mobilise knowledge to break the monopoly on it and enable youth to have information they need for competent citizenship (Checkoway & Richards-Schuster, 2003).
4. Active participation in democratic society. Participation can activate adolescents' civic engagement and enable reflection about problems in their community as well as acting in civil society (Checkoway & Richards-Schuster, 2003). It can also empower them to create social change (Powers & Tiffany, 2006).
5. Social development. Adolescent participation can encourage social development in adolescents by increasing their involvement, organisational development and their capacity to generate change in their community (Checkoway & Richards-Schuster, 2003). Adolescents can also serve as role models to other youth as experts with local knowledge about issues that affect them (Powers & Tiffany, 2006).
6. New relationships. Adolescents can form new relationships with adults and members of the broader community (Powers & Tiffany, 2006).

Participation can also foster psychological well-being (de Winter & Noom, 2003) and civic engagement as well as increased self-confidence (Van Staa et al., 2009) and an opportunity for meaning-making for research participants. Van Staa et al. (2009) found that taking part in the study turned participants' illness into a positive experience (Van Staa et al., 2009).

Fox et al. (2010) argue that the lack of access to civic engagement is sometimes misinterpreted as a lack of motivation. It should be noted that significant differences in race and social class can lead to uneven opportunities of participation for children and adolescents. M. Fox et al. (2010) identified poor, working-class youth of colour and immigrant adolescents as more likely to have fewer opportunities for meaningful involvement in civic engagements and have too many family responsibilities that hinder their full participation. Fox et al. (2010) enumerated five principles that are crucial for critical adolescent engagement. These principles share many similarities with participatory research principles:

1. Children and adolescents are a source of knowledge and power. Children and adolescents have important knowledge about their social conditions and have ideas about social change, meaning they have political wisdom and an understanding of injustice. Traditional epistemologies where researchers and elders are the ones in possession

of valid knowledge are questioned. Instead, multigenerational collectives of adults and adolescents gather to share their experience, knowledge and ideas about social inquiry. In the research context, research questions, methodological approaches and data analysis are made across the different age groups.

2. A critical analysis to facilitate critical consciousness of history, privilege and power. Adolescents' engagement requires the spaces designated for critical community education where adolescents can develop a systemic perspective of their life circumstances and the impact on their lives of issues like racism, sexism, homophobia and classism which perpetuate inequality. This understanding is the basis of planning, researching, mobilising and campaigning for change.
3. Youth leadership in partnership with adults. At the core of critical youth engagement is adolescent voice and empowerment. The role of adults is to actively guide and educate adolescents with a spirit of mutual inquiry, collaboration and problem-solving. The role of adolescents is to take the lead to generate ideas, facilitate meetings and make decisions. To support adolescents in this role, adults can help them identify relevant information, share knowledge and insights, role play, rehearse, listen and challenge.
4. Intersectionality. Analysing and organising across sectors of everyday life: Critical youth engagement is founded on the idea that different sectors of public life are not separate but are woven into the lives and communities of adolescents. These sectors are health, criminal justice, education, housing, immigration status and economics. Adolescents study and organise within and across all these sectors. Understanding these aspects that shape the lives of adolescents creates the conditions for critically envisioning an alternative future. Cook and Krueger-Henney (2017) additionally consider that unequal structures, such as marginalisation and discrimination, impact adolescents in different ways; every adolescent is implicated as they are bound within the same sociopolitical power dynamics.
5. Collective action for social change. Adults and adolescents can use an intersectional lens to analyse problems in a historical and structural manner to mutually develop strategies for collective action which challenges those same problems. This creates a sense of collective efficacy where everyone must contribute to the effort. This collective efficacy means everyone shares a perception of mutual trust and willingness to help community members in need. This is further supported when it has positive effects on health and student academic achievement.

Participatory research methods are also beneficial for researchers. Sharpe et al. (2022) explained that participatory methods are very suitable for researchers who want to use their creativity to develop inclusive, accessible and adolescent-centred research.

Participatory research also has challenges. It can be more research-intensive, time-consuming, complicated and less efficient than traditional research (Van Staa et al., 2009).

