# YOUTH ENGAGEMENT IN HEALTH RESEARCH, POLICY, AND PRACTICE: A QUALITATIVE EVIDENCE SYNTHESIS

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A mini thesis submitted in partial fulfilment of the requirements for the degree of Master of Public Health in the Department of Public Health, University of the Western Cape.

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**KEYWORDS**

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Young people

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**ABSTRACT**

**Introduction:**

Promoting the active engagement of youth in health research, policy, and practice holds significant importance as it can generate valuable insights, informing the development of targeted strategies and contributing essential knowledge for effective health policies and practices.

Despite increasing research on problems impacting youth, there is a notable gap in including them in the actual research, policy, and practice decision-making processes. Whether and how youth are engaged in health research, policy, and practice, and under what circumstances, remains largely unexplored.

Therefore, this qualitative evidence synthesis (QES) aims to identify and synthesise global literature on youth engagement in health research, policy, and practice. It provides a comprehensive understanding of the conceptualisation of youth engagement, including activities, processes, outcomes and strategies employed in health research, policy, and practice. It is expected that this review will increase awareness of effective strategies for engaging youth in health research, policy, and practice.

**Methodology:**

Three electronic databases – PubMed, Scopus, and Web of Science – were searched to identify both qualitative and mixed-method studies that described youth engagement in health research, policy, and practice. Studies were eligible for inclusion into the review if they: (1) included youth between the ages of 15 to 24 years old; (2) applied qualitative data collection and qualitative analysis methods; and (3) were reported in English. Titles, abstracts, and full-text records were assessed against the eligibility criteria after which data were extracted using a study-specific extraction form. Data analysis and synthesis were done by using a thematic synthesis approach. The methodological quality of the included studies was assessed using the Critical Appraisal Skills Programme (CASP) tool. The study protocol was registered on PROSPERO (REF: CRD42022359977).



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**Findings:**

Fifty studies were included in this review. The majority of studies included in the review (n = 45) were conducted in high-income countries and included youth between the ages of 15 and 22 years. Fourteen themes emerged from the literature pertaining to conceptualisations of youth engagement in health research, policy, and practice. These themes encapsulated youth engagement activities, processes, outcomes, and strategies. The key lessons learned from the fourteen themes were: (1) youth are experts on youth; (2) active engagement of youth and the role of key stakeholders; (3) the experiences and skills gained by youth through being engaged; and (4) the benefits of youth engagement for youth, the research, and the broader community.

**Conclusion:**

It is evident from this review that there are a variety of conceptualisations regarding youth engagement, especially focussing on activities, processes, and strategies on how youth are, and can be engaged. Youth want to be included in matters that affect them and they want to make a difference in their own lives, the lives of their peers and their community. Therefore, it is important to do research "with", or have research done "by" youth, rather than to do research "on", "about", or "for" them.

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**DECLERATION**

I declare that *Youth engagement in health research, policy, and practice: a qualitative evidence synthesis* is my own work, that it has not been submitted for any degree or examination in any other university, and that all the sources I have used or quoted have been indicated and acknowledged by complete reference.

Full name: Claudine Karin Jordaan Date: 6 December 2023

Signed: 

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**TABLE OF CONTENTS**





http://etd.uwc.ac.za/

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http://etd.uwc.ac.za/

UNIVERSITY of the WESTERN CAPE



http://etd.uwc.ac.za/

**LIST OF TABLES**



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http://etd.uwc.ac.za/

**LIST OF FIGURES**



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## LIST OF ABBREVIATIONS

| | |
|---|---|
| CASP: | Critical Appraisal Skills Programme |
| FGD: | Focus Group Discussions |
| HIC: | High Income Countries |
| HIV: | Human Immunodeficiency Virus |
| LGTBQ+: | Lesbian Gay Transgender Bisexual Queer and more |
| LMIC: | Low to Middle-Income Countries |
| PRISMA: | Preferred Reporting Items for Systematic Reviews and Meta-Analyses |
| QES: | Qualitative Evidence Synthesis |
| TB: | Tuberculosis |
| TYPE: | Typology of Youth Participation and Empowerment |
| UN: | United Nations |
| UNDESA: | United Nations Department of Economics and Social Affairs |
| WHO: | World Health Organisation |
| WH&Y: | Wellbeing Health & Youth |

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# CHAPTER 1: INTRODUCTION

## 1.1. Layout of the mini thesis

This mini thesis consists of six chapters. Chapter one provides a short background to the review and describes the problem statement and rationale for conducting this review. Chapter two consists of a review of the literature. Chapter three provides an overview of the methods used to conduct this qualitative evidence synthesis (QES), such as the study design, search methods, selection of studies and the ethical considerations. Chapter four presents the findings of the QES, and chapter five discusses the findings. The final chapter concludes the mini thesis and provides a summary of the key findings, limitations, and recommendations for future studies.

## 1.2. Introduction

Community engagement can be defined as "working collaboratively with and through groups of people affiliated by geographic proximity, special interest, or similar situations to address issues affecting the well-being of those people" (Clinical and Translational Science Awards, 2011:7). Through engaging the community, more sustainable outcomes can be achieved, especially health-, policy-, and practice related outcomes (PennSate, 2023). Different subgroups can be found within a community – youth being one such subgroup – and is broadly defined as being a transition period from the dependence of childhood to the independence of adulthood (United Nations Department of Economics and Social Affairs [UNDESA], 2023a). Unlike other fixed-aged categories, "youth" is a more fluid category with no consensus on the definition (UNDESA, 2023a). For statistical purposes, the United Nations (UN) and the World Health Organisation (WHO) defines youth as people between the ages of 15 to 24 years, without favouring or biasing other definitions provided by Member States, as some have increased age ranges up until 35 years (UN, n.d.; Youthpolicy.org, 2014; WHO, 2022; UNDESA, 2023a). Estimates indicate that the global youth population is approximately 1.2 billion people (15.5% of the global population), with projections suggesting that the population will grow to 1.29 billion by 2030 and 1.38 billion by 2050 (UN, 2019; UN, 2020).

Youth are in a crucial developmental phase, where interaction with the physical, cognitive, emotional, and economic environment shapes the competencies they take into adulthood, and where lifelong health behaviours and patterns are established (Patton *et al.*, 2016; Waller *et al.*,



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2022). When the health of youth is improved during their developmental phase it provides what is known as a "triple dividend" – optimal development of youth, ~~improve~~improves the long-term trajectory of their health, and it provides the healthiest start for the next generation (Waller *et al.*, 2022). Youth are integral in contributing to the growth and development of their communities, as well as whole nations, as they are strong, dynamic, and innovative (Finamore, 2019; Uzoma, 2019; United Nations Development Programme [UNDP], 2023). ~~Estimates indicate that the global youth population is approximately 1.2 billion people (15.5% of the global population), with projections suggesting that the population will grow to 1.29 billion by 2030 and 1.38 billion by 2050 (UN, 2019; UN, 2020).~~

Youth are affected by a variety of complex challenges and threats, including unequal access to education and health care; unemployment; poor environmental conditions (e.g., infectious diseases, interpersonal violence, and injuries); gender inequality; lack of experience on how to navigate healthcare systems; communicable diseases such as the Human Immunodeficiency Virus (HIV) and Tuberculosis (TB); malnutrition, especially obesity and micronutrient deficiencies; early pregnancy and childbirth; mental health challenges; substance abuse (alcohol, drugs, and tobacco); poverty; and concerns regarding cost, stigma, and confidentiality (UN, n.d.; Allensworth, 2011; Patton *et al.*, 2016; Finamore, 2019; Uzoma, 2019; Wilson *et al.*, 2020; Waller *et al.*, 2022; WHO, 2023). As youth are directly impacted by these challenges and threats, they **can** provide authenticity, relevance, understanding, and diverse perspectives to research, policy, and practice. They can easily identify the problems that need improvement, ~~they can do~~ **conduct** research to understand these problems, ~~as well as the~~ **explore** possible solutions, and ~~can then~~ advocate for change based on the evidence gathered from their research (Ozer & Piatt, 2017). **For instance, youth in South Africa are a population particularly vulnerable to the risk of contracting HIV. Therefore, engaging youth as co-researchers is a tailored approach to develop prevention products that meet their needs (Hartmann *et al.*, 2021). Similarly, involving youth as co-researchers in mental health research, not only enhances the quality of research but also promotes equity in addressing mental health issues (Wright *et al.*, 2024).** Youth are seeking to have more fair, equitable, and forward-thinking solutions, and opportunities to address these challenges and threats that they face and therefore they need to be engaged as partners in health research, policy, and practice to adequately address their needs and perspectives (UN, n.d.; Powers & Tiffany, 2006).



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~~When the health of youth is improved during their developmental phase it provides what is known as a "triple dividend" – optimal development of youth, improve the long-term trajectory of their health, and it provides the healthiest start for the next generation (Waller *et al.*, 2022).~~

There is a growing call ~~to increase the importance~~ **to enhance the relevance** of engaging youth in health research, policy, and practice as it will empower them to influence policies and programmes that have an effect on their lives (Ozer & Piatt, 2017). However, the degree to which youth are engaged in health research, policy, and practice is not fully known, especially in low- and middle-income countries (LMIC). ~~as y~~ Youth are often seen as "problems", **for example, youth of colour are frequently portrayed as school dropouts, drug users and crime offenders**, but when youth are used as "resources", they will be equipped to see themselves as change agents in their communities (Checkoway & Gutierrez, 2008). Brady and colleagues state that when those who are the primary focus of the research, such as youth, are involved in the process, it has positive effects on the research area, the way in which the research is conducted and the impact of the research findings on the youth themselves and the larger community (Brady *et al.*, 2018).

### 1.3. Problem statement

**Youth today face a multitude of challenges, with injuries, mental health disorders, maternal conditions, and interpersonal violence, being the leading causes of death among youth (WHO, 2023). More than 1.5 million youth died in 2021 due to these challenges. Injuries, including road traffic accidents and drowning, contributed to 145,000 youth deaths in 2019 (WHO, 2023). Mental health disorders, such as anxiety, behavioural disorders, and depression, are one of the key causes of disability and illness in youth, with suicide being the fourth leading cause of death in youth (WHO, 2023). In LMIC, approximately 777,000 girls, younger than 15 years, give birth each year. Complications experienced during pregnancy and childbirth are one of the leading causes of death among young girls (WHO, 2023). Violence contributes to a third of young male deaths in LMIC and increases the risks of mental health disorders, infections, injuries, and reproductive health issues (WHO, 2023).**

At present there is substantial academic research regarding these challenges that youth face; however, youth are not necessarily included as decision-makers or equal partners in the research process itself (Goodman *et al.*, 2018), and the extent to which they are engaged has



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not yet been fully explored (Checkoway & Gutierrez, 2008; Anderson & Lowen, 2010; Mendenhall, Gagner & Hunt, 2015; Efuribe *et al.,* 2020; Asuquo *et al.,* 2021). This is a widespread problem with various studies highlighting the need to create more opportunities for youth to be engaged in health research, policy, and practice (Goodburn & Ross, 2000; Brady, 2017; Eric, 2019; Doyle *et al.,* 2022). Excluding youth risks the design of research studies, development of policies, and implementation of health practices that misunderstand the needs and interests of the youth (Macdonald, *et al.,* 2023). Currently, there is a disconnect between the intentions related to engaging youth in the research process and policy decisions, and what is implemented in practice (Prati & Albanesi, 2023).

Since it is a fundamental right for youth to participate in research, and policy development, especially when it is aimed at them, excluding them from the research undermines their rights and can possibly weaken the validity of the research (Schelbe *et al.,* 2014). There is a gap in research between the perspectives of adults and that of youth, and therefore more in-depth research needs to be done on how youth are engaged in health research, policy, and practice. ~~it is important to fill this gap in research.~~ A QES can provide both reliable and rich interpretations of how youth are an important part of health research, policy, and practice.

### 1.4. Rationale for this review

It is important to address this gap in research on how youth are engaged in health research, policy, and practice as well as the gap in the understanding and implementation of youth engagement strategies. The evidence that will be synthesised from this review will contribute to a deeper understanding of strategies for youth engagement in health research, policy, and practice**, as youth are seeking more opportunities to address the challenges and threats they face**. The findings can also potentially be utilised by health researchers, policy developers, and health practitioners to successfully engage with youth, thereby protecting the health of both the current and the future youth populations. This review can also identify further gaps in research related to youth engagement, which can then inform future research studies.

### 1.5. Aim and objectives

This QES therefore aims to identify and synthesise literature on how youth are engaged in health research, policy, and practice globally. The review will provide insights into the conceptualisations and strategies of youth engagement in health research, policy, and practice,



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and provide an opportunity for creating a new, or enhancing an existing, conceptual framework of youth engagement.






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## CHAPTER 2: LITERATURE REVIEW

This chapter is a critical synthesis of the background literature review conducted for this review. The researcher sought to better understand what youth engagement in health research, policy, and practice is and how the activities, processes, and outcomes of youth engagement are conceptualised in the literature. This chapter will synthesise the literature by highlighting the known perspectives and practices of youth engagement in health research, policy, and practice, the strategies used to engage youth in health research, policy, and practice, conceptualisations of activities, processes, and outcomes of youth engagement, and explore the conceptual frameworks that have already been developed with regards to youth engagement. The researcher will also synthesise literature discussing the barriers and the benefits of youth engagement in health research, policy, and practice. This chapter will conclude by reviewing why youth engagement in health research, policy, and practice is important and why a QES is the most suitable methodology to answer the review question.

### 2.1. Perspectives and practices of youth engagement

Upon examination of the literature concerning youth engagement in health research, policy, and practice, a nuanced understanding emerges, revealing diverse perspectives and practices. Various definitions and key aspects are highlighted, collectively shedding light on the complexities and essential dimensions of authentic youth engagement. There are a wide variety of perceptions and practices of what youth engagement (also referred to as youth involvement, youth voice, youth in governance, or youth participation), especially in the areas of health research, policy, and practice, means (Youth Power, n.d; Bozlak, 2014; Sprague Martinez, Jones & Connolly, 2020; Falkenburger, Gray & Daly, 2021; Act for Youth, 2022). Cardarelli and colleagues define authentic youth engagement as "providing meaningful opportunities to practice skills (e.g., leadership) in real-life settings and recognising youth voices as valuable, with the goal of instilling a sense of confidence that their efforts can make a difference" (Cardarelli *et al.*, 2021:2), while Augsberger and colleagues defines youth engagement as "meaningful participation and influence of youth at the community and organisational level that takes into consideration the strengths, skills, interests and developmental needs of young people" (Augsberger *et al.,* 2023:411).



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Furthermore, several key aspects of youth engagement are highlighted in the literature: (1) youth engagement is considered a *basic human right* – if a programme is designed for youth, they should have input into how the programme is developed and implemented (Youth Power, n.d); (2) *active involvement* of youth advocating for actions to improve their communities and create positive changes is emphasised (Act for Youth, 2022); (3) *relationship-building* between adults and youth is promoted through intentional, mutually beneficial, and inclusive interactions (Falkenburger, Gray & Daly, 2021); and (4) youth engagement is viewed as an *ongoing process* where youth is involved in the decisions, systems, and organisations that have an impact on their lives (Bozlak, 2014; Sprague Martinez, Jones & Connolly, 2020).

These definitions and key aspects are acknowledged by the UNDESA as well as Warraitch and colleagues, as they convey that engagement of youth in health and wellbeing-related decisions is widely acknowledged as a fundamental right (Warraitch *et al.*, 2023; UNDESA, 2023b). The UNDESA also acknowledges that when youth are actively engaged in health-related decisions, they feel empowered to not only play an important role in their own development (such as acquiring new life skills), but also in that of their communities (better health outcomes for all) (UNDESA, 2023b). In recent years youth have been playing a pivotal role in fighting for equity and equality in matters important to them, such as the 2015 #FeesMustFall protests in South African universities, the 2019 international climate strikes, the 2020 Black Lives Matter movement, and the annual silent protest of South African university students, during August, in solidarity with rape victims.

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However, Prati and Albanesi takes a divergent perspective on the definitions and key aspects of youth engagement. They state that involving youth in health-related decision-making processes, especially in policy development, is not a simple matter and describes youth engagement as a "fuzzy" concept (Prati & Albanesi, 2023). They further assert that there is a significant disconnect between what organisations say they are doing, in terms of engaging youth in decisions, and how youth are engaged in decisions in practice. To address this disconnect, they recommend that youth themselves should define what it means to be meaningfully engaged in health-related decisions (Prati & Albanesi, 2023).

### 2.2. Youth engagement in health research, policy, and practice

The UNDESA and Warraitch and colleagues aligned their acknowledgement of youth engagement in health-related decisions as a fundamental right (Warraitch *et al.*, 2023;



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UNDESA, 2023b). In 1989 at the UN Convention on the Rights of the Child, it was said that it is a fundamental right for youth to be engaged in the research design and development processes of health practices and policies, especially those aimed at serving them (Efuribe *et al.*, 2020). Warraitch and colleagues made a similar point, emphasising that one way to allow youth to make decisions is to engage them in the research process, especially health research, as it informs the design of healthcare policies, and practices that provide care to youth (Warraitch *et al.*, 2023).

Youth have a better understanding of their own, as well as their peers', needs, capabilities, and preferences, as they are experts on being young (Wilson *et al.*, 2020). Therefore, they are more equipped to make decisions that influence their lives and to identify specific research processes that fit the challenges they experience, resulting in better-informed research studies, policies, and services (Wilson *et al.*, 2020; Giordano, *et al.*, 2023; Nesrallah *et al.*, 2023). There is growing evidence that when youth are engaged in all research phases, specifically participating in research pertaining to them, the research findings produce vital knowledge for the development of appropriate and effective health-related policies and practices (Njelesani & Hunleth, 2020; Giordano *et al.*, 2023). Youth engagement has great value across all research disciplines, including general health and wellbeing, health promotion, and mental health, as well as in issues of community development, social inequity, education reform, and organisational change (Hawke *et al.*, 2020). Nesrallah and colleagues found that in mental health research, engaging with youth has demonstrated to enhance the effectiveness of decision-making processes and to strengthen the credibility of the research findings (Nesrallah *et al.*, 2023).

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Conversely, Mpanza states that although youth participation is widely acknowledged, this participation is limited to a form of community engagement or social action and not necessarily as being involved in the formal development of a public policy (Mpanza, 2019). She illustrates this point through an example of the new National Health Insurance policy in South Africa. Throughout the development of this policy youth have not been consulted as key stakeholders, even though the policy will have implications for the youth of today and the youth of the future (Mpanza, 2019). Macauley and colleagues reiterates this stating that, in the United Kingdom, the voices of youth are underrepresented in the health policy development process (Macauley *et al.*, 2022).



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### 2.3. Youth engagement strategies in health research, policy, and practice

Acknowledging that youth are experts on being young, it is important to involve them in health research, policy, and practice, therefore conduct research 'with' or 'by' them rather than 'to', 'about', or 'for' them (Warraitch *et al.,* 2023). The question that remains is how to effectively engage youth in these processes.

There are a variety of youth engagement strategies identified by Doyle and colleagues that include anything from youth being consultants, youth as informants to youth being decision-makers (Doyle *et al.,* 2022). Other youth engagement strategies listed in the literature include peer education, youth focus groups, youth advisory boards, youth-led planning, youth councils, youth organisations, youth-centred programmes and policy designs, and youth participatory action research (Youth Power, n.d; Ozer *et al.,* 2020; Falkenburger, Gray & Daly, 2021). Strategies also include the integration of youth into youth development programming, particularly in advocacy initiatives, governance, and evaluation, achieved through methods such as strategic planning, institutional decision-making, civic action, and service learning (Youth Power, n.d; Falkenburger, Gray & Daly, 2021).

A more recent engagement approach is through harnessing the power of social media. When incorporated into youth programmes, social media represents a way to prioritise the research interests of the youth, enhancing the in-person programme by broadening youth participation (Andrade *et al.,* 2018; Sivaratnam *et al.,* 2022). Ozer and colleagues further categorise these engagement strategies as either formal or informal strategies – formal strategies encompass youth-led councils and advisory boards, as well as the planning, structuring, and designing of processes to address the problems they experience (Ozer *et al.,* 2018). In contrast, informal strategies may involve the sharing of opinions and experiences, in venues that are mostly adult led (Ozer *et al.,* 2018).

### 2.4. Youth engagement activities, processes, and outcomes in health research, policy, and practice

Exploring activities and processes related to youth engagement in health research, policy, and practice, it becomes evident that whether youth are engaged through formal or informal decision-making strategies, the outcomes are more likely to align with their specific needs and priorities. Additionally, these activities and processes may enhance the adoption and



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implementation of findings, potentially resulting in the generation of sustainable outcomes (Hawke *et al.*, 2020). There are several key activities and processes in which youth can be involved. These include surveys, research evaluations, health impact assessments, education data collection, cultural organising, community needs assessments, media creations, internships, event attendance or participation (Falkenburger, Gray & Daly, 2021).

Asuquo and colleagues conducted a scoping review of how youth are engaged in HIV prevention research in sub-Saharan Africa (Asuquo *et al.*, 2021). To categorise youth engagement, they used Hart's ladder (Hart, 1979) of children's participation and adapted the levels of engagement for youth. These adapted measures of youth engagement included (1) substantial engagement – youth are co-researchers and have considerable decision-making powers; (2) moderate engagement – youth are invited as content creators and have some decision-making powers; (3) minimal engagement – youth are only consulted but have no decision-making powers; and (4) no engagement (Asuquo *et al.*, 2021). Giordano and colleagues, as well as Faithfull and colleagues, identified similar measures of youth engagement in health research activities and processes, they just classified it as 'ways of engagement' (Giordano *et al.*, 2023) or 'levels of engagement' (Faithfull *et al.*, 2019). These 'ways or levels' includes: (1) youth are engaged as the participants – a one-way process where adults are conducting the research and the youth are the research subjects, e.g., youth completing a questionnaire; (2) youth as consultants – adults seek the views of youth to increase their knowledge about an issue and to get the feedback of the youth on the research study or policy, but the research are still conducted by the adults, e.g., youth steering groups; (3) youth in a partnership with adults as co-researchers – the youth are collaboratively part of the whole project as equal partners, e.g., youth are assisting with the data collection and analysis; and (4) youth as the research leaders – youth lead every step of the way through identifying the research problem and formulating the research question, developing the process and methods, collecting and analysing the data, interpreting ~~interpretating~~ and disseminating the findings, while maintaining control of the whole process and the adults are only involved as facilitators or advisors (Faithfull *et al.*, 2019; Wilson *et al.*, 2020; Doyle *et al.*, 2022; Giordano *et al.*, 2023).

There is however limitations or barriers that can hinder youth engagement in these activities and processes, such as adults not feeling in control of the research process anymore and therefore losing power when they engage youth as co-researchers (limitations and barriers will be discussed in detail later in the chapter). It is evident from the literature that the most



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favourable outcomes arise when youth are actively engaged at each level and have significant decision-making opportunities, therefore, when they are engaged as research leaders and have substantial engagement.

### 2.5. Youth engagement frameworks in health research, policy, and practice

Over the years, a multitude of theoretical and conceptual frameworks have emerged addressing a broad spectrum of age groups, from children to youth, involved in health research, policy development and practice. Hart's "ladder of participation" was one of the first influential frameworks as it outlined children's engagement moving from nonparticipation to increased participation, therefore stating that optimal participation is when children share the decision-making power with adults (Hart; 1992; Villa-Torres & Svanemyr, 2014; Augsberger *et al.*, 2023). Treseder and Smith questioned the "ladder of participation" framework proposed by Hart and contended that it may not consistently be pragmatic, feasible, or suitable (Treseder & Smith, 1997). Prati and Albanesi supports this questioning of Hart's ladder, suggesting that the young people-initiated activities, positioned at the top of the ladder, may not be the most effective approach for empowerment (Prati & Albanesi, 2023). Their argument, rooted in this perspective, asserts that no specific participation type, for instance the youth-adult participation proposed in Hart's ladder, is inherently superior or preferrable to another participation type (Prati & Albanesi, 2023).

Shier built on Hart's framework and proposed a framework that focuses on different elements of meaningful engagement, including five levels of participation. This framework emphasised the significance of having both institutional and adult readiness to share the power with youth. The three commitment stages (*openings, opportunities, and obligations*) clarify the way in which these individuals and institutions view their degree of commitment to the process (Shier, 2001; Augsberger *et al.*, 2023). Because this framework is relatively easy to use and to understand, it is one of the most used frameworks for youth engagement (Warraitch *et al.*, 2023).

In contrast with Hart and Shier, Wong, Zimmerman and Parker's Typology of Youth Participation and Empowerment (TYPE) pyramid does not presume the meaning of "meaningful", they see youth-adult partnerships as meaningful when there is the capacity to empower the youth (Prati & Albanesi, 2023). Their TYPE pyramid identifies different degrees



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of youth-adult participation, with the pinnacle of the pyramid being shared control between adults and youth.

What the aforementioned frameworks all have in common, is that they were all developed by adults. On the contrary, in 2019, Australian researchers co-produced an engagement framework with youth from the Wellbeing Health & Youth (WH&Y) Commission. This framework includes a set of values and practical questions to help prompt decision-making and responses that in turn will promote ethical practices of engaging with youth (Swist *et al.,* 2019; Giordano *et al.,* 2023). The WH&Y framework requires that at every phase, activity, or process of your research, it is important to check in with yourself, your institution, and the young people to make sure that you consider how the value set (*mutual trust and accountability; equity and responsiveness; and diversity and inclusion*) apply (Giordano *et al.,* 2023).

While numerous theoretical and conceptual frameworks exist, they all share a common objective – to provide guidance for health researchers, policy developers and healthcare practitioners in the meaningful engagement of youth and the measurement of their engagement at the level and depth they determine. Synthesising these theoretical and conceptual frameworks offers advantages by allowing for comparisons of youth engagement activities, processes, and outcome priorities on a global scale.

### 2.6. Benefits of youth engagement in health research, policy, and practice

Engaging youth in a meaningful manner yields evident benefits for the health and overall wellbeing of youth (WHO, 2020). When youth are engaged in activities and processes, they gain an in-depth knowledge about specific health problems, they develop an increase sense of belonging, they acquire important life skills and characteristics, such as integrity, accountability, communication, teamwork, and responsibility, and they feel valued and empowered (King *et al.,* 2015; Goodman *et al.,* 2018; Simmons *et al.,* 2019; Efuribe *et al.,* 2020; Wilson *et al.,* 2020). These new skills all contribute to more personal growth leading to a greater understanding of where their future is heading (Simmons *et al.,* 2019; Wilson *et al.,* 2020). Furthermore, youth engagement plays a pivotal role in enhancing organisational capacity, effecting environmental change, and strengthening social development (Checkoway & Gutierrez, 2008).



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In addition to the benefits that engagement has for youth, there are also benefits for the research and development process as well as the larger community. The benefits for the research process includes a more polished agenda-setting stage where research question(s) align more closely with the experiences and priorities of the youth; youth can provide vital information on recruitment strategies, which could improve participant recruitment and retention; youth can collect authentic and relevant data and they bring a unique perspective to the data collection analysis process; and there is a wider dissemination of the research findings as they can share it within their communities as well as with other researchers and policymakers (Wilson *et al.*, 2020; Warraitch *et al.*, 2023). The benefits to the larger community include youth raising awareness within their community regarding specific health problems, which can lead to community action, and to youth being more civically engaged within their communities (Wilson *et al*., 2020).

Asuquo and colleagues found that when the youth were engaged in HIV interventions (as participants), their knowledge about HIV increased, the stigma surrounding HIV decreased, and it facilitated behaviour change (Asuquo *et al*., 2021). When they were engaged in the research process, the recruitment process was more effective, and more youth-friendly interventions were created, which, in turn, promoted dissemination and increased sustainability of the findings (Asuquo *et al*., 2021).

### 2.7. Limitations and gaps of youth engagement in health research, policy, and practice

While the benefits of youth engagement in health research, policy, and practice is evident, it is important to acknowledge that there are also barriers and limitations of youth engagement that exist. Since the UN Convention on the Rights of the Child, there has been an increase in recognising the necessity to provide youth with a "voice" especially in the areas affecting their lives, however, the extent to which youth are engaged in research remains a subject of controversy as many researchers still feel that youth should be passive participants in the process rather than actively participating in solving the problems they experience (Jardine & James, 2012).

As the next generation, youth must be prepared for society and the workforce; however, often they are not invited to be equal collaborators in research studies or policy development proceedings (Wilson *et al.*, 2020). This lack of momentum in youth engagement can be due to approval of research by ethical review boards, especially with regards to youth consent and a



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lack of support from the relevant institution (McCabe *et al.,* 2022). It can also be due to several practical issues such as researchers not feeling confident with employing youth-friendly research methods, difficulties in recruiting youth, and financial barriers (McCabe *et al.*, 2022). Key limitations that hinder meaningful youth engagement includes differing understandings, attitudes, and perceptions of what youth engagement is; that adult researchers fear losing control of the research process, and are cautious of the responsibilities and the risks of engaging youth under the age of 18 years; concerns of rigour, especially with regards to the youth's competing demands and changing interests which can cause difficulty in sustaining a partnership over the duration of the projects (King *et al.*, 2015; Faithfull *et al.,* 2019; Hawke *et al.,* 2020; Sprague Martinez, Jones & Connolly, 2020; Asuquo *et al.,* 2021; Fletcher, 2022; McCabe *et al.,* 2023). Other limitations include adults viewing youth through a deficit perspective, leading to youth questioning their own legitimacy and therefore not seeing themselves as change-makers, hindering their own engagement (King *et al.*, 2015). In addition, many countries are experiencing war as well as poverty, which makes engagement in health-related activities a low priority for youth (Dunne *et al.,* 2017).

These limitations can lead to negative health consequences for youth as the health services and interventions are not fulfilling their needs (Doyle *et al.*, 2022). For example, one of the Malawian government's primary focusses was on the sexual and reproductive health of young females. However, the government's conversation was notably missing the voices of the young females themselves. This lack of inclusion in the government's discussions may contribute to challenges in addressing issues effectively, exemplified by Malawi having one of the highest youth pregnancy rates in the world (Wigle *et al.*, 2020). In South Africa, studies that were conducted on how youth participate in governance, such as policy development, indicated that due to youth's lack of experience and the necessary skills, it hinders meaningful engagement (Mpanza, 2019).

When youth are only partially engaged, or not engaged in health research, policy development, and practice designed for their benefit, significant opportunities, such as health promotion initiatives, health education, youth development programmes, and preventive measures, may go unexplored (Bozlak, 2014; Sprague Martinez, Jones & Connolly, 2020). This limited engagement can also potentially constrain the effectiveness of research, policy, and practice outcomes because it might not address the needs of the youth (Bozlak, 2014; Sprague Martinez, Jones & Connolly, 2020).



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Youth are often the targets of health research, policy, and practice, and although substantial academic research has been done on youth and their problems, they are often not decision-makers in the research process (Bozlak, 2014; Goodman *et al.,* 2018; Sprague Martinez, Jones & Connolly, 2020). This is a considerable gap in youth-aimed research, policy and practice as the interventions are designed for youth but without the input of the youth (Doyle *et al*., 2022). When youth are engaged as decision-makers it leads to more appropriate youth-centred designs, increasing the uptake and effectiveness thereof, and in turn, health researchers, policy developers, and health practitioners gain a better understanding of the multitude of factors that influence youth (Sprague Martinez, Jones & Connolly, 2020; Doyle *et al*., 2022).

### 2.8. Contribution of this review on youth engagement in health research, policy, and practice

Youth are often underutilised as resources (King *et al.,* 2015). When youth are part of the process – planning, implementation, and evaluation – in health research, policy, and practice it might potentially lead to tailored, and therefore more effective programs addressing their specific needs (Powers & Tiffany, 2006; King *et al.,* 2015). Researchers, policy developers and health practitioners need to shift their perspectives from seeing youth as being "problems" to seeing, and using, them as "resources" (Checkoway & Gutierrez, 2008). A QES will provide rich and reliable interpretations of how youth are an important part of health research, policy, and practice. This review therefore aims to identify and synthesise literature on how youth are engaged in health research, policy, and practice globally, and the findings can then be used by health researchers, policy developers, and health practitioners to engage youth successfully.

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# CHAPTER 3: RESEARCH DESIGN AND METHODOLOGY

This chapter outlines the methodology used to conduct this review, including the review design and why it is appropriate, and the eligibility criteria for the review. The search methods, selection and extraction of studies, methodological quality assessment, and ethical considerations are also be discussed.