Finally, a concept closely related with participation is co-participation. Although they are presented as separate concepts in research, they have many commonalities. Co-participation, as well as participation, defines children and young people as co-constructors of knowledge as well as co-designers and facilitators of research (Purdy & Spears, 2020). For co-participatory research, the process of research inquiry is as important as the product, findings, outputs and outcomes (Purdy & Spears, 2020).

1.7 Participatory Methods

The following sections of this book explore different methods that share participatory principles but have some epistemological and practical differences. These should not be used interchangeably in research, even if they have shared similarities; these are methods in their own right.

1.7.1 Community-Based Participatory Research

A method included under the participatory research umbrella is community-based participatory research (CBPR), which is a collaborative approach involving all partners equally in the research process and recognising the strengths they bring (Merves et al., 2015). CBPR begins with a research topic relevant to the community which combines knowledge and action for social change (Flicker, 2008). Therefore, the main objective of CBPR is to combine knowledge and action to achieve social change and improvements in the community (Merves et al., 2015), as well as to integrate knowledge gained into policy change to improve health and quality of life of participants (Israel et al., 2005). CBCR is increasingly recognised as a strategy that can lead to eliminate health disparities, achieve community change and improve health indicators (Ballonoff et al., 2006). It has the potential to be transformative and empowering, enabling individuals and communities to achieve sustainable personal and social change (Flicker, 2008). Empowering, however, can go wrong or set up unrealistic expectations for adolescents (Flicker, 2008); this must be prevented by good and ethical practices in research.

Research has identified several benefits of CBPR. Flicker (2008) identified benefits for the research, the researchers and the adolescent participants (Table 1.4). Benefits, however, happen because of substantial investment and may not be equally distributed (Flicker, 2008).

Table 1.4 *Benefits of research for stakeholders*

Research	Stakeholders: Youth	Stakeholders: Academics
Better questions: adolescents helped develop questions that met their needs. **Better recruitment**: adolescents designed the recruitment materials in youth-friendly formats and placed them where they looked for information themselves. **Better data collection:** protocols were revised according to feedback provided by adolescents and considering confidentiality and anonymity. **Better analysis:** adolescents provided new perspectives and understandings for the data. **Better dissemination:** all involved (team, researchers, community providers, adolescents) led dissemination towards their target audiences. **Better action:** community-based organisations integrated recommendations in their work immediately.	**Heard:** those in a position of authority listened to and acted upon adolescent recommendations. **Feeling part of:** adolescents thought it was important to be part of a productive and socially respected team. **Structure:** the project provided structure without school or work, considering their skills and abilities and their barriers including their illness. **Access:** the project facilitated links to other economic supports and social services. **Confidence:** some adolescents experienced confidence in their education and their analytical and research skills. Some considered going back to education. **Learning:** adolescents learnt several social and practical skills transferable to other settings.	**Youth:** academics had an opportunity to demonstrate their passion and commitment to work for youth. **Inspiration:** adolescents were inspired by youth talents and imagination. **Mentoring:** academics found satisfaction in their roles as mentors for the community and graduate students.

Researchers may also experience different challenges when using CBPR. It requires a significant amount of time. According to Flicker (2008), the CBPR project that was undertaken took longer than expected and was demanding for the research team workload as well as partner organisations. Difficulties finding sustainable funding were described, as well as the different perspectives of stakeholders when writing applications (Flicker, 2008).

Israel et al. (2005) identified several potential challenges of using CBPR:

1. Costs incurred and lack of resources. There are community and academic partners involved in CBPR. Developing partnerships requires time and infrastructure, remuneration for involvement and cost coverage.
2. Institutional constraints. Institutional requirements may not match the timelines and needs of communities, for example requirements from review boards, overhead issues, long delays due to data analysis, among others.
3. Lack of trust and respect. Maintaining trust between researchers and communities can be challenging, particularly if there are historical challenges.
4. Ensuring community participation and influence. Building relationships in the community is essential for collaborative and equitable partnerships. This requires skill, time and commitment from all partners to ensure participation and shared decision-making. Flicker (2008) also recognises that with certain topics, such as HIV in adolescents, partnering was crucial as this enabled a new and sensitive territory to be entered in a respectful manner.
5. Lack of training and experience in conducting CBPR. Many researchers and community partners may lack training in CBPR.
6. Different emphasis on goals, values, priorities and perspectives. There are no right or wrong ways in which partnerships work; these should instead accommodate diverse perspectives and cultures.
7. Different languages and communication styles. Members of partnerships and researchers may have different styles of communication.