## 3.1. Review design

This review utilises a QES design, which according to the WHO (2021) is a systematic review that identifies primary qualitative studies and then appraise and synthesise them in a systematic way. The findings from a QES draw on the lived experiences of people's conditions, and their experiences on how they receive or deliver interventions to help interpret and then explain the meanings that they attach to a certain health phenomenon (Harris *et al.,* 2018). Synthesising findings from qualitative research studies, while preserving and respecting the vital complexity and context of the studies, will bring the findings together for a wider audience (Thomas & Harden, 2008). Therefore, a QES is a suitable design to answer questions on how youth are engaged in health research, policy, and practice globally.

## 3.2. Review protocol

The review protocol was registered with PROSPERO ("*an international database of prospectively registered systematic reviews … where there is a health-related outcome*" (National Institute for Health Research, n.d)) (REF: CRD42022359977).

## 3.3. Eligibility criteria for studies for this review

### 3.3.1. Study types

Qualitative research explores perceptions, experiences, and interactions of people and therefore, information regarding the engagement of young people in health research, policy and practice is typically found in qualitative studies (Cleland, 2017). Empirical and conceptual studies that used (i) qualitative data collection methods (e.g., focus group discussions, interviews, and observations) and (ii) qualitative data analysis methods (e.g., thematic analysis, grounded theory, etc.) were included in this review. ~~Mixed method studies were also included~~



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~~in this review, however only if the studies used both qualitative- data collection and -data analysis methods.~~ This review also incorporated mixed method studies, but only **when a given study utilised** both ~~those that utilised both~~ qualitative data collection and **qualitative data** analysis methods.

3.3.2. Phenomenon of interest

The primary focus of this review was youth engagement in health research, policy, and practice, as perceived and experienced by relevant stakeholders. Studies that reported on various aspects, such as perspectives, experiences, and practices of youth engagement in various aspects of health research, policy, and practice, including sexual- and reproductive-, environmental-, mental-, clinical- or general-, nutritional-, and public health were included. Furthermore, studies that defined and conceptualised youth engagement in health research, policy, and practice, encompassing the various activities, processes, and outcomes, were included. Relevant studies on the phenomenon of interest from anywhere in the world were included.

3.3.3. Types of participants

The WHO defines youth as individuals between the ages of 15 to 24 years (WHO, 2022). Nevertheless, alternative definitions of youth from included studies were considered in the data analysis. The stakeholders representing youth included youth themselves, parents and/or caregivers of youth and advocates or community activists working on youth-related issues. Additionally, other relevant stakeholders such as academics, health researchers, private organisations, and policymakers were of interest.

**3.4. Search methods**

The following electronic databases were searched for relevant studies: 1) PubMed 2) Scopus 3) Web of Science. The search did not apply publication date or geographic restrictions but did apply an English language filter. The search strategy was developed in PubMed and then adapted for the other databases with the help of a UWC librarian. The search strategy was as follow:

("youth" OR "young people" OR "young adults" OR "young adulthood" OR "adolescent" OR "adolescence" OR "young male" OR "young men" OR "adolescent male" OR "young female" OR "young women" OR "adolescent female") AND ("engagement" OR "engage" OR



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"empower" OR "empowerment" OR "participate" OR "participation" OR "voice" OR "in governance" OR "involvement") AND ("health" OR "well-being" OR "environmental health" OR "public health" OR "reproductive health" OR "sexual health" OR "general health" OR "clinical health" OR "mental health" OR "nutritional health") AND ("research" OR "research activity") AND ("policy" OR "strategy" OR "strategies" OR "interventions" OR "guidelines" OR "models") AND "practice". A summary of the search is included in Table 1.

**Table 1: Summary of search by databases after applying the search strategy**

| Name of database | Number of articles found |
|---|---|
| PubMed | 4639 |
| Web of Science | 2305 |
| Scopus | 5037 |

### 3.5. Selection of studies

The researcher searched the three databases, after which a total of 11 981 records were exported to Endnote (NWU 3092075101 EndNote 20.6), a reference manager that helps with formatting citations (EndNote, 2023). All search records were then imported into Covidence, a systematic review tool (Covidence, n.d.), where duplicates were removed. Covidence was selected as it is an online software that organises the imported records and removes all duplicates (Soobiah *et al.,* 2020). An additional 138 records were identified manually searching through the reference lists of the included records. At this point, 2871 records were identified as duplicates by Covidence and were removed.

Titles and abstracts of the ~~92849~~248 search records were assessed against the eligibility criteria of the review and 9017 records were excluded. Full-text papers (n = 2) were retrieved for those titles and abstracts that were potentially eligible and were assessed by the researcher. Quality checks were performed by the supervisors, through checking a sample of the selected studies. In Figure 1, a Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) flowchart is included of the search records.



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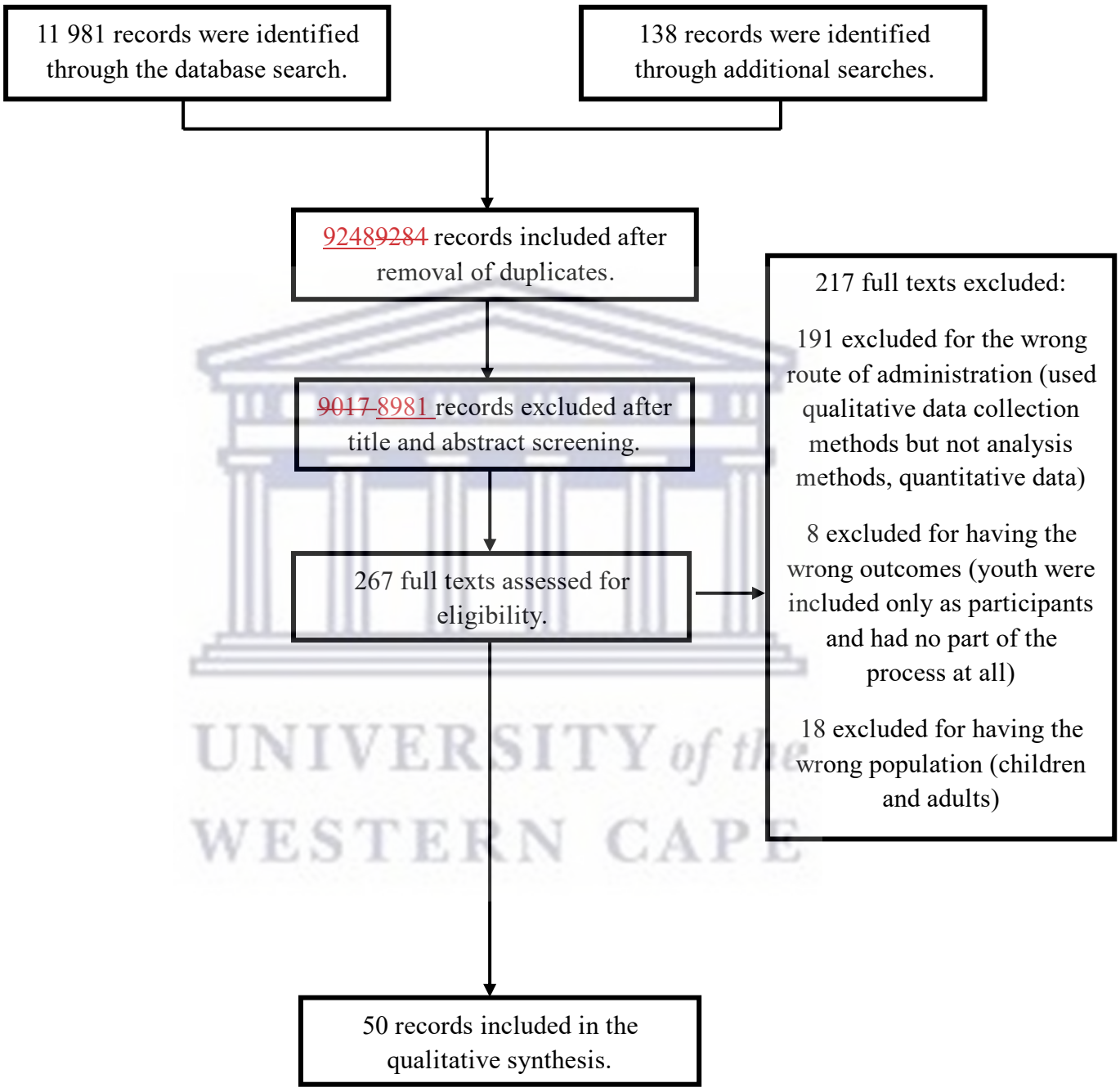


**Figure 1: PRISMA flowchart of the selection of studies process**



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### 3.6. Data extraction

Data extraction was carried out using a data extraction form specifically developed for this study (Annexure 1). The form was used by the researcher, therefore one person, to extract all relevant data. Extracted data were cross-checked for accuracy by the supervisors. Information extracted included the study number, author details, publication date, study title, country of origin, primary purpose/study aim/objectives, study design (qualitative or mixed methods), participant group (age and gender), methods (data- collection and analysis), conceptualisations of youth engagement (including activities, processes, and outcomes), strategies, definitions, whether a framework (conceptual or theoretical) was included and any additional comments. Microsoft Excel software was used to organise the data and clearly present the extracted data in a table. A sample of the extracted data is included in Annexure 2. The general characteristics of the 50 included records are described in Table 2.

### 3.7. Methodological quality assessment

Qualitative research focuses on understanding social phenomena, as well as human experiences and perspectives, therefore, it is important to assess the methodological quality when doing a QES as it ensures credibility, trustworthiness, and rigour (Williams, Boylan & Nunan, 2020). Key reasons for conducting methodological quality assessment in a QES includes assessing the (i) validity and reliability, (ii) credibility of the synthesised findings, and (iii) transparency and reproducibility. Other key reasons include to (iv) identify biases and limitations, (v) enhancing the trust in the synthesis, (vi) informing implications and recommendations, and (vii) to provide quality assurance. Each of the seven points are discussed briefly:

(i) Validity and reliability – when evaluating the rigour of the study design, data collection, and data analysis methods, the researchers can assess the reliability of the findings.

(ii) Credibility of the synthesised findings – a QES provides an accurate and comprehensive summary of the qualitative research available for a specific topic. When assessing the methodological quality, it helps to identify studies with methodological flaws or biases and then exclude these studies, contributing to the overall credibility of the synthesised findings.

(iii) Transparency and reproducibility – transparency is provided through systematically assessing the methodological quality of included studies, which in turn improves the reproducibility of the synthesis as a clear method is provided.



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(iv) Identifying biases and limitation – it is important to identify the biases and limitations in included studies to help researchers make informed decisions on whether the findings will be generalisable.

(v) Enhancing trust in the synthesis – if the methodological quality of the included studies is rigorously assessed, other stakeholders will be more likely to trust the findings. This trust is crucial, especially for the application of the synthesised evidence in practice.

(vi) Informing implications and recommendations – the assessment of methodological quality can inform future research and practice as an understanding of the strengths and weaknesses of studies already conducted helps researchers make better decisions and more well-informed suggestions for future research or application.

(vii) Quality assurance – assessing the methodological quality is part of a broader quality assurance process ensuring that the synthesis adheres to standards and are conducted rigorously, therefore improving the overall quality of the research findings.

The researcher critically assessed the methodologies of each of the included studies using the Critical Appraisal Skills Programme (CASP) for qualitative studies tool (CASP, 2018). The CASP tool is suitable for methodological quality assessment as the ten questions are used as a checklist:

1. Was the aim of the research clearly stated?
2. Is a qualitative methodology appropriate?
3. Was the research design appropriate to address the aim(s) of the study?
4. Was the recruitment strategy appropriate to the aim(s) of the study?
5. Was the data collected in such a way that addressed the research issue?
6. Has the relationship between the researcher(s) and the participants been adequately considered?
7. Have any ethical issues been taken into consideration?
8. Was the data analysis sufficiently rigorous?
9. Is there a clear statement of the study findings?
10. How valuable is the research?

The researcher answered each one of the ten questions for all included studies and presented the findings using Microsoft Excel software. Since the CASP checklist do not use a scoring system, a scoring system used in a systematic review done by Ibrahim and colleagues was applied. Each CASP item that was assessed as a 'yes' was scored with one point and each item



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that was assessed as a 'no' or 'can't tell' was scored with zero points (Ibrahim *et al.*, 2020). The percentage score for the 10-item CASP checklist was then calculated and studies scoring more than 60% were graded as good quality, studies scoring between 45% and 59% were considered fair quality, and studies that scored below 45% were rated poor quality.

GRADE CERQual was not applied to the review findings, because the review question focused on a range of conceptualisations and definitions of youth engagement. CERQual is not directly appropriate for this type of review question, and the diversity of the included studies was limited, as most studies occurred in high income countries. It was also not feasible to apply CERQual within a mini thesis due to the limited time and capacity of the researcher.

### 3.8. Data management and synthesis

A thematic synthesis approach was used to analyse and narratively synthesise the data. This approach is appropriate to arrive at the findings of numerous qualitative studies in a systematic review (Thomas & Harden, 2008; Harden & Thomas, 2022). Five steps were followed to analyse and synthesise the data from included studies: (1) the researcher familiarised herself with the data through the extraction process as well as the assessment of the methodological quality; (2) the researcher coded the data of one selected included study, line-by-line, to build a coding list. The researcher and the supervisors then discussed the codes and the coding list which was used to code the remaining studies; (3) the researcher sorted through the different codes and clustered similar codes to form themes for which a narrative summary was written; (4) the themes were reviewed to see if some themes can be grouped together and if some themes needed to be divided into sub-themes; (5) the researcher finalised the names of the themes and developed the key findings.

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**Table 2: General characteristics of the included studies**

| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 1 | Ali, S., de Viggiani, N., Abzhaparova, A., Salmon, D. & Gray, S | 2020 | Exploring young people's interpretations of female genital mutilation in the UK using a community-based participatory research approach | United Kingdom | Qualitative |
| 2 | Altares, A., Hobbs, S., Sobel, D., Nelson, T., Serpa, M. & Bellows, L. L. | 2022 | Cultivating community change to promote food access and healthy eating through participatory action research with youth | United States of America | Qualitative |
| 3 | Atkiss, K., Moyer, M., Desai, M. & Roland, M. | 2013 | Positive youth development: An integration of the developmental assets theory and the socio-ecological model | United States of America | Qualitative |
| 4 | Chiaramonte, D., Ellefson-Frank, R. & Miller, R. L. | 2022 | Breaking the binary: Restriction and reclamation of power among transgender and gender diverse young adults | United States of America | Qualitative |
| 5 | Cleverley, K., McCann, E., O'Brien, D., Davies, J., Bennett, K., Brennenstuhl, S., Courey, L., Henderson, J., Jeffs, L., Miller, J., Pignatiello, T., Rong, J., Rowland, E., Stevens, K. & Szatmari, P. | 2021 | Prioritizing core components of successful transitions from child to adult mental health care: a national Delphi survey with youth, caregivers, and health professionals | Canada | Mixed methods |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 6 | Doyle, A. M., Chikwari, D. D., Majozi, N., Simwinga, M., Mayingire, G. R., Simbeye, K., Dringus, S. & Bernays, S. | 2022 | Adolescent health series: Engagement with young people as partners in health research: Four case studies from Sub-Saharan Africa | Sub-Saharan Africa – Zambia, Zimbabwe, South Africa | Qualitative |
| 7 | Dunn, V., O'Keeffe, S., Stapley, E. & Midgley, N. | 2018 | Facing shadows: working with young people to coproduce a short film about depression | United Kingdom | Qualitative |
| 8 | Fern, L. A., Taylor, R. M., Whelan, J., Pearce, S., Grew, T., Brooman, K., Starkey, C., Millington, H., Ashton, J. & Gibson, F. | 2013 | The art of age-appropriate care - Reflecting on a conceptual; model of the cancer experience for teenagers and young adults | United Kingdom | Qualitative |
| 9 | Findholt, N. E., Michael, Y. L. & Davis, M. M. | 2010 | Photovoice engages rural youth in childhood obesity prevention | United States of America | Qualitative |
| 10 | Fisher-Borne, M. & Brown, A. | 2018 | A case study using photovoice to explore racial and social identity among young black men: Implications for social work research and practice | United States of America | Qualitative |
| 11 | Fletcher, S. & Mullett, J. | 2016 | Digital stories as a tool for health promotion and youth engagement | Canada | Qualitative |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 12 | Ford, T., Rasmus, S.& Allen, J. | 2012 | Being useful: achieving indigenous youth involvement in a community-based participatory research project in Alaska | United States of America | Qualitative |
| 13 | Genuis, S. K., Willows, N., Alexander First Nation. & Jardine, C. | 2014 | Through the lens of our cameras: children's lived experience with food security in a Canadian indigenous community | Canada | Qualitative |
| 14 | Hart, A., Flegg, M., Rathbone, A., Gant, N., Buttery, L., Gibbs, O. & Dennis, S. | 2020 | Learning from the resilience playtest: increasing engagement in resilience promoting games through participatory design | United Kingdom | Mixed methods |
| 15 | Kendal, S. E., Milnes, L., Welsby, H., Pryjmachuk, S. & Co-researcher group | 2017 | Prioritizing young people's emotional health support needs via participatory research | United Kingdom | Qualitative |
| 16 | Lam, G. Y. H., Holden, E., Fitzpatrick, M., Mendez, L. R. & Berkman, K. | 2020 | "Different but connected": Participatory action research using photovoice to explore well-being in autistic young adults | United States of America | Qualitative |
| 17 | Livingood, W. C., Monticalvo, D., Bernhardt, J. M., Wells, K. T., Harris, T., Kee, K., Hayes, J., George, D. & Woodhouse, L. D. | 2017 | Engaging adolescents through participatory and qualitative research methods to develop a digital communication intervention to reduce adolescent obesity | United States of America | Qualitative |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 18 | Marx, R. A. & Regan, P. V. | 2021 | Lights, camera, (youth participatory) action! Lessons from filming a documentary with trans and gender non-conforming youth in the USA | United States of America | Qualitative |
| 19 | Milnes, L. J., McGowan, L., Campbell, M. & Callery, P. | 2012 | Developing an intervention to promote young people's participation in asthma review consultations with practice nurses | United Kingdom | Qualitative |
| 20 | Moscou, K. | 2022 | Planting seeds of change: Voices of indigenous youth on wholistic health | Cananda | Qualitative |
| 21 | Partridge, S. R., Raeside, R., Latham, Z., Singleton, A. C., Hyun, K., Grunseit, A., Steinbeck, K. & Redfern, J. | 2019 | Not to be harsh but try less to relate to 'the teens' and you'll relate to them more': Co-designing obesity prevention text messages with adolescents | Australia | Qualitative |
| 22 | Patchen, L., Ellis, L., Ma, T. X., Ott, C., Chang, K. H. K., Araya, B., Atreyapurapu, S., Alyusuf, A. & Lanzi, R. G. | 2020 | Engaging African American youth in the development of a serious mobile game for sexual health education: mixed methods study | United States of America | Mixed methods |
| 23 | Pavlopoulou, G. | 2020 | A good night's sleep: Learning about sleep from autistic adolescents' personal accounts | United Kingdom | Qualitative |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 24 | Pickering, C. J., Al-Baldawi, Z., McVean, L., Adan, M., Amany, R. A., Al-Baldawi, Z., Baker, L. & O'Sullivan, T. | 2022 | Insights on the COVID-19 pandemic: Youth engagement through photovoice | Canada | Qualitative |
| 25 | Salami, B., Denga, B., Taylor, R., Ajayi, N., Jackson, M., Asefaw, M. & Salma, J. | 2021 | Access to mental health for black youths in Alberta | Canada | Qualitative |
| 26 | Sangalang, C. C., Ngouy, S. & Lau, A. S. | 2015 | Using community-based participatory research to identify health issues for Cambodian American Youth | United States of America | Mixed methods |
| 27 | Shearn, K., Brook, A., Humphreys, H. & Wardle, C. | 2021 | Mixed methods participatory action research to inform service design based on the capabilities approach, in the North of England | United Kingdom | Mixed methods |
| 28 | Swist, T., Collin, P., Nguyen, B., Davies, C., Cullen, P., Medlow, S., Skinner, S. R., Third, A. & Steinbeck, K. | 2021 | Guiding, sustaining and growing the public involvement of young people in an adolescent health research community of practice | Australia | Qualitative |

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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 29 | Teela, L., Verhagen, L. E., Gruppen, M. P., Santana, M. J., Grootenhuis, M. A. & Haverman, L. | 2022 | Including the voices of paediatric patients: Cocreation of an engagement game | Netherlands | Qualitative |
| 30 | Toraif, N., Augsberger, A., Young, A., Murillo, H., Bautista, R., Garcia, S., Sprague Martinez, L. & Gergen Barnett, K. | 2021 | How to be an antiracist: Youth of color's critical perspectives on antiracism in a youth participatory action research context | United States of America | Qualitative |
| 31 | Valdez, E. S., Valdez, L. & Garcia, D. O. | 2021 | Using participatory methods to enhance youth engagement in substance use research | United States of America | Qualitative |
| 32 | Vaughan, C. | 2010 | "When the road is full of potholes, I wonder why they are bringing condoms?" Social spaces for understanding young Papua New Guineans' health-related knowledge and health-promoting action | Papua New Guinea | Qualitative |
| 33 | Whale, K., Beasant, L., Wright, A. J., Yardley, L., Wallace, L. M., Moody, L. & Joinson, C. | 2021 | A smartphone app for supporting the self-management of daytime urinary incontinence in adolescents: Development and formative evaluation study of URApp | United Kingdom | Qualitative |
| 34 | Wintels, S. C., Smits, D., van Wesel, F., Verheijden, J. & Ketelaar, M. | 2018 | How do adolescents with cerebral palsy participate? Learning from their personal experiences | Netherlands | Qualitative |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 35 | Yonas, M. A., Burke, J. G. & Miller, E. | 2013 | Visual voices: A participatory method for engaging adolescents in research and knowledge transfer | United States of America | Qualitative |
| 36 | Brady, L., Templeton, L., Toner, P., Watson, J., Evans, D., Percy-Smith, B. & Copello, A. | 2018 | Involving young people in drug and alcohol research | United Kingdom | Qualitative |
| 37 | Brooks, H., Syarif, A. K., Pedley, R., Irmansyah, I., Prawira, B., Lovell, K., Opitasari, C., Ardisasmita, A., Tanjung, I. S., Renwick, L., Salim, S. & Bee, P. | 2021 | Improving mental health literacy among young people aged 11-15 years in Java, Indonesia: the co-development of a culturally appropriate, user-centred resource (The IMPeTUs Intervention) | Indonesia | Qualitative |
| 38 | Fisher, H., Chantler, T., Finn, A., Kesten, J., Hickman, M., Letley, L., Mounier-Jack, S., Thomas, C., Worthington, K., Yates, J. & Audrey, S. | 2022 | Development of an educational package for the universal human papillomavirus (HPV) vaccination programme: a co-production study with young people and key informants | United Kingdom | Qualitative |
| 39 | Hackett, M., Gillens-Eromosele, C. & Dixon, J. | 2015 | Examining childhood obesity and the environment of a segregated, lower-income US suburb | United States of America | Qualitative |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 40 | Thomson, A., Peasgood, E. & Robertson, S. | 2022 | The youth patient and public involvement café - A youth-led model for meaningful involvement with children and young people | United Kingdom | Qualitative |
| 41 | Halsall, T., Daley, M., Hawke, L., Henderson, J. & Matheson, K. | 2022 | "You can kind of just feel the power behind what someone's saying": a participatory-realist evaluation of peer support for young people coping with complex mental health and substance use challenges | Canada | Mixed methods |
| 42 | McCalman, J., Bainbridge, R. G., Redman-MacLaren, M., Russo, S., Rutherford, K., Tsey, K., Ungar, M., Wenitong, M. & Hunter, E. | 2017 | The development of a survey instrument to assess Aboriginal and Torres Strait Islander students' resilience and risk for self-harm | Australia | Qualitative |
| 43 | Povey, J., Sweet, M., Nagel, T., Lowell, A., Shand, F., Vigona, J. & Dingwall, K. M. | 2022 | Determining priorities in the Aboriginal and Islander mental health initiative for youth app second phase participatory design project: Qualitative study and narrative literature review | Australia | Qualitative |
| 44 | Pullmann, M. D., Ague, S., Johnson, T., Lane, S., Beaver, K., Jetton, E. & Rund, E. | 2013 | Defining engagement in adolescent substance abuse treatment | United States of America | Qualitative |



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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 45 | Cooke, P., Duara, R. & Madill, A. | 2022 | The big picture': Developing community-led approaches to substance use disorder through participatory video; the aim was to increase the involvement of young people in India in the active development of practice and policy with regards to Substance Use Disorder (SUD) | India | No data collected |
| 46 | Garwick, A. W., Rhodes, K. L., Peterson-Hickey, M. & Hellerstedt, W. L. | 2007 | Native Teen Voices: Adolescent pregnancy prevention recommendations | United States of America | Qualitative |
| 47 | Powers, J. L. & Tiffany, J. S. | 2006 | Engaging youth in participatory research and evaluation | United States of America<br><br>Bosnia and Herzegovina | Qualitative |
| 48 | Visser, M. (retrieved from Asuquo SR) | 2007 | HIV/AIDS prevention through peer education and support in secondary schools in South Africa | South Africa | Mixed methods |

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| | Authors | Publication year | Study Title | Country | Study design |
|---|---|---|---|---|---|
| 49 | Van Schelven, F., Van Der Meulen, E., Kroeze, N., Ketelaar, M. & Boeije, H. | 2020 | Patient and public involvement of young people with a chronic condition: lessons learned and practical tips from a large participatory program | Netherlands | Mixed methods |
| 50 | Hardt, J., Canfell, O. J., Walker, J. L., Webb, K., Brignano, S., Peu, T., Santos, D., Kira, K. & Littlewood, R. (retrieved from Freire SR) | 2020 | Healthier Together: Co-design of culturally tailored childhood obesity community prevention program for Maori and Pacific Islander children and families | Australia | Qualitative |

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### 3.9. Rigour

To ensure rigour, the researcher led and implemented all the steps in this review:

1. To promote transparency of the review process, the protocol was registered on PROSPERO.
2. Before the development of the search strategy, the researcher identified a few relevant studies and then developed the search strategy together with a UWC librarian through an iterative process.
3. Three databases were searched that maximised the number of eligible studies and avoided missing any relevant studies. The researcher used clear eligibility criteria to screen the titles, abstracts, and full-texts of the eligible studies. The list of included studies was checked by the supervisors.
4. The researcher extracted the data form the included studies after which the supervisors did quality checks of the data. The data extraction form was piloted with two included studies and cross-checked with the supervisors, to improve its accuracy. The researcher completed the CASP checklist for each one of the included studies to assess the methodological quality. The supervisors reviewed the methodological quality assessment of a sample of the included studies.
5. The researcher coded two of the included studies which were then checked by the supervisors to confirm the codes. After completion of the coding, the coding list was again checked by the supervisors. The researcher analysed and synthesised the data by clustering codes together to form themes and sub-themes. The analysis and synthesis process were checked by the supervisors to ensure transparency and credibility.

### 3.10. Ethical considerations

Ethical approval to conduct the review was not required, however, the review protocol was registered with PROSPERO (REF: CRD42022359977). Unlike primary research, this review involved secondary analysis of already published literature; therefore, no human participants were recruited, and no consent were necessary as no confidential, personal, or sensitive information were collected. However, to ensure rigour, the literature searches were conducted with the help of a librarian and the screening of study titles and abstracts were double-checked



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by the researcher, and quality checked by the supervisors. Three databases were searched to maximise the number of eligible studies and to avoid missing any relevant studies. The researcher, librarian, and supervisors, maintained objectivity, integrity, and thoroughness throughout the searches, to ensure the accurate execution of studies and non-bias. All collected data are stored on a personal, password-protected, computer. The collected data will be kept for up to five years after the successful completion and submission of the mini thesis.


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## CHAPTER 4: PRESENTATION OF FINDINGS

This chapter details the review findings of the fifty included studies. An overview of the characteristics of the included studies is presented as well as the fourteen themes.

### 4.1. Characteristics of the included studies

#### 4.1.1. Setting

Majority of the studies (n = 45) were conducted in high income countries (HICs): Australia (n = 5) (McCalman *et al.*, 2017; Partridge *et al.*, 2019; Hardt *et al.*, 2020; Swist *et al.*, 2021; Povey *et al.*, 2022), Canada (n = 7) (Genius *et al.*, 2014; Flether & Mullett, 2016; Cleverley *et al.*, 2021; Salami *et al.*, 2021; Halsall *et al.*, 2022; Moscou, 2022; Pickering *et al.*, 2022), Netherlands (n = 3) (Wintels *et al.*, 2018; Van Schelven *et al.*, 2020; 2022; Teela *et al.*, 2022), United Kingdom (n = 12) (Milnes *et al.*, 2012; Fern *et al.*, 2013; Kendal *et al.*, 2017; Brady *et al.*, 2018; Dunn *et al.*, 2018; Ali *et al.*, 2020; Hart *et al.*, 2020; Pavlopoulou, 2020; Shearn *et al.*, 2021; Whale *et al.*, 2021; Fisher *et al.*, 2022; Thomson, Peasgood & Robertson, 2022), and the United States of America (n = 18) (Powers & Tiffany, 2006; Garwick *et al.*, 2007; Findholt, Michael & Davis, 2010; Ford, Rasmus & Allen, 2012; Atkiss *et al.*, 2013; Pullmann *et al.*, 2013; Yonas, Burke & Miller, 2013; Hackett, Gillens-Eromosele & Dixon, 2015; Sangalang, Ngouy & Lau, 2015; Livingood *et al.*, 2017; Fisher-Borne & Brown, 2018; Lam *et al.*, 2020; Patchen *et al.*, 2020; Marx & Regan, 2021; Toraif *et al.*, 2021; Valdez, Valdez & Garcia, 2021; Altares *et al.*, 2022; Chiaramonte, Ellefson-Frank & Miller, 2022).

Nine studies were conducted in LMICs: Bosnia and Herzegovina (n = 1) (Powers & Tiffany, 2006), India (n = 1) (Cooke, Duara & Madill, 2022), Indonesia (n = 1) (Brooks *et al.*, 2021), Papua New Guinea (n = 1) (Vaughan, 2010), South Africa (n = 2) (Visser, 2007; Doyle *et al.*, 2022), Zambia (n = 1) (Doyle *et al.*, 2022), and Zimbabwe (n = 2) (Doyle *et al.*, 2022).



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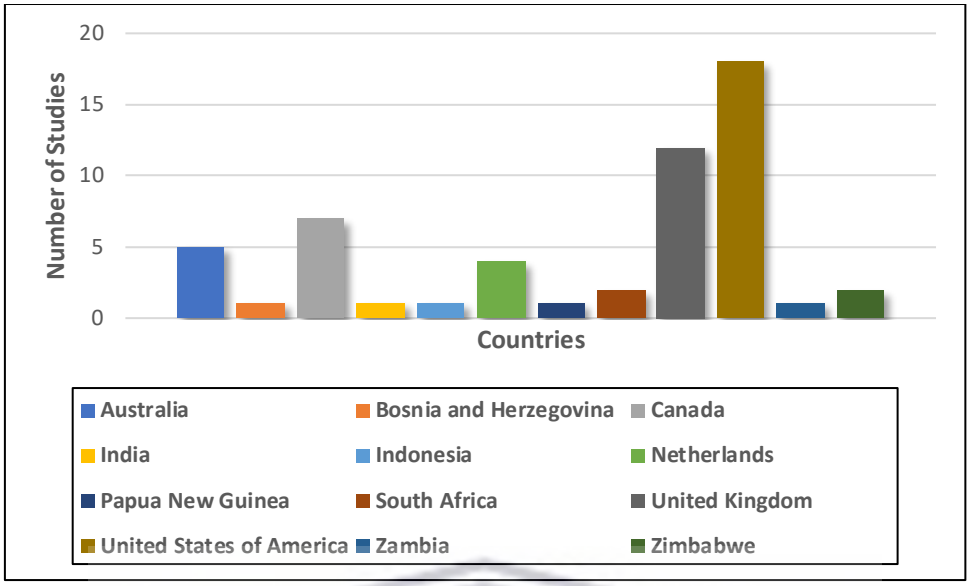


**Figure 2: Study setting**

4.1.2. Studies focusing on health research or practice

Thirty-seven studies engaged youth for research purposes (Powers & Tiffany, 2006; Garwick *et al.*, 2007; Visser, 2007; Findholt, Michael & Davis, 2010; Vaughan, 2010; Ford, Rasmus & Allen, 2012; Fern *et al.*, 2013; Pullmann *et al.*, 2013; Yonas, Burke & Miller, 2013; Genius *et al.*, 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Kendal *et al.*, 2017; Livingood *et al.*, 2017; McCalman *et al.*, 2017; Brady *et al.*, 2018; Fisher-Borne & Brown, 2018; Wintels *et al.*, 2018; Ali *et al.*, 2020; Hardt *et al.*, 2020; Lam *et al.*, 2020; Pavlopoulou, 2020; Van Schelven *et al.*, 2020; Cleverley *et al.*, 2021; Marx & Regan, 2021; Salami *et al.*, 2021; Shearn *et al.*, 2021; Swist *et al.*, 2021; Toraif *et al.*, 2021; Valdez, Valdez & Garcia, 2021; Altares *et al.*, 2022; Chiaramonte, Ellefson-Frank & Miller, 2022; Doyle *et al.*, 2022; Halsall *et al.*, 2022; Moscou, 2022; Pickering *et al.*, 2022).