By itself, CBPR cannot create sustainable change (Ballonoff et al., 2006) – a supportive and comprehensive strategy is required. This will involve a cycle of research, evaluation, planning, implementation, youth organising and youth policy development which leads to social action (Ballonoff et al., 2006). Specifically, regarding health, social change requires time to understand the profound causes and implications of health inequalities

Table 1.5 *Wingspread Declaration*

Community-based Participatory Research and Evaluation with Young People Wingspread Declaration (2002)

- Youth participation in community research and evaluation transforms its participants. It transforms our ways of knowing, the strategies we devise, the methods we employ and our programme of work.
- Youth participation promotes youth empowerment. It recognises the experience and expertise of all young people, and respects their leadership capacities and potential contributions.
- Youth participation builds mutually liberatory partnerships. It values the assets of all ages and fosters supportive and respectful youth/youth and youth/adult working relationships.
- Youth participation equalises power relationships between youth and adults. It establishes a level playing field clarifying for participants the purpose of the process and the power imbalances between groups. It structures environments that respect the involvement of young people, and trains adults in supporting genuine youth decision-making and leadership development.
- Youth participation is an inclusive process that recognises all forms of democratic leadership, young and old. It involves diverse populations and perspectives, especially those who are traditionally underserved and underrepresented.
- Youth participation involves young people in meaningful ways. Young people participate in all stages of the process, from defining the problem, to gathering and analysing the information, to making decisions and taking action.
- Youth participation is an ongoing process, not a one-time event. Participants continuously clarify and reflect upon its purpose and content. Research and evaluation are viewed as an integral part of knowledge development, programme planning and community improvement.

(Ballonoff et al., 2006). Adolescent involvement in social change can lead to meaningful health reforms and health delivery systems that serve the needs of adolescents (Ballonoff et al., 2006).

The Wingspread Declaration of Principles (Table 1.5) is the outcome of a collaboration between adolescents and adults in the Wingspread Symposium on Youth Participation Community Research in 2002. These are useful principles to ensure researchers are adhering to the principles of CBPR.

1.7.2 Co-design

Co-design is another method that is usually associated with participatory methods. It consists of a space where adults and young people work together in the creation of something new (Bowler et al., 2021). According to Malloy et al. (2023) co-design arose from participatory design, and it consists of several participatory methods which seek to understand and integrate real-life experiences from participants to improve services in an ethical and pragmatic way. Co-design therefore shares some similarities with PAR, as both approaches enact the views of adolescent participants and validate the participants' lived experiences (Bowler et al., 2021). One of the challenges of co-design is the lack of clarity around its definition and there is also a need for evaluative research to determine its impact. These two elements have been described as 'especially unhelpful' for the field (King et al., 2022).

Co-design interventions have the advantage that these will be better used and accepted, if they are co-designed with the target populations, particularly if these are traditionally vulnerable populations. These interventions can be useful to reduce inequality (King et al., 2022). One of the challenges with co-creation is the clarity and transparency of the method and its application. Bowler et al. (2021) consider that co-designing with children and adolescents can seem like a 'black box' as there should be transparency in what happens in the collaborative space, and this is not always the case.

1.7.3 Co-creation

Co-creation is the 'collaborative generation of knowledge by academics working alongside stakeholders from other sectors' (Ito-Jaeger et al., 2022, p. 1634). Fisher and Jensen (2013) defined co-creation as an approach where researchers, users and others work as a team through direct involvement in the design of a product, in this case. The product can be the research study. Leask et al. (2019) defined co-creation as the process where solutions are tailored based on the needs of individuals and circumstances in collaboration with these individuals. Co-creating places with adolescents will enable critical inquiry about their lived experiences towards acting and this can be a healing process (Goessling, 2020). Participatory methods have also been described as a 'co-creation' between researchers and participants (Mallan & Singh, 2010), so both concepts may be closely related yet not equivalent.

From the perspective of co-creation, adults have a duty of self-awareness and self-reflection on the impact they have on the research process. 'Conscious co-design' consists of a self-reflective and deliberate planning from the adults involved in the process, preventing already existing problematic dynamics which may affect less empowered participants; these should not be reinforced in the co-design process (Bowler et al., 2021).

According to Bowler et al. (2021) this represents an 'ethical stance'; the role of all participants should be transparent and demonstrate respect for all participants, independent of their level of involvement.

In terms of suggested sample sizes for co-creation, Leask et al. (2019) recommends having between 6 and 12 participants when using methods such as focus groups. Having the upper range also enables the group to be divided into smaller groups for other types of activities.

1.7.4 Participatory Design

Participatory design is a method in which the end user has an active role in the design process (Bowler et al., 2021). It also shares principles of participatory research. Users and designers engage in a collaborative relationship where users are members of the design team. Children, adolescents and adults actively shape technology development and advancement (Bowler et al., 2021). Including end users does not lead directly to equality; this will only be achieved when adolescents are recognised as partners.

Participatory designs have also been applied in other areas such as healthcare, civic engagement and cultural heritage, moving from focus on a specific product to improving quality of life more generally (Bowler et al., 2021).

1.7.5 Participatory Action Research

Participatory action research (PAR) is an empowerment approach for social change (Flicker et al., 2008) and has a strong social justice orientation (Rodriguez & Brown, 2009). It encourages participation and leadership, as it enables participants to develop autonomy as they are creators of knowledge (Teixeira et al., 2021). It is not a method but an epistemological orientation which emphasises the significance of subjective experiences in knowledge construction (Shamrova & Cummings, 2017). It is a '[c]-ooperative, iterative process of research and action in which non-professional community members are trained as researchers and change agents, and power over decisions [is] shared among the partners in the collaboration' (Ozer & Douglas, 2013, p. 66). Shamrova and Cummings (2017) have defined PAR as a response from academia to ensure the implementation of children's rights to participate and challenge adult centrism.

Under the umbrella of PAR there are various approaches including community-based participatory research, collaborative research and community-centred research, among others (Shamrova & Cummings, 2017). These approaches have different components in common which are: participation, engagement, empowerment, mutual learning, capacity building and fulfilment of research and action agendas (Shamrova & Cummings, 2017). E-PAR is the online version of PAR which encourages youth to carry out research using media methods they are familiar with and to develop strategies for change (Flicker et al., 2008).

Hart (1992) described the essential features of PAR:

1. Research is carried out by or with the people concerned.
2. Researchers have a commitment to the participants and to their control of the research analysis.
3. Participants themselves identified the concrete problem which initiates the research.
4. PAR proceeds to investigate the underlying causes of the problem so that participants can address them.
5. The researcher has the role of providing technical assistance in the research process.

PAR assumes that communities have local knowledge, which is crucial in understanding and addressing their own problems and issues (Flicker et al., 2008). Therefore, it is vital for researchers to be clear about their theory of social change and this must be shared with participants in a democratic way early in the research process (Hart, 1992). The validity of the knowledge generated by PAR does not depend on the objectivity of an outsider, rather on the closeness of the participant to the issues (Chen et al., 2010). One very important issue that Chen et al. (2010) added is that validity of the knowledge is also determined by the degree to which the knowledge is translated into actions to address the issues.

Rodriguez and Brown (2009) developed a set of guiding principles to work with PAR and marginalised adolescents. These principles are intended to improve adolescent well-being and development, creating a more democratic society. The authors do not provide a specific definition of marginalised youth in their research, but they refer, for example, to adolescents of colour who are being systematically removed from their schools and their communities. These principles are useful, however, when working with adolescents in PAR, not only for a specific group.