Eight studies engaged youth to influence a health practice (Atkiss *et al.*, 2013; Dunn *et al.*, 2018; Partridge *et al.*, 2019; Hart *et al.*, 2020; Brooks *et al.*, 2021; Whale *et al.*, 2021; Cooke, Duara & Madill, 2022; Teela *et al.*, 2022; Thomson, Peasgood & Robertson, 2022). Four studies engaged youth in both the research process and the practice, e.g., research was conducted, and an application-based game were designed (Milnes *et al.*, 2012; Patchen *et al.*, 2020; Fisher *et al.*, 2022; Povey *et al.*, 2022). There were no studies that described the process of how youth were engaged in policy development.



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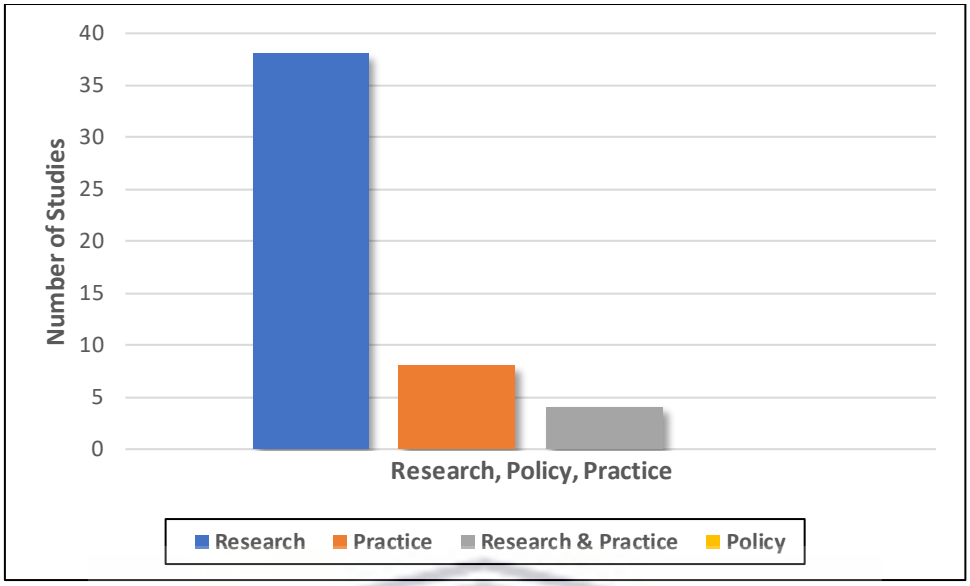


**Figure 3: Studies focusing on health research or practice**

4.1.3. Health research field of the studies

Majority of the studies (n = 14) pertained to a general health field (e.g., health promotion, developing a game, participating in an involvement café etc.) (Powers & Tiffany, 2006; Ford, Rasmus & Allen, 2012; Atkiss *et al.*, 2013; Yonas, Burke & Miller, 2013; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Fisher-Borne & Brown, 2018; Shearn *et al.*, 2021; Swist *et al.*, 2021; Toraif *et al.*, 2021; Doyle *et al.*, 2022; Moscou, 2022; Teela *et al.*, 2022; Thomson, Peasgood & Robertson, 2022). Eight studies focused on mental health research and practices (Kendal *et al.*, 2017; McCalman *et al.*, 2017; Dunn *et al.*, 2018; Brooks *et al.*, 2021; Cleverley *et al.*, 2021; Salami *et al.*, 2021; Halsall *et al.*, 2022; Povey *et al.*, 2022) while another nine focused on clinical health and practices (Milnes *et al.*, 2012; Fern *et al.*, 2012; Wintels *et al.*, 2018; Hart *et al.*, 2020; Lam *et al.*, 2020; Pavlopoulou, 2020; Van Schelven *et al.*, 2020; Whale *et al.*, 2021; Pickering *et al.*, 2022). Eight studies pertained to sexual and reproductive health and practices (Garwick *et al.*, 2007; Visser, 2007; Vaughan, 2010; Ali *et al.*, 2020; Patchen *et al.*, 2020; Marx & Regan, 2021; Chiaramonte, Ellefson-Frank & Miller, 2022; Doyle *et al.*, 2022), while seven studies focussed on nutrition (Findholt, Michael & Davis, 2010; Genius *et al.*, 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Livingood *et al.*, 2017; Partridge *et al.*, 2019; Hardt *et al.*, 2020; Altares *et al.*, 2022), and five studies focused on environmental health (Pullmann *et al.*, 2013; Brady *et al.*, 2018; Valdez, Valdez & Garcia, 2021; Cooke, Duara & Madill, 2022; Fisher *et al.*, 2022).



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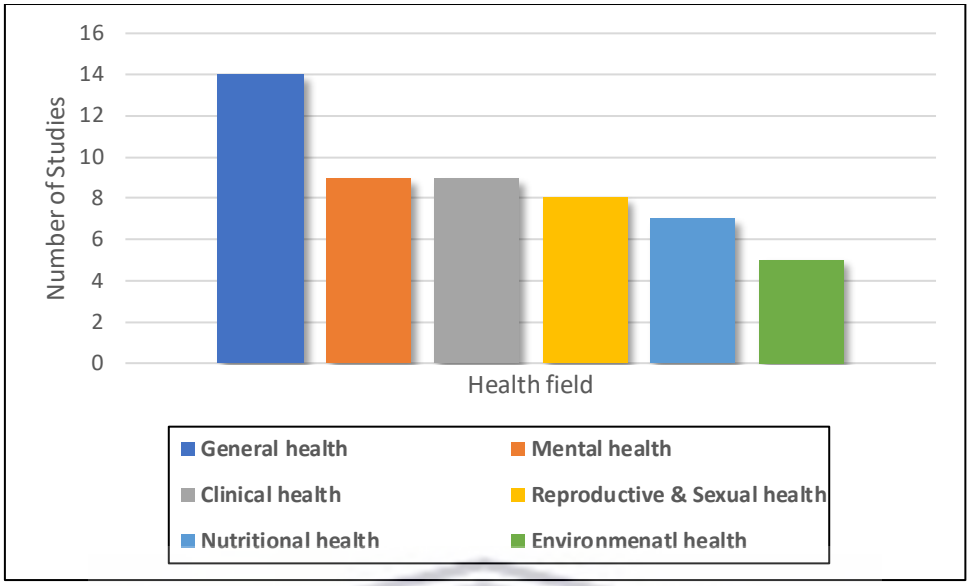


**Figure 4: Health research field of the studies**

4.1.4. Age categories

Included in the age group categories are the ages of the youth co-researchers as well as the study participants (children, youth, and adults). The highest number of participants (n = 44) were between the ages of 15 years and 22 years, falling within the UNs and WHOs definition of young people (Powers & Tiffany, 2006; Garwick *et al.*, 2007; Visser, 2007; Findholt, Michael & Davis, 2010; Vaughan, 2010; Milnes *et al.*, 2012; Atkiss *et al.*, 2013; Fern *et al.*, 2013; Pullmann *et al.*, 2013; Genius *et al.*, 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Kendal *et al.*, 2017; Livingood *et al.*, 2017; McCalman *et al.*, 2017; Brady *et al.*, 2018; Fisher-Borne & Brown, 2018; Wintels *et al.*, 2018; Partridge *et al.*, 2019; Ali *et al.*, 2020; Hart *et al.*, 2020; Lam *et al.*, 2020; Patchen *et al.*, 2020; Pavlopoulou, 2020; Cleverley *et al.*, 2021; Marx & Regan, 2021; Salami *et al.*, 2021; Shearn *et al.*, 2021; Swist *et al.*, 2021; Toraif *et al.*, 2021; Valdez, Valdez & Garcia, 2021; Whale *et al.*, 2021; Chiaramonte, Ellefson-Frank & Miller, 2022; Doyle *et al.*, 2022; Halsall *et al.*, 2022; Moscou, 2022; Pickering *et al.*, 2022; Povey *et al.*, 2022; Teela *et al.*, 2022). The younger age category of 8 years to 15 years (n = 21) mostly included the ages of young participants (i.e., youth were the co-researchers and children were the participants in the study) (Powers & Tiffany, 2006; Garwick *et al.*, 2007; Visser, 2007; Milnes *et al.*, 2012; Yonas, Burke & Miller, 2013; Genius *et al.*, 2014; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; McCalman *et al.*, 2017; Partridge *et al.*, 2019; Hart *et al.*, 2020; Pavlopoulou, 2020; Marx & Regan, 2021; Shearn *et al.*, 2021; Swist *et al.*, 2021; Valdez, Valdez & Garcia, 2021;



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Whale *et al.*, 2021; Fisher *et al.*, 2022; Pickering *et al.*, 2022; Povey *et al.*, 2022; Teela *et al.*, 2022). Thirteen studies had youth co-researchers or participants between 22 years and 29 years (Vaughan, 2010; Fern *et al.*, 2013; Fletcher & Mullett, 2016; Fisher-Borne & Brown, 2018; Lam *et al.*, 2020; Salami *et al.*, 2021; Swist *et al.*, 2021; Toraif *et al.*, 2021; Chiaramonte, Ellefson-Fran & Miller, 2022; Doyle *et al.*, 2022; Halsall *et al.*, 2022; Moscou, 2022; Thomson, Peasgood & Robertson, 2022), and two studies had participants older than 29 years (i.e., adults were the participants) (Cleverley *et al.*, 2021; Salami *et al.*, 2021). There were also 7 studies that did not specify a certain age group and only referred to youth or adults.

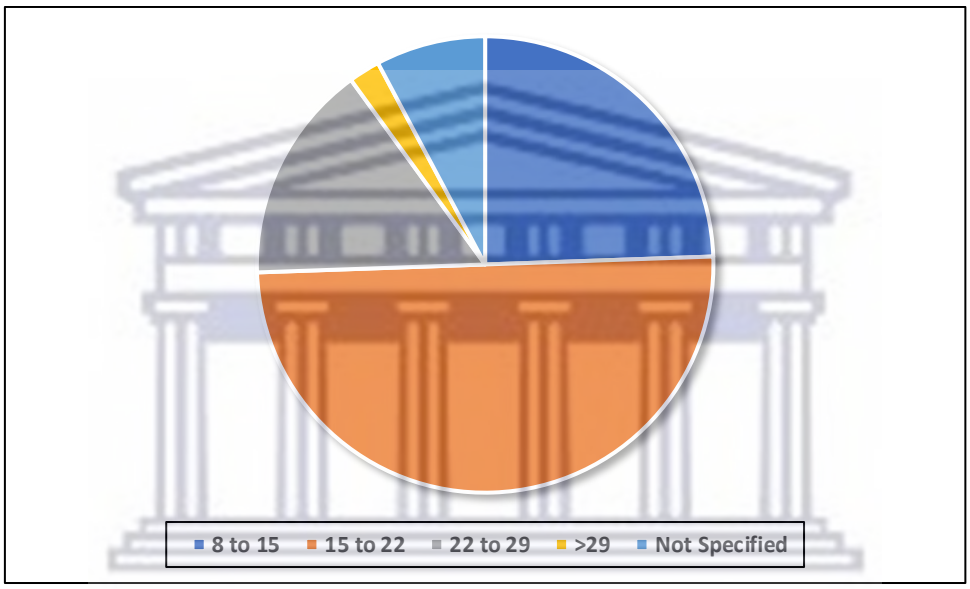


**Figure 5: Age categories**

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4.1.5. Gender

Youth co-researchers and participants who identified as either male or female were equally distributed across the studies (n = 30), with only a small number of studies (n = 6) having youth co-researchers and participants who identified as part of the Lesbian Gay Transgender Bisexual Queer and more (LGTBQ+) community (including non-binary, and gender-fluid) (Patchen *et al.*, 2020; Pavlopoulou, 2020; Salami *et al.*, 2021; Toraif *et al.*, 2021; Moscou, 2022; Povey *et al.*, 2022). Quite a large number of studies (n = 21) did not indicate the gender of the participants (Powers & Tiffany, 2006; Ford, Rasmus & Allen, 2012; Atkiss *et al.*, 2013; Pullmann *et al.*, 2013; Genius *et al.*, 2014; Fletcher & Mullett, 2016; Livingood *et al.*, 2017; McCalman *et al.*, 2017; Hardt *et al.*, 2020; Hart *et al.*, 2020; Van Schelven *et al.*, 2020; Brooks *et al.*, 2021; Marx & Regan, 2021; Shearn *et al.*, 2021; Valdez, Valdez & Garcia, 2021; Altares



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*et al.,* 2022; Chiaramonte, Ellefson-Frank & Miller, 2022; Cooke, Duara & Madill, 2022; Fisher *et al.,* 2022; Thomson, Peasgood & Robertson, 2022).

## 4.2. Methodological characteristics of the included studies

### 4.2.1. Study design

Forty-one of the included studies used a qualitative study design, with eight studies employing a mixed-methods design (Visser, 2007; Sangalang, Ngouy & Lau, 2015; Hart *et al.,* 2020; Patchen *et al.,* 2020; Van Schelven *et al.,* 2020; Cleverley *et al.,* 2021; Shearn *et al.,* 2021; Halsall *et al.,* 2022). One study (Cooke, Duara and Madill, 2022) did not use a specific design as they described how youth were involved in a filmmaking process.

### 4.2.2. Data collection and analysis methods

Most of the studies (n = 41) used interviews, focus group discussions, photovoice, workshops and qualitative surveys as their data collection methods, with thematic analysis being the main data analyses method used. Other data collection methods included project reports, field notes, meetings, conversation cafés and arts-based methods, while other data analyses methods included content-, framework, and quantitative analyses. Nine studies did not conduct any analyses or did not specify the analyses method used (Powers & Tiffany, 2006; Fletcher & Mullett, 2016; Kendal *et al.,* 2017; Dunn *et al.,* 2018; Partridge *et al.,* 2019; Swist *et al.,* 2021; Valdez, Valdez & Garcia, 2021; Cooke, Duara & Madill, 2022; Doyle *et al.,* 2022).

## 4.3. Methodological assessment of the included studies

The CASP checklist was used to critically assess the quality of the included studies. Forty-seven of the included studies scored more than 60% indicating that they were of good quality Three studies were scored as being of a fair quality, and none of the included studies scored below 45% (being of poor quality).

## 4.4. Review findings

Fourteen themes emerged from the included studies addressing the conceptualisations and strategies of youth engagement in health research, and practice. None of the included studies



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addressed youth engagement in health policies. A summary of the themes is provided in Table 3.

**Table 3: Summary of the fourteen themes**

| **Conceptualisations of youth engagement in health research and practice** |
|---|
| **Descriptions of youth engagement in health research and practice** |
| Theme 1: Active engagement in research design and execution, and health practices |
| Theme 2: Importance of youth voices in health research and practice |
| Theme 3: Engaging youth in health research and practice through a community-based approach |
| **Activities of youth engagement in health research and practice** |
| Theme 4: Youth as co-researchers and/or participants |
| **Processes of youth engagement in health research and practice** |
| Theme 5: Youth as experts on youth |
| Theme 6: Role of key contacts, stakeholders and/or organisations |
| Theme 7: Importance of relationships with all relevant stakeholders |
| Theme 8: Youth involved in the data analysis process |
| **Outcomes of youth engagement in health research and practice** |
| Theme 9: Youth's experience on being engaged in the process |
| Theme 10: Youth part of the dissemination of findings |
| Theme 11: Skills gained by youth through engagement |
| Theme 12: Benefits of engaging youth in health research and practice |
| **Strategies of youth engagement in health research and practice** |
| Theme 13: Advisory boards |
| Theme 14: Youth engaged in key stages of the research process and practice development |

4.4.1. Conceptualisations of youth engagement in health research and practice

4.4.4.1. Descriptions of youth engagement in health research and practice

Majority of the included studies (n = 35) described youth engagement in a way that was relevant and suitable for their study. Three main themes related to descriptions of youth engagement emerged from the included studies, namely (1) active engagement in research design and execution, and health practices; (2) importance of youth voices in health research



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and practice; and (3) engaging youth in health research and practice through a community-based approach. These three themes provide a summary of the elements found in different descriptions of youth engagement in health research and practice.