1.7.5.1 Situated and Inquiry Based

This principle is based on research and learning that reflects on and addresses adolescents' real-life issues, desires and experiences. This guides the creation of policies and practices which are meaningful and relevant to their participation. Social researchers help adolescents to theoretically situate their lived experiences within broader structural and cultural contexts. Adolescents, therefore, see their own experiences as worthy of investigation and their knowledge validated. These frameworks are crucial to validate the research and inform the subsequent data analyses (Rodriguez & Brown, 2009).

1.7.5.2 Participatory

This principle consists of the commitment to collaborative methodological and pedagogical processes which validate the skills of adolescents as researchers and support critical and creative engagement. Adolescents are invited to draw on personal experiences and connect them to those of others and to broader theories.

1.7.5.3 Transformative and Activist

This third principle is a commitment to research and learning that actively seeks to transform knowledge and practices to improve the lives of adolescent participants. Adolescents are intentionally engaged in a critical analysis of their worlds. In the specific case of marginalised adolescents, for example, Rodriguez and Brown (2009) encouraged them to connect their daily experiences to broader systems of oppression in society, for example being silenced in school and experiences of political suppression.

1.7.6 Youth-Led Participatory Action Research

Youth-led participatory action research (YPAR) is a form of participatory research whereby adolescents are trained and supported to conduct research on topics that they have identified as affecting their lives (Bautista et al., 2013; Gibbs et al., 2020; Ozer & Wright, 2012). It is guided by issues of interest and importance for adolescents' lives, communities and institutions (Cook & Krueger-Henney, 2017). Overall, an emphasis is placed on uncovering the power structures and inequities that are limiting adolescents' wellness, mental health and positive educational outcomes by acting and eliminating those oppressive systems in their lives (Cook & Krueger-Henney, 2017). YPAR is advocating for changes based on research evidence and is grounded in principles of equity (Ozer, 2016).

YPAR is not a method but an epistemological challenge to dominant social science and educational research (Aldana & Richards-Schuster, 2021). YPAR as an epistemology represents a stand against the dominant research ideology, as it privileges adolescents' capacity and power to conduct research (Cook & Krueger-Henney, 2017). It provides a systemic and ecological view of a problem, weighing evidence, communication, teamwork and advocacy (Ozer, 2017). It is not an intervention but a process (Ozer & Douglas, 2015), which means that YPAR as an iterative process will unfold differently in a specific context as well as vary between research and action.

Although YPAR has similarities to other participatory approaches, it is different because it places more emphasis on research coupled with action (Ozer & Piatt, 2017). The core epistemological assertion of YPAR is that adolescents have the capacity to create expert knowledge and to understand and address their development and well-being (Ozer, 2016). It is a youth-centred form of CBPR, which is targeted at reducing health disparities engaging communities and organisations (Oridota et al., 2023). YPAR can be used for adolescents to conduct research on how to improve issues that affect their lives (Gibbs et al., 2020). It is focused on achieving sustainable changes in settings, services, programmes or policies (Gibbs et al., 2020).

The approach of YPAR is well suited to address inequalities in adolescents' health and education by creating opportunities to enhance their own knowledge, skills and motivation, have a meaningful influence and voice issues that affect them (Ozer, 2016). Adolescents may be motivated to get involved to increase their sociopolitical skills, influence their schools and communities and raise their participatory behaviour (Ozer & Douglas, 2013). This can enhance their identity formation and sense of purpose (Ozer & Douglas, 2013). The process of YPAR can be used to understand the lives and priorities of adolescents as part of needs assessments and evaluation of services or to design, monitor and adapt programmes and initiatives targeted at them (Ozer & Piatt, 2017).

Adolescents lead YPAR themselves and it is intended at promoting social change and improving healthy development in the community (Ozer & Piatt, 2017). It can foster positive development and civic participation among economically disadvantaged adolescents, for example (Ozer & Douglas, 2013). Adolescents can be 'collaborators' and 'change agents' not just research participants (Ozer, 2016). YPAR repositions adolescents as co-creators, co-leaders, co-visionaries, co-authors and co-owners of their own and group goals (Cook & Krueger-Henney, 2017). It promotes critical reflection, motivation and action that pushes youth beyond individual-level explanations to broader factors in the community and society (Ozer, 2016).

'YPAR aims to shift power over to one of power with research participants' (Aldana & Richards-Schuster, 2021, p. 657). Adolescents are trained to identify major concerns in their communities, carry out research on these issues and take a leadership role to influence policy and decisions that have an impact on them and their peers (Ozer & Douglas, 2013). Therefore, YPAR can be beneficial for communities and local organisations, as actions initiated and led by youth are aligned to the needs of their communities (Anselma et al., 2020). Research has identified other benefits of YPAR for adolescents including increased psychological autonomy, collective sense of identity and purpose, responsibility, positive ethnic identity, more academic skills, increased sense of community, improved communication skills, psychological empowerment, strategic thinking, more perceived control and a sense of moral identity (Ozer, 2017). It enables adolescents to see themselves as leaders with a vision and direction (Cook & Krueger-Henney, 2017).

YPAR is suitable:

1. to develop supportive, cooperative relationships between adolescents and adults
2. to give opportunities to build skills in communication, inquiry and group work
3. for belonging opportunities
4. for meaningful participation and roles.

Adults also have an important role in YPAR. Adults engaged in YPAR need constant reflection on what it means to be an adult working with adolescents (Texeira et al., 2021). Texeira et al. (2021) described the role of adults in YPAR as a 'dance', as they need to take the lead at times but should step back and enable young people to lead at other times. This process is not linear; it is 'back and forth' (Teixeira et al., 2021). Adults interested in engaging adolescents in YPAR research should begin by 'preparing the ground' through activities that build trust and communication skills both between adolescents and between adults and adolescents (Ozer & Piatt, 2017). R. Fox (2013) explains some of the strategies that can be used to support critical reflection. For example, the author kept a fieldwork diary with a record of the sessions, how to improve them in the future, identification of topics which may interest the adolescents more and improvements the facilitator can do in future sessions.

Adults in YPAR should ensure adolescents keep the control when it comes to choosing a topic and design and interpretation of the data. Adults are also in charge of providing a helpful structure to enable adolescent participation, breaking down tasks and keeping timelines (Ozer & Piatt, 2017). Timelines are fundamental in YPAR as taking too long may delay or impede the time needed for change; however, jumping too fast into a solution may lead to a lack of depth and understanding of the issues which can also impede the change (Ozer & Piatt,2017). Adults can also act as problem-solvers, supporting adolescents to deal with personal conflicts as well as navigating institutional and policy change (Ozer & Piatt, 2017).

Researchers can evaluate if they are respecting and following YPAR principles. Ozer and Douglas (2015) created a scale (the YPAR process template) to determine if the YPAR implementation is carried out to a 'good enough' standard. Due to the nature of YPAR not being a structured intervention, the purpose of this measure is to inform a continuous improvement of practice and more effective YPAR approaches.

Ozer and Piatt (2017) provided a phase-based approach of how to apply YPAR in a research study (Table 1.6).

Table 1.6 *Phases of a YPAR study*

Phase	Description
1. Issue selection	The adolescent-led research group reflects on their authentic concerns, which they care about and want to influence. These concerns should not be influenced by adult facilitators. Strategies like anonymous votes can be used to stop social desirability. Once an agreement is reached on the research topic, adolescents can define their research questions, hypotheses and methods.
2. Research design and methods	Adolescents engage in decision-making about the research design, methods and interpretation of the data collected. Some commonly used methods in YPAR are focus groups, interviews, mapping, observations, photovoice and surveys.
3. Data analysis and interpretation	Data should lead to high-quality evidence appropriate to the developmental and literacy levels of the adolescents as well as being in line with time, ethical and financial constraints. Data analysis should be fun and user-friendly with no expectations of adolescents having experience in working with numbers or any science background. Analysis can be carried out low tech or with software available online.
4. Reporting back and taking action for change	Adolescents and adult facilitators can identify the actions that will be carried out to tackle the problem as well as report back the findings to all relevant stakeholders to work towards change. Dissemination of results can be more credible if other adolescents have been involved in the analysis and generation of the evidence.