Theme 1: Active engagement in research design and execution, and health practices

Descriptions of youth engagement in included studies described youth as experts in their own lives, and that involving them in the research process can enhance research outcomes. Youth can identify the problems at hand in their community and collaborate with adults to address these issues (Altares *et al.,* 2022). However, it is essential to ensure that youth are treated as equals to adult stakeholders and that the research is conducted "with" or "by" them, not just "on", "about" or "for" them (Dunn *et al.,* 2018; Lam *et al.,* 2020; Thomson, Peasgood & Robertson, 2022).

Several included studies (n =21) had positive outcomes when actively engaging youth. These positive outcomes pertained to the researchers, the research process, and the youth themselves. Examples included researchers gaining a deeper understanding of youth's perceptions and attitudes (Ali *et al.,* 2020); youth being provided with hands-on experience to develop logistical, communicative, and problem-solving skills (Altares *et al.,* 2022); and youth generating the overall idea of films, decided on the film's main audience, and creating the visual and audio material based on their own ideas and experiences (Dunn *et al.,* 2018). Ford, Rasmus and Allen found that youth who were involved in the research wanted to continue, even after the research project ended, and they took ownership of the issues in their communities (Ford, Rasmus & Allen, 2012). Kendal and colleagues reiterate these findings stating,

> "…that youth participatory research is best achieved where young people can steer all stages of a research project, from planning to evaluation, leading to co-produced, individually tailored design with more chance of success" (Kendal *et al.,* 2017:268).

Theme 2: Importance of youth voices in health research and practice

If adult stakeholders want to understand the thoughts and feelings of youth, especially when it pertains to an issue affecting them, it is essential to ask the youth themselves about their personal experiences. Several studies emphasised the significance of having youth voices heard in health research and practice (Genius *et al.,* 2014; Hackett, Gillens-Eromosele & Dixon,



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2015; Kendal *et al.,* 2017; Brady *et al.,* 2018; Wintels *et al.,* 2018; Lam *et al.,* 2020; Marx & Regan, 2021; Salami *et al.,* 2021; Shearn *et al.,* 2021; Cooke, Duara & Madill, 2022; Halsall *et al.,* 2022; Moscou, 2022; Pickering *et al.,* 2022). Quotations from two studies encapsulate the importance of having youth voices heard in research and practice:

> "…young people's voices should be heard so they can represent their own experiences, rather than adult imposed values" (Shearn *et al.,* 2021:451)

> "…a focus on youth voice can establish a culture where youth involvement is viewed as a universal community principle" (Hackett, Gillens-Eromosele & Dixon, 2015:249)

When youth are provided with the opportunity to control the conversation around their health, they can harness the power and gain the confidence to shape their own narratives (Marx & Regan, 2021). Toraif and colleagues found that youth who are more actively involved in the research process regularly engage in self-reflection, are willing to confront social problems, and can more easily suggest solutions that are impactful to their communities (Toraif *et al.,* 2021).

Theme 3: Engaging youth in health research and practice through a community-based approach

To inspire community-based change, it is important to involve the community that are affected by the problem, for example, when youth are engaged through a participatory action research framework or a community-based participatory research approach, it is because the researchers see them as the representatives of all the youth in that area (Altares *et al.,* 2022). In Fletcher and Mullett, the youth were asked to create stories that reflected the interests of their community and themselves (Fletcher & Mullett, 2016). Youth led the recruitment of participants in the study of Valdez, Valdez and Garcia and agreed that all collected data are owned by the community and can be used to develop better tailored interventions and strategies for the youth (Valdez, Valdez & Garcia, 2021). Livingood and colleagues emphasised the importance of engaging youth through a community-based approach as an

> "…academic-community partnership approach emphasises filling the gaps in youth participation while building on existing community assets…" (Livingood *et al.,* 2017:572)



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4.4.4.2. Activities of youth engagement in health research and practice

Theme 4: Youth as co-researchers and/or participants

In the included studies, youth were part of the process either as co-researchers, thus involved in the actual research (having more decision-making power), or as participants, where they are involved based on the researchers needs (having less decision-making power). In some of the included studies, youth played a dual role – being a co-researcher and a participant, depending on the activity (Visser, 2007; Fern *et al.,* 2013; Kendal *et al.,* 2017; Livingood *et al.,* 2017; Shearn *et al.,* 2021; Moscou, 2022; Thomson, Peasgood & Robertson, 2022).

Half of the included studies engaged youth as co-researchers, conceptualised as youth playing an active role in the research, especially in data collection and analysis (Powers & Tiffany, 2006; Garwick *et al.,* 2007; Visser, 2007; Ford, Rasmus & Allen, 2012; Pullmann *et al.,* 2013; Genius *et al.,* 2014; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Kendal *et al.,* 2017; Livingood *et al.,* 2017; Partridge *et al.,* 2019; Ali *et al.,* 2020; Lam *et al.,* 2020; Brooks *et al.,* 2021; Marx & Regan, 2021; Salami *et al.,* 2021; Shearn *et al*., 2021; Swist *et al.,* Toraif *et al.,* 2021; Altares *et al.,* 2022; Chiaramonte, Ellefson-Frank & Miller, 2022; Doyle *et al.,* 2022; Moscou, 2022). Youth that were included as co-researchers received training in various aspects of the research process, such as qualitative research methodologies, including identifying research questions, developing the study design, data collection and analysis, and dissemination of findings. Youth co-researchers also received training on how to recruit peers or adult stakeholders for the study, and how to conduct ethical research.

Youth that were involved in conducting and facilitating focus groups discussions (FGDs) and interviews received training on reasons for conducting FGDs and interviews, the role of the facilitators, how to ask probing but not leading questions, and how to build a trusting relationship with the participants (Powers & Tiffany, 2006; Garwick *et al.,* 2007; Fern *et al.,* 2013; Genius *et al.,* 2014; Kendal *et al.,* 2017; Livingood *et al.,* 2017; Dunn *et al.,* 2018; Ali *et al.,* 2020; Marx & Regan, 2021; Salami *et al.*, 2021; Toraif *et al.,* 2021; Doyle *et al.,* 2022; Pickering *et al.,* 2022). Ali and colleagues stated that the goal of training youth as co-researchers is to support them, as well as the younger participants in the study, to openly express their perceptions to their peer group:



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> "…young people would discuss topics amongst their peer more openly than they would with adult researchers" (Ali *et al.,* 2020:6),

While Fern and colleagues said that:

> "…recognizing that TYAs [teenagers and young adults] are likely to share more in-depth information about themselves with each other (Fern *et al.,* 2013:E29)"

When youth are engaged as co-researchers, it allows for a less hierarchical relationship between the researcher and the youth.

In several of the included studies (n = 29) youth did not receive training as co-researchers and were not part of the decisions made in most of the key research stages. However, youth were also not only participants, i.e., in some instances they played a role in one or two key stages of the research process, primarily in the data collection process. For example, in some studies youth took photographs and added accompanying descriptions to answer the research questions (Vaughan, 2010; Genius *et al.,* 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Fletcher & Mullett, 2016; Fisher-Borne & Brown, 2018; Pavlopoulou, 2020; Valdez, Valdez & Garcia, 2021; Altares *et al.,* 2022; Cooke, Duara & Madill, 2022; Moscou, 2022). In other studies, youth were part of piloting the research questionnaires, providing feedback on the content of the questionnaire as well as the comprehension and relevancy of the questionnaire (McCalman *et al.,* 2017; Van Schelven *et al.,* 2020). In Shearn and colleagues, youth that piloted the questionnaire were a distinct group from youth co-researchers (Shearn *et al.,* 2021).

Youth were also participants in testing a new mobile-based health game or a health application in several studies (Hart *et al.,* 2020; Patchen *et al.,* 2020; Whale *et al.,* 2021; Povey *et al.,* 2022; *Teela et al.,* 2022). In Patchen and colleagues, youth tested the usability of a sexual health education game. They reviewed both the design and content of the game, and their feedback was used to modify the game (Patchen *et al.,* 2020). Whale and colleagues created an application for adolescents experiencing daytime urinary incontinence – the youth tested the application, and their immediate reactions to the application were recorded and used to update the applications before the final pilot (Whale *et al.,* 2021).



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4.4.4.3. Processes of youth engagement in health research and practice

In 49 of the 50 included studies youth were engaged in several different processes during the research stages. These processes are summarised into four themes: (5) youth as experts on youth; (6) the role of key contacts, stakeholders and/or organisations; (7) the importance of relationships with all relevant stakeholders; and (8) youth involved in the data analysis process.

Theme 5: Youth as experts on youth

Several studies (n = 7) (Sangalang, Nguoy & Lau, 2015; Livingood *et al.,* 2017; Ali *et al.,* 2020; Lam *et al.,* 2020; Cleverley *et al.,* 2021; Swist *et al.,* 2021; Chiaramonte, Ellefson-Frank & Miller, 2022) indicated a lack of research, particularly in areas such as youth's experiences with female genital mutilation (Ali *et al.,* 2020), the needs of autistic youth (Lam *et al.,* 2020), and minority youth (Livingood *et al.,* 2017). Therefore, as youth are experts on youth, it is important to involve them in the research processes. They possess expert knowledge on the challenges that youth face, and they have the ability to clarify certain important concepts that adult researchers might not be familiar with. Examples of the knowledge that youth contributed to the research findings included their understanding of HIV and health (Vaughan, 2010), wholistic health (author's term), especially in indigenous communities (Moscou, 2022), social problems concerning youth, such as the use of plastic and climate change (Partridge *et al.,* 2019), as well as knowledge on the research process itself, i.e.,

> "…the youth coalition determined that students might not want to participate in the study due to legal and personal safety concerns" (Valdez, Valdez & Garcia, 2021:749).

Youth also played a critical role in clarifying research language to make it more understandable for other youth, i.e., ensuring that research tools have more accessible and understandable language (Powers & Tiffany, 2006) and phrasing the questions aimed at eliciting responses from youth (Valdez, Valdez & Garcia, 2021).

Theme 6: Role of key contacts, stakeholders and/or organisations

It was evident from several included studies (n = 33) that recruitment of youth, whether as co-researchers or participants, was more successful when conducted through key contacts, stakeholders, and organisations. The key contacts, stakeholders, and organisations used for youth recruitment included community organisations, established student advisory boards,



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youth or student organisations, personal contacts of the researchers, religious organisations, local networks, fitness groups, community leaders, and parent or caregiver groups (Powers & Tiffany, 2006; Garwick *et al.,* 2007; Visser, 2007; Findholt, Michael & Davis, 2010; Ford, Rasmus & Allen, 2012; Atkiss *et al.,* 2013; Fern *et al.,* 2013; Yonas, Burk & Miller, 2013; Hackett, Gillens-Eromosele & Dixon, 2015; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Kendal *et al.,* 2017; Livingood *et al.,* 2017; Dunn *et al.,* 2018; Fisher-Borne & Brown, 2018; Ali *et al.,* 2020; Hardt *et al.,* 2020; Hart *et al.,* 2020; Lam *et al.,* 2020; Pavlopoulou, 2020; Brooks *et al.,* 2021; Cleverley *et al.,* 2021; Marx & Regan, 2021; Shearn *et al.,* 2021; Swist *et al.,* 2021; Valdez, Valdez & Garcia, 2021; Whale *et al.,* 2021; Altares *et al.,* 2022; Doyle *et al.,* 2022; Fisher *et al.,* 2022; Halsall *et al.,* 2022; Moscou, 2022; Povey *et al.,* 2022). Another essential recruitment channel was school administrators, including principals, teachers, and counsellors, as highlighted in the studies by Findholt, Michael and Davis, Shearn and colleagues, and Visser:

> "…asked the school principals, career counsellors, and teachers to inform students of the photovoice opportunity" (Findholt, Michael & Davis, 2010:187)

> "Two teachers…acted as mediators to invite the co-researchers to participate" (Shearn *et al.,* 2021:453)

> "Teachers responsible for HIV education in schools were consulted and were eager to participate" (Visser, 2007:681)

The most frequently used methods to recruit youth were through email, flyers or posters, student centres, telephone, in-person meetings, word of mouth and social media. The importance of utilising key contacts was emphasised in Valdez, Valdez and Garcia:

> "Because the PI [principal investigator] was a white academic outsider, it was important to work closely with the youth coalition coordinator who was bicultural, bilingual, and civically engaged member of the community" (Valdez, Valdez & Garcia, 2021:748).

It is also crucial to note that fostering good relationships between key contacts and youth, as mentioned in Fisher and colleagues, is key to a smooth and successful recruitment process (Fisher *et al.,* 2022).



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Theme 7: Importance of relationships with all relevant stakeholders

A few studies (n = 15) established that a significant factor playing a role in successfully engaging youth is trust – building trustworthy relationships with both the youth and their parents or caregivers (Visser, 2007; Yonas, Burke & Miller, 2013; Hackett, Gillens-Eromosele & Dixon, 2015; McCalman *et al.,* 2017; Dunn *et al.,* 2018; Ali *et al.,* 2020; Hardt *et al.,* 2020; Brooks *et al.,* 2021; Marx & Regan, 2021; Shearn *et al.,* 2021; Valdez, Valdez & Garcia, 2021; Whale *et al.,* 2021; Chiaramonte, Ellefson-Frank & Miller, 2022; Pickering *et al.,* 2022; Povey *et al.,* 2022). Gaining consent from parents or caregivers is not only a crucial ethical requirement but also a vital tool for building trust. Ali and colleagues attributed the success of their study to having the parents involved:

> "…it was essential to engage and gain consent from parents in this project. The reasons for this were twofold. Firstly, following conversations with gatekeepers, it was anticipated that young people were more likely to attend meetings and training if their parents had consented for them to do so. Secondly, mothers brought their children to attend the interviews and focus groups. The successful completion of this study was, therefore, attributed to parental involvement, as well as the trust built with the communities" (Ali *et al.,* 2020:6)

To build trust with the youth co-researchers themselves, Valdez, Valdez and Garcia took extra measures to ensure confidentiality. They obtained a certificate of confidentiality from the National Institutes of Health, assured youth that their responses would be deidentified and securely stored. These steps intended that the youth felt trusted and, as a result, were willing to participate (Valdez, Valdez & Garcia, 2021).

Theme 8: Youth involved in the data analysis process

Youth were consistently involved in the data analysis process in some way or form in 33of the included studies (Powers & Tiffany, 2006; Findholt, Michael & Davis, 2010; Ford, Rasmus & Allen, 2012; Fern *et al.,* 2013; Pullmann *et al.,* 2013; Yonas, Burke & Miller, 2013; Genius et al., 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Sangalang, Ngouy & Lau, 2015; Kendal *et al.,* 2017; Livingood *et al.,* 2017; Dunn *et al.,* 2018; Fisher-Borne & Brown, 2018; Wintels *et al.,* 2018; Ali *et al.,* 2020; Hart *et al.,* 2020; Lam *et al.,* 2020; Pavlopoulou, 2020; Van Schelven et al., 2020; Brooks *et al.,* 2021; Cleverley *et al.,* 2021; Marx & Regan, 2021; Salami



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*et al.,* 2021; Shearn *et al.,* 2021; Toraif et al., 2021; Valdez, Valdez & Garcia, 2021; Chiaramonte, Ellefson-Frank & Miller, 2022; Doyle *et al.,* 2022; Halsall *et al.,* 2022; Moscou, 2022; Pickering *et al.,* 2022; Teela *et al.,* 2022; Thomson, Peasgood & Robertson, 2022). Most frequently, they were asked to provide their input, particularly in the formulation of themes. Genius and colleagues employed 'member checking' with the youth co-researchers to evaluate the emerging themes (Genius *et al.,* 2014). Several key quotes from the included studies highlighted the importance of involving youth in the data analysis process. Hart and colleagues found that when youth were provided with the opportunity to comment on the findings,

> "…the young people and facilitators agreed that the findings were in line with their own experiences and views…". (Hart *et al.,* 2020:441)".

Ford, Rasmus and Allen (2010) discovered that youth enriched the findings through providing their local interpretations and ensuring that the findings reflected the local experience. Kendal and colleagues determined that when youth were part of their own analysis it privileged their perspectives in the final report (Kendal *et al.,* 2017). Salami and colleagues shared similar experiences when involving youth in the data analysis process:

> "Including youths in the data collection, analysis and writing phases allowed for greater transparency ownership and legitimacy of findings within the community…" (Salami *et al.,* 2021).

Van Schelven and colleagues, however, raised an important point regarding the capability of youth to be part of the analysis process:

> "…analysing open-ended questions is difficult for young people who are not researchers and who have no experience with studying other people's opinion and experiences. They emphasised their own experiences over the data" (Van Schelven *et al.,* 2020:11).

4.4.4.4. Outcomes of youth engagement in health research and practice

In 41 of the included studies, the main findings that emerged from the included studies were (1) youth's experiences on being engaged in the process; (2) how youth were engaged in disseminating research findings; (3) the skills that youth gained through being engaged; and (4) the benefits of youth engagement in health research and practice.



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Theme 9: Youth's experience on being engaged in the process

Eighteen of the included studies reported on the experiences of the youth being part of the engagement process, and how these experiences are a significant indicator of success in youth engagement (Powers & Tiffany, 2006; Visser, 2007; Vaughan, 2010; Findholt, Michael & Davis, 2010; Atkiss *et al.,* 2011; Fern *et al.,* 2013; Genius *et al.,* 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Fletcher & Mullett, 2016; Livingood *et al.,* 2017; Brady *et al.,* 2018; Fisher-Borne & Brown, 2018; Hart *et al.,* 2020; Van Schelven *et al.,* 2020; Marx & Regan, 2021; Cooke, Duara & Madill, 2022; Doyle *et al.,* 2022; Thomson, Peasgood & Robertson, 2022). In the included studies, the youth's experiences were consistently positive. In Atkiss and colleagues' study, the youth reported eight ways in which they personally grew during the engagement process (Atkiss *et al.,* 2013). These findings were echoed in other research, including an increased commitment to academic work and learning (Findholt, Michael & Davis, 2010); the development of positive values such as increased care; gaining social competencies like making new friends and learning professionalism (Thomson, Peasgood & Robertson, 2022); having a more positive identity leading to an increased sense of purpose and ownership (Findholt, Michael & Davis, 2010; Doyle *et al.,* 2022); feeling supported by peers and research staff (Doyle *et al.,* 2022); feeling empowered to make a change in their communities and to play a role in future studies or events (Livingood *et al.,* 2017; Doyle *et al.,* 2022); gaining new experiences and setting higher standards for themselves; and learning effective time management.

Other experiences included feeling proud (Vaughan, 2010), having a voice and a sense of belonging, as articulated by one of the young people in Fletcher and Mullett (2016):

> "Since that weekend [the workshop] I feel like I am living where before I was only existing" (Fletcher & Mullett, 2016:e185).

The thoughts and experiences of two of the youth advisors involved in Brady and colleagues' study about substance use provide a good summary of what most youth experienced:

> "…we have sort of walked the walk, so we know that stuff that other young people using have to go through on a daily basis…I want to make things better…if I can help develop something that prevents that then I will" (Young person A – Brady *et al.,* 2018:31)



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> "…a project for young people should definitely consult young people and should be based around their views…I'm very much used to discussing my substance use history in a very negative light with no real benefit as the end, but this project has helped me realise that a negative experience has made me wiser" (Young person B – Brady *et al.,* 2018:31)

Theme 10: Youth part of the dissemination of findings

In nearly half of the included studies youth actively participated in the dissemination of findings by presenting them at various events and engaging with key community stakeholders (Powers & Tiffany, 2006; Findholt, Michael & Davis, 2010; Vaughan, 2010; Atkiss *et al.,* 2013; Hackett, Gillens-Eromosele & Miller, 2015; Pullmann *et al.,* 2013; Yonas, Burke & Miller, 2013; Genius *et al.,* 2014; Sangalang, Ngout & Lau, 2015; Livingood *et al.,* 2017; Dunn *et al.,* 2018; Lam *et al.,* 2020; Pavlopoulou, 2020; Van Schelven *et al.,* 2020; Shearn *et al.,* 2021; Swist *et al.,* 2021; Altares *et al.,* 2022; Cooke, Duara & Madill, 2022; Doyle *et al.,* 2022; Halsall *et al.,* 2022; Pickering *et al.,* 2022). One method of dissemination used were exhibitions where youth showcased their work to local leaders (Vaughan, 2010; Hackett, Gillens-Eromosele & Miller, 2015; Yonas, Burke & Miller, 2013; Pickering *et al.,* 2022). These exhibitions provided a space where youth and adult stakeholders could actively engage and discuss youth health. Other dissemination methods included television appearances by youth (Dunn *et al.,* 2018), presenting findings to research committees, universities, or national conferences (Powers & Tiffany, 2006; Findholt, Michael & Davis, 2010; Pullmann *et al.,* 2013; Genius *et al.,* 2014; Shearn *et al.,* 2021), at graduation ceremonies or coalition meetings (Lam; Livingood), and at community forums (Sangalang, Ngouy & Lau, 2015).

Youth used these platforms to network with key stakeholders, including parents, school staff, government officials, healthcare professionals, business leaders, newspaper reporters, community members, funders, peers, and policymakers (Powers & Tiffany, 2006; Findholt, Michael & Davis, 2010; Yonas, Burke & Miller, 2013). These networking opportunities were crucial for both youth and the community. In Atkiss and colleagues' study, youth realised that to have a more significant impact, they should extend their reach beyond the school and into the community (Atkiss *et al.,* 2013), and the community of Roosevelt (Hackett, Gillens-Eromosele & Miller, 2015) reacted positively to the youth's engagement in the research.



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Theme 11: Skills gained by youth through engagement

A number of studies (n = 15) found that a vital aspect of engaging youth in health research and practice is that they should acquire new skills through their engagement in the process (Powers & Tiffany, 2006; Visser, 2007; Findholt, Michael & Davis, 2010; Atkiss *et al.,* 2011; Fletcher & Mullett, 2016; Dunn *et al.,* 2018; Ali *et al.,* 2020; Salami *et al.,* 2021; Swist *et al.,* 2021; Altares *et al.,* 2022; Chiaramonte, Ellefson-Frank & Miller, 2022; Cooke, Duara & Madill, 2022; Doyle *et al.,* 2022; Moscou, 2022; Thomson, Peasgood & Robertson, 2022). In the included studies, youth gained several skills after participating in different stages of the process. These skills encompassed conflict resolution (Atkiss *et al.,* 2013), job-related skills such as resumé building and interview techniques (Atkiss *et al.,* 2013, Altares *et al.,* 2022), increased self-efficiency and self-confidence, especially in public speaking (Powers & Tiffany, 2006; Findholt, Michael & Davis, 2010; Atkiss *et al.,* 2013; Altares *et al.,* 2022), enhanced knowledge about health-related problems (Atkiss *et al.,* 2013; Doyle *et al.,* 2022), network building (Atkiss *et al.,* 2013), communication and facilitation skills (Fletcher & Mullett, 2016; Altares *et al.,* 2022; Doyle *et al.,* 2022; Moscou, 2022), and advocacy skills (Altares *et al.,* 2022). Specific research skills developed by youth included how to plan and design projects, develop research instruments, use different procedures and methodologies, working with data, and interpreting findings (Powers & Tiffany, 2006).

Another essential skill acquired by the youth was leadership (Powers & Tiffany, 2006; Atkiss *et al.,* 2013; Fletcher & Mullett, 2016; Salami *et al.,* 2021; Swist *et al.,* 2021; Cooke, Duara & Madill, 2022; Moscou, 2022). Youth assumed leadership roles throughout all study stages, and by working together with researchers, youth were able to guide and co-create health research (Salami *et al.,* 2021; Swist *et al.,* 2021). Finally, Powers and Tiffany (2006) made an important statement regarding leadership in youth:

> "…when young people have opportunities to hold leadership positions, to be responsible, and to hold significant roles in governance, program, planning, and implementation, multiple benefits are reaped by youth, organizations, and communities" (Powers & Tiffany, 2006:S84).



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Theme 12: Benefits of engaging youth in health research and practice

The benefits of engaging youth in health research and practice are extensive and span from improvements in the research process to advantages for the broader community, as stated in 22 included studies. The quality of research improved through having better access to the populations of interest (Powers & Tiffany, 2006; Valdez, Valdez & Garcia, 2021) and continued research collaborations with communities even after the initial project ended (Hackett, Gillens-Eromosele & Miller, 2015). Some youths were promoted to more permanent research positions, co-authoring papers, finalising and disseminating findings, and contributing to new projects (Powers & Tiffany, 2006; Fern *et al.,* 2013; Swist *et al.,* 2021; Doyle *et al.,* 2022). Through involving youth, the research process was improved through trusting relationships, mutual learning, and long-term collaborations (Hackett, Gillens-Eromosele & Miller, 2015; Swist *et al.,* 2021), resulting in better designed, therefore more suitable, research instruments (Powers & Tiffany, 2006; Valdez, Valdez & Garcia, 2021).

Engaging youth also led to better health outcomes for the broader community. The experiences of youth informed the practices of healthcare professionals (Fern *et al.,* 2013), brought community change through serving as a concrete method of promoting healthy eating (Genius *et al.,* 2014), and delivered culturally sensitive interventions (Livingood *et al.,* 2017; Teela *et al.,* 2022). Community stakeholders and policymakers were persuaded because youth were directly involved and gave powerful arguments for why action is needed (Powers & Tiffany, 2006; Hackett, Gillens-Eromosele & Miller, 2015).

In their study on LGTBQ+ youth, Marx and Regan provided a good summary on what the benefits of including youth in research are:

> "…by including the population of interest in every step of the research process, we were able to create a richer, more meaningful text that ultimately offers many ways forward for the health of trans and gender non-conforming youth" (Marx & Regan, 2021:137).

4.4.2. Strategies of youth engagement in health research and practice

Strategies for youth engagement identified in 48 of the included studies can be summarised as two themes: (13) advisory boards; and (14) youth engaged in different stages of research and practice.



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Theme 13: Advisory boards

More than half of the included studies (n = 30) indicated that a good strategy to engage youth, in a meaningful way, is to have an advisory board or expert panel, since members of such a board most often have lived experiences therefore making them expert advisors. The advisory boards in the included studies were typically comprised of only youth, only adults, or a mixture of both. The members that were commonly included to be part of the advisory boards were youth (Powers & Tiffany, 2006; Ford, Rasmus & Allen, 2012; Milnes *et al.,* 2012; Atkiss *et al.,* 2013; Pullmann *et al.,* 2013; Livingood *et al.,* 2017; Brady *et al.,* 2018; Wintels *et al.,* 2018; Patchen *et al.,* 2020; Pavlopoulou, 2020; Van Schelven *et al.,* 2020; Brooks *et al.,* 2021; Cleverley *et al.,* 2021; Salami *et al.,* 2021; Toraif *et al.,* 2021; Whale *et al.,* 2021; Doyle *et al.,* 2022; Fisher *et al.,* 2022; Pickering *et al.,* 2022; Povey *et al.,* 2022; Teela *et al.,* 2022; Thomson, Peasgood & Robertson, 2022); family members, in particular parents or caregivers and siblings (Ford, Rasmus & Allen, 2012; Hardt *et al.,* 2020; Brooks *et al.,* 2021; Cleverley *et al.,* 2021); community leaders or elders (Garwick *et al.,* 2007; Ford, Rasmus & Allen, 2012; Hardt *et al.,* 2020); and adults in the fields of healthcare (e.g., clinicians and nurses) (Milnes *et al.,* 2012; Pullmann *et al.,* 2013; Hardt *et al.,* 2020; Brooks *et al.,* 2021; Whale *et al.,* 2021; Teela *et al.,* 2022); government (Brooks *et al.,* 2021); education (e.g., teachers) (Visser, 2007; McCalman *et al.,* 2017; Brooks *et al.,* 2021); and research (Garwick *et al.,* 2007; Pullmann *et al.,* 2013; Partridge *et al.,* 2019; Hardt *et al.,* 2020; Patchen *et al.,* 2020; Swist *et al.,* 2021; Moscou, 2022; Teela *et al.,* 2022).

The role of these advisory boards depended on the needs of the study. Typically, it was to provide expert advice on some, if not all stages of the research, including formulation of the research objectives, procedures, and tools, identifying key themes, examining findings, and capturing it for dissemination (McCalman *et al.,* 2017; Wintels *et al.,* 2018; Partridge *et al.,* 2019; Pavlopoulou, 2020; Doyle *et al.,* 2022). In Atkiss and colleagues, the role of the youth advisory board was to combine two pre-existing projects into one project and then used this project to advocate for better healthcare practices at their school (Atkiss *et al.*, 2013). The youth advisory board in Patchen and colleagues provided input on the design of a new health game (Patchen *et al.,* 2020).



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Theme 14: Youth engaged in key stages of the research process and practice development

Almost all the included studies (N = 44) engaged youth across different stages of research and practice (Powers & Tiffany, 2006; Findholt, Michael & Davis, 2010; Ford, Rasmus & Allen, 2012; Milnes *et al.,* 2012; Atkiss *et al.,* 2013; Fern *et al.,* 2013; Hackett, Gillens-Eromosele & Miller, 2015; Pullmann *et al.,* 2013; Genius *et al.,* 2014; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Kendal *et al.,* 2017; Livingood *et al.,* 2017; McCalman *et al.,* 2017; Brady *et al.,* 2018; Dunn *et al.,* 2018; Wintels *et al.,* 2018; Partridge *et al.,* 2019; Ali *et al.,* 2020; Hardt *et al.,* 2020; Hart *et al.,* 2020; Lam *et al.,* 2020; Patchen *et al.,* 2020; Pavlopoulou, 2020; Brooks *et al.,* 2021; Cleverley *et al.,* 2021; Marx & Regan, 2021; Salami *et al.,* 2021; Shearn *et al.,* 2021; Swist *et al.,* 2021; Toraif *et al.,* 2021; Whale *et al.,* 2021; Chiaramonte, Ellefson-Frank & Miller, 2022; Cooke, Duara & Madill, 2022; Doyle *et al.,* 2022; Fisher *et al.,* 2022; Halsall *et al.,* 2022; Moscou, 2022; Pickering *et al.,* 2022; Povey *et al.,* 2022; Teela *et al.,* 2022; Thomson, Peasgood & Robertson, 2022). Youth provided advice, made decisions, developed research materials (e.g., focus group and interview guides), and shared ideas and experiences to influence the outcome of the research projects and practice endeavours. Youth played crucial parts in the conception of the research, the research design, recruitment, duration of the project, development of the research tools, implementation of the study, data collection and analysis, and in the dissemination of findings, translating them into community actions and co-authoring publications.

From the included studies, three quotes stood out with regards to the importance of engaging youth in these key stages:

> "…achieve more equitable partnerships and greater degree of youth participation, YP [young people] need to be more formally included at the earliest stage. YP should be involved in determining critical early decisions on study focus and design" (Doyle *et al.,* 2022:8)

> "…dissemination of findings, shaped by the contextual perspectives of youth, was transformed to action through collaboration efforts with youth" (Ford, Rasmus & Allen, 2012:6)

> "Incorporating the views of the target users…throughout the development, design, and testing processes increases the likelihood that the educational package will be



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acceptable, engaging, persuasive, and easy to use. In turn, this is intended to promote engagement, implementation and, ultimately, effectiveness" (Fisher *et al.,* 2022:3)

A predominant strategy used to engage youth in key stages of research and practice was dialogue, in the form of workshops and meetings (either facilitated by adult researchers or youth co-researchers) (Powers & Tiffany, 2006; Visser, 2007; Findholt, Michael & Davis, 2010; Vaughan, 2010; Milnes *et al.,* 2012; Atkiss *et al.,* 2013; Fern *et al.,* 2013; Pullmann *et al.,* 2013; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Livingood *et al.,* 2017; Brady *et al.,* 2018; Dunn *et al.,* 2018; Fisher-Borne & Brown, 2018; Hart *et al.,* 2020; Lam *et al.,* 2020; Patchen *et al.,* 2020; Pavlopoulou, 2020; Brooks *et al.,* 2021; Marx & Regan, 2021; Shearn *et al.,* 2021; Swist *et al.,* 2021; Whale *et al.,* 2021; Altares *et al.,* 2022; Doyle *et al.,* 2022; Fisher *et al.,* 2022; Halsall *et al.,* 2022; Moscou, 2022; Povey *et al.,* 2022; Teela *et al.,* 2022; Thomson, Peasgood & Robertson, 2022).