1.7.7 YPAR 2.0

YPAR 2.0 is the technological application of YPAR. Technology can support the scaling of YPAR (Gibbs et al., 2020). This is confirmed by Akom et al. (2016) who coined the term YPAR 2.0 to refer to the incorporation of technology and digital platforms to extend the traditional forms of YPAR. Technology should not be perceived as a 'panacea'; according to Akom et al. (2016), nothing can replace people's own power and ability to transform the social and material conditions that oppress them. Technology and digital platforms can help by democratising decision-making by amplifying the narratives that question the mainstream narratives, particularly in low-income and marginalised communities (Akom et al., 2016).

1.7.8 Youth as Researchers

Youth-led research builds youth capacities and engages youth to produce evidence for research, but it also contributes to real-life issues (UNESCO, 2022). It is based on the premise that young people are the ones who know their problems better but also know the best solutions for their generation (UNESCO, 2022). Youth research avoids describing adolescents as 'disempowered, disinterested or at risk' as there is instead an awareness that participants have a motivation for their participation (Lohmeyer, 2019). Motivation is crucial to understand how the project may appeal to adolescents (Lightfoot & Sloper, 2002) and, therefore, how to engage them in the study. Having youth as researchers can be very powerful: 'Despite who is listening to the story, the act of telling changes the young person's world' (Lohmeyer, 2019, p. 47).

1.7.9 Peer Research

Peer research consists of creating knowledge collaboratively, challenging dominant discourses, reversing exclusion and amplifying the voices of those who have been denied the right to be experts in their own lives (Terry & Cardwell, 2016). It is for this reason that it has been described as 'ethically imperative', and Terry and Cardwell (2016) argue that naming peer researchers as co-authors is fundamental. Peer research is based on the premise that shared experiences add the qualities of understanding and empathy to research, which enables it to be more meaningful and higher quality (Terry & Cardwell, 2016). Peers, therefore, are qualified based on their lived experience. Peers have also been defined as having similarities like age rather than being due to a shared lived experience (Terry & Cardwell, 2016). Peer research is linked to 'action research'; therefore it should be driven by community needs and achieving positive change for that community (Terry & Cardwell, 2016). Dissemination is a crucial part of peer research as it will enable action.

Peer research can make a study more relevant and effective. According to Terry and Cardwell (2016), it has other benefits such as changing traditional hierarchical practice, promoting personal development for participants, increasing confidence, reversing marginalisation and objectification, and promoting community activism. Other benefits of peer research include participation in civil society, critical thinking and social responsibility, teamwork, knowledge of services and improved employability, for example developing skills such as how to write a CV or obtaining a professional reference (Terry & Cardwell, 2016).

Peer research can be a relaxing experience for participants, as this is a reassurance that the interviewer understands their views, improving the reliability and honesty of data (Terry & Cardwell, 2016). Peers can have 'insider knowledge' that enables them to ask questions and understand the language (slang) and terminology used by the participants (Terry & Cardwell, 2016). This knowledge can also be used in the design phase, selecting the topic and designing the research materials (Terry & Cardwell, 2016). This can also be relevant in the analysis of the data (Terry & Cardwell, 2016). Peer research, therefore, increases the external validity of the research by involving new, unheard perspectives which widen the focus and include issues that may be underexamined (Terry & Cardwell, 2016).

Another important aspect of peer research is training. Peer researchers need to have the tools, knowledge and language to actively participate in the research as 'equals'. This may require training in research methods as well as understanding the policy and social context surrounding the research topic (Terry & Cardwell, 2016). Peers need appropriate training to avoid issues in the research such as unintentionally biasing interviews, using leading questions or focusing on their own interests and priorities (Terry & Cardwell, 2016).

Training for peer researchers should include techniques that cater to lower levels of education and literacy rates. Terry and Cardwell (2016) argue that this should not be perceived as a 'deficit model' but as a model to cater to the natural strengths and interests of these groups. Additional and ongoing support should also be provided for peers if upsetting or sensitive disclosures trigger traumatic or upsetting memories in their own lives (Terry & Cardwell, 2016). Another option is to provide debriefings or have a named worker who could provide support for peer researchers after each interview (Terry & Cardwell, 2016). Researching sensitive topics can be demoralising, depressing or shocking for peer researchers and it can be frustrating if research projects do not lead to policy changes (Terry & Cardwell, 2016). The authors argue that having the experience does not necessarily mean participants are ready to take the role of peer researchers. Some groups may be particularly ‘chaotic’, and some researchers may have limited patience to accommodate the needs of these populations in their projects. Terry and Cardwell (2016) suggest, for example, that peer research should overrecruit participants to plan for dropouts.

Terry and Cardwell (2016) also criticise the role that peer researchers are given in the research, for example commenting on topic guides or carrying out supervised interviews. It is rare to find research projects where peer researchers are involved in the overall research topic and ethical frameworks. Training programmes for researchers rarely include input from them and their lived experiences (Terry & Cardwell, 2016).

Chapter 3 of this book is focused on ethical considerations of participation research with adolescents in general. There are, however, ethical considerations specific to peer research that should be considered specifically when researchers are working from this perspective.

1. Safety. Peer researchers need to keep their participants and peers safe.
2. Privacy. Privacy is an important consideration in peer research as peers are often working with members of their community where they live and socialise. These spaces can be very small, for example a prison. This can have a negative impact on confidentiality as personal data and interview transcripts may not be kept in a secure environment (Terry & Cardwell, 2016).
3. Consent. Peers should provide consent before taking part in the research (Terry & Cardwell, 2016). It is also crucial to disclose any potential breaches to privacy and confidentiality.
4. Payment. Compensations and payment should be given serious consideration as payment may result in a potential disruption for anyone receiving welfare benefits. Money may be dangerous for anyone at risk of robbery or relapse. Payment, however, may be necessary to compensate for peers’ time, skills, effort (Terry & Cardwell, 2016) and their knowledge and expertise.

1.7.10 Integrated Knowledge Translation

Integrated knowledge translation (IKT) emerged as a funder innovation, initially developed by the Canadian Health Services Research Foundation. It shares principles with CBPR which emphasise the need to create partnerships between researchers and knowledge end users (Jull et al., 2017). It also shares a user–researcher knowledge exchange in every stage of the research process: develop research questions, methodology, data collection, tool development, understanding findings and dissemination. IKT emerged to bridge the gap between health researchers and knowledge users (Jull et al., 2017). It tailors knowledge to specific contexts to generate evidence-based decisions to improve healthcare delivery systems and health outcomes.

1.7.11 Youth–Adult Partnerships

Youth–adult partnerships (YAP) have been recently used, particularly in the United States, for organisational and community change, by engaging adults and adolescents in shared decision-making (Zeldin et al., 2006). One of the advantages of YAP is maximising a sense of community in adolescents while ensuring they are active agents in their development and the social organisations where they live (Zeldin et al., 2006). According to Zeldin et al. (2006) YAP has been adopted by public agencies, foundations and non-profit organisations; however, cultural and organisational barriers remain, for example there may be resistance from stakeholders or a lack of understanding about the purpose of involving adolescents in a process of change. There may also be issues of power in organisations, as adults usually have the fiduciary and fiscal responsibility; however, these issues can be dissipated through role clarification (Zeldin et al., 2006). Sustainability may be an issue as well, as organisations need to build infrastructure that formally holds new roles, expectations and boundaries of change and innovation over time (Zeldin et al., 2006).

Diamond Ranking

Diamond ranking (Fallon et al., 2008) is an activity which can be used to help adolescents identify relevant research topics:

1. Discuss and negotiate in the group to identify the importance of each topic.
2. The most important topic is placed at the top of the diamond.