4.4.3. Conceptual frameworks of youth engagement in health research and practice

Twelve of the included studies touched on conceptual or theoretical frameworks, and levels of engagement (Powers & Tiffany, 2006; Ford, Rasmus & Allen, 2012; Fern *et al.,* 2013; Livingood *et al.,* 2017; Brady *et al.,* 2018; Dunn *et al.,* 2018; Hart *et al,* 2020; Shearn *et al.,* 2021; Swist *et al.,* 2021; Doyle *et al.,* 2022; Moscou, 2022; Thomson, Peasgood & Robertson, 2022). Four, already established, conceptual frameworks were identified in the included studies – Hart's ladder of participation, Wong, Zimmerman and Parker's TYPE pyramid, the flower of participation, and Lansdown's conceptual framework for measuring outcomes of adolescent participation (Ford, Rasmus & Allen, 2012; Doyle *et al.,* 2022).

Hart's ladder of participation (Annexure 3) consists of eight elements, three non-participation elements (manipulation, decoration, tokenism) and five degrees of participation elements (assigned but informed, consulted and informed, adult-initiated and shared decisions with children, child-initiated and directed, child-initiated and shared decisions with adults) (Ford, Rasmus & Allen, 2012; Fern *et al.,* 2013; Doyle *et al.,* 2022). The TYPE pyramid of Wong, Zimmerman and Parker (Annexure 3) includes five elements that are divided between three control elements – adult control (vessel, symbolic), shared control (pluralistic), and youth control (independent, autonomous) (Ford, Rasmus & Allen, 2012). The flower of participation (Annexure 3) is a metaphorical framework which describes how youth can be engaged and how this engagement can grow and flourish in different, but meaningful, ways (Youth Do It,



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n.d.; Doyle *et al.,* 2022). The roots of the flower consist of six elements namely freedom of choice, information, responsibility, decision-making power, voice, and commitment from youth. The leaves represent youth which are either consultants or appointed a more permanent role. The petals of the flower represent the level of partnerships between youth and adults, ranging from adult-led to youth-led to youth-adult partnerships (Youth Do It, n.d.; Doyle *et al.,* 2022). Lansdown's conceptual framework for measuring outcomes of adolescent participation (Annexure 3) identifies five key elements of meaningful youth participation: space, voice, audience, influence, and empowerment (Lansdown, 2018). In this conceptual framework, youth can be engaged in three modes of participation – adolescent-led, collaborative, and consultive – however, these modes should always comply with opportunities for audience, voice, space, and influence (Lansdown, 2018).

Two of the included studies had youth part of the process to develop a new conceptual framework – the capabilities framework (Shearn *et al.,* 2021) and the WH&Y engagement framework (Swist *et al.,* 2021). The capabilities framework (Annexure 3) consisted of five ideas – people and relationships; places, spaces and time for me; learning and skills; freedoms rights and responsibilities; and health and wellbeing. Each one of these five ideas were then accompanied by two to six themes, for example, people and relationships (idea) were accompanied by the theme of to be able to "develop trusted adults to young persons relationships" (Shearn *et al.,* 2021:458). The WH&Y engagement framework (Annexure 3) is based on a set of practical questions and values that prompt thought, exploration, and action about ethical practices on how to engage youth (Swist *et al.,* 2021). The three elements of the framework include equity and responsiveness, mutual trust and accountability, and diversity and inclusion (Swist *et al.,* 2021).



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# CHAPTER 5: DISCUSSION

## 5.1. Summary of the findings

The aim of this review was to ~~is review aimed to~~ identify and synthesise literature on how youth are engaged in health research, policy, and practice globally. Fourteen themes emerged from the literature, as summarised in Table 3. The key lessons learned across all the themes is that: (1) youth are experts on youth; (2) active engagement of youth and the role of key stakeholders; (3) the experiences and skills gained by youth through being engaged; and (4) the benefits of youth engagement for the youth, the research, and the broader community. To provide a more comprehensive picture of youth engagement, the obstacles of engaging youth are also discussed. The exploration of enhancing a conceptual framework to indicate best practices on how to engage youth is also included.

### 5.1.1. Youth being the experts on youth

Since youth themselves are young, it makes them experts on the challenges that youth face. It is therefore important to ask youth about their perceptions regarding these challenges, for example unequal access to health care facilities and education, and to have their voice heard in the health research process and the development of health practices (Genius *et al.,* 2014; Hackett, Gillens-Eromosele & Dixon, 2015; Kendal *et al.,* 2017; Brady *et al.,* 2018; Wintels *et al.,* 2018; Lam *et al.,* 2020; Marx & Regan, 2021; Salami *et al.,* 2021; Shearn *et al.,* 2021; Cooke, Duara & Madill, 2022; Halsall *et al.,* 2022; Moscou, 2022; Pickering *et al.,* 2022). However, historically, people with lived experiences were excluded from the research process outside of just being participants (Bettis *et al.,* 2023).

Findings from Shearn and colleagues, who conducted a study to inform service design, reported that youth should represent their own experiences and not what adults impose on them (Shear *et al.,* 2021). Marx and Regan, who filmed a documentary together with trans and gender non-conforming youth, state that when youth are given the opportunity to control the conversation regarding their health, they gain the confidence to shape their own narratives (Marx & Regan, 2021). Similar findings were reported by Fox, Kahn and Battle (2022), who wrote a piece on youth mental health, and how the lived experiences of the youth, and their families, should be included in every step of the research process to increase the relevancy and the value of the



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research. The reports compiled by the National Academies of Sciences, Engineering, and Medicine (NASEM) usually only involve researchers and policymakers – stakeholders which are considered as 'experts in the field'. However, in 2020, NASEMs Board on Children, Youth, and Families took a different approach and included youth voices in the report. They recognised that because the report examined adolescent risk behaviours and made recommendations for research, policies, and practices, it was necessary to have youths input to ensure that the final recommendations are practical and tangible (Fox, Kahn & Battle, 2022). Similarly, Pickering and colleagues stated in their study on engaging youth through photovoice, during the pandemic, that adult stakeholders need to challenge their understanding of who qualifies as an 'expert' and start to include those who have lived experiences (Pickering *et al.,* 2022).

Acknowledging the expertise of young people in understanding and navigating the challenges they face is thus paramount. By actively involving youth voices in research, policymaking, and health practices design, we not only enhance the relevance and value of the outcomes but also empower young individuals to shape their own narratives, fostering confidence and meaningful contributions to discussions surrounding their health and wellbeing. The shift towards inclusivity, as seen in recent studies, emphasises the importance of challenging traditional notions of expertise and embracing the unique perspectives offered by those with lived experiences.

5.1.2. Active engagement of youth and the role of key stakeholders

Youth are a powerful and influential part of society, and are now, more than ever, more active in discussions and actions that pertain to their lives, such as better healthcare, climate change, and human rights (UNDESA, 2023b). Again, it was seen that as youth are experts in their own lives, involving them in the research process can enhance the research outcome. They can identify the challenges they experience and can then collaborate with adults to address these challenges (Altares *et al.,* 2022). It is, however, crucial to treat youth and adult stakeholders as equals therefore ensuring that the research is not only conducted "on", "for" or "about" youth, but rather "by" or "with" youth (Dunn *et al.,* 2018; Lam *et al.,* 2020; Thomson, Peasgood & Robertson, 2022).

Falkenburger, Gray and Daly, who developed a guidebook on community voice and power sharing, stated that youth are mainly engaged as participants in activities and processes including research evaluations, surveys, health- and community needs assessments, and



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participation (Falkenburger, Gray & Daly, 2021). However, this review clearly showed that youth are involved in activities and processes as youth co-researchers and/or participants. Youth that are involved as co-researchers are often trained in various research aspects, such as research question formulation, research design, data collection and analysis, interpretation, and dissemination of findings. Youth also developed FGD and interview guides and then used these guides to conduct or facilitate the FGDs and/or interviews. (Powers & Tiffany, 2006; Garwick *et al.,* 2007; Visser, 2007; Ford, Rasmus & Allen, 2012; Fern *et al.,* 2013; Pullmann *et al.,* 2013; Genius *et al.,* 2014; Sangalang, Ngouy & Lau, 2015; Fletcher & Mullett, 2016; Kendal *et al.,* 2017; Livingood *et al.,* 2017; Dunn *et al.,* 2018; Partridge *et al.,* 2019; Ali *et al.,* 2020; Lam *et al.,* 2020; Brooks *et al.,* 2021; Marx & Regan, 2021; Salami *et al.,* 2021; Shearn *et al*., 2021; Swist *et al.,* Toraif *et al.,* 2021; Altares *et al.,* 2022; Chiaramonte, Ellefson-Frank & Miller, 2022; Doyle *et al.,* 2022; Moscou, 2022; Pickering *et al.,* 2022).

A key strategy that emerged from this review was to engage youth in various key research and practice development stages. Ozer and colleagues, who conducted a review on youth participatory approaches and equity, as well as Falkenburger, Gray and Daly, who wrote a guidebook on power sharing and youth voice, supported the strategies identified in this review on engaging youth in key research and practice development stages (Ozer *et al.,* 2020; Falkenburger, Gray & Daly, 2021).

The levels of youth engagement mentioned by Faithfull and colleagues, Asuquo and colleagues, and Giordano and colleagues – substantial, moderate, minimal, and no engagement – also supports these youth engagement strategies (Faithfull *et al.,* 2019; Asuquo *et al.,* 2021; Giordano *et al.,* 2023). In the four case studies discussed in Doyle and colleagues, on how youth are engaged as partners in health research, the levels of youth engagement aligned with those identified by Faithfull, Asuquo, and Giordano. This encompassed scenarios where youth served as consultants and informants, participated in shared decision-making within adult-led processes, and took a leading role in decision-making within processes guided by adults (Doyle *et al.,* 2022).

It is evident from the included studies that active engagement of youth in research and practice development is crucial as youth are more likely to share in-depth information with their peers than with adults (Fern *et al.,* 2013; Ali *et al.,* 2020). However, in order to recruit youth to be part of these research activities as active co-researchers or participants, it is important to build trustworthy relationships with not only them, but also key stakeholders in their communities.



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When key stakeholders, such as youth organisations, community leaders, religious organisations, and school administrators, are used to recruit youth as co-researchers or participants, the recruitment is more successful as youth trust these stakeholders more often. Metz and colleagues, who proposed a theoretical model on how trusting relationships can support implementation, validate this finding stating that having a trusting relationship with a stakeholder increases motivation and opportunity for a more sustainable project and therefore a more positive outcome (Metz *et al.,* 2022).

Actively engaging youth in the research processes, treating them as equals, and engaging them as co-researchers empower them to collaboratively identify and address the challenges they face. The numerous strategies highlighted in this review, underscore the importance of incorporating youth perspectives in various stages of research and practice development. Building trustworthy relationships with both youth and key community stakeholders emerges as an important factor in successfully engaging youth as active co-researchers or participants, emphasising the significance of fostering connections for sustainable and impactful outcomes.

5.1.3. Experiences and skills gained by youth through being engaged

Considering the experiences of youth engagement is essential when engaging them in the research process, as it serves as a potential indicator of the research project's success. From this review, it is evident that youth consistently had positive experiences of being engaged in the research process. They gained important social competencies such as caring for their community, making new friends, learning how to be professional and what to expect in the workplace, having a better sense of purpose and therefore taking more ownership of the challenges they experience (Findholt, Michael & Davis, 2010; Atkiss *et al.,* 2013; Doyle *et al*., 2022; Thomson, Peasgood & Robertson, 2022). Contrasting the positive experiences found in the included studies, Wattar and colleagues, who conducted a study on youth's experiences, perceptions, and promotion of wellbeing in Paamiut Greenland, reported that a percentage of the youth felt embarrassed to share their opinions and they had a bad experience whilst being engaged in FGDs. Youth also reported that they did not feel like their perceptions were heard during the study (Wattar, Fanous & Berlinger,2012).

Apart from youth's experiences as a measure of success, it is also vital to see if they have gained any new skills after being engaged in the research process. One essential skill to acquire is that of leadership (Powers & Tiffany, 2006; Atkiss *et al.,* 2013; Fletcher & Mullett, 2016;



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Salami *et al.,* 2021; Swist *et al.,* 2021; Cooke, Duara & Madill, 2022; Moscou, 2022). Ammann, who did a thesis on youth leadership and the importance thereof in youth organisations, reported similar findings stating that by allowing youth to obtain leadership skills, they will make better decisions, have a better understanding of their values and environment, and will be able to better communicate with others (Ammann, 2010). These skills will not just enable them to be successful leaders, but also enable them to lead a more successful life. Other skills acquired from their involvement in research included conflict resolution, communication, increased knowledge, and advocacy (Atkiss *et al.,* 2013; Fletcher & Mullett, 2016; Altares *et al.,* 2022; Doyle *et al.,* 2022). These skills empower youth to play a vital role in their own as well as their community's development. The findings from this review are supported by several studies reporting on youth gaining more knowledge on specific health problems, developing a sense of belonging, and important characteristics such as accountability, communication, integrity, and responsibility (King *et al.*, 2015; Goodman *et al.*, 2018; Simmons *et al.*, 2019; Efuribe *et al.*, 2020; Wilson *et al.*, 2020).

Recognising and evaluating youth experiences in the research process is crucial, not only as a measure of project success but also for understanding the broader impact on young individuals. This review reveals a consistent positive trend in youth engagement, with reported benefits ranging from the development of social competencies and a sense of purpose to the acquisition of essential skills like leadership, conflict resolution, and communication. While positive experiences align with increased knowledge and empowerment, it is equally important to acknowledge instances where youth may face challenges, such as feeling unheard or embarrassed during engagement. This comprehensive understanding underscores the significance of fostering a supportive and skill-building environment for youth in research, ultimately contributing to their personal development and the betterment of their communities.

5.1.4. Benefits for the youth, the research, and the community

The benefits of including youth in health research and practice are extensive and span from improvements in the research process to advantages for the youth and the broader community. The skills that youth acquire through being involved in the research enable them to have more personal growth and therefore a better sense of the direction of their future. In some cases, youth are also appointed in paid positions as research assistants where they contribute to new projects, focusing on research areas important to them, and co-authoring publications (Powers & Tiffany, 2006; Fern *et al.,* 2013; Swist *et al.,* 2021; Doyle *et al.,* 2022). When youth are



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meaningfully engaged, they take more ownership leading to positive relationships with their peers and other community members. Peng wrote a blog post on why youth engagement is important and reported similar benefits, stating that youth who are involved in these research processes are also more likely to have a more decisive role later in life (Peng, 2020).

The quality of research also improves as researchers have better accessibility to the populations they are interested in, which can lead to sustained research collaborations (Powers & Tiffany, 2006; Hackett, Gillens-Eromosele & Miller, 2015; Valdez, Valdez & Garcia, 2021). Wilson and colleagues, as well as Warraitch and colleagues, both who conducted studies on involving youth in health research, reported that when research question(s) are aligned more closely with the priorities of the youth; the collected data will be more relevant and authentic leading to a wider dissemination of findings and more uptake of the recommendations (Wilson *et al.,* 2020; Warraitch *et al.,* 2023).

Youth engagement also leads to better health outcomes for the broader community as their experiences inform more culturally sensitive interventions which improves the practices of healthcare professionals as well as the community. Community stakeholders and policymakers are also persuaded more to act when youth are directly involved and can therefore give powerful arguments for why action is needed (Powers & Tiffany, 2006; Hackett, Gillens-Eromosele & Miller, 2015). Similar findings were reported by Flores, Goeke and Perez, who wrote a discussion paper on the power of youth in improving health in communities. The authors stated that youth engagement is crucial as youth live the everyday reality of their communities and have a better understanding of values and the culture with their community. Therefore, youth's insights contribute to more authentic, community-based solutions which assures more buy-in from the community (Flores, Goeke & Perez, 2014).

The inclusion of youth in health research and practice yields extensive benefits, fostering personal growth, positive relationships, and providing them with opportunities for paid positions. This engagement enhances research quality, aligns questions with youth priorities for more authentic data, and contributes to culturally sensitive interventions, ultimately influencing healthcare practices and persuading stakeholders and policymakers to take meaningful action for improved community health.



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### 5.2. Obstacles of youth engagement

Even though it is clear from this review that involving youth in health research and practice is an important factor, there are still several obstacles in engaging youth. These obstacles include youth "aging out" of the advisory board or as co-researchers (Livingood *et al.,* 2017), difficulty in building trust with youth, especially those with chronic conditions (Ali *et al.,* 2020; Van Schelven *et al.,* 2020), and in sustaining these relationships (Yonas, Burke & Miller, 2013; Van Schelven *et al.,* 2020; Povey *et al.,* 2022). Flexibility is an important concept when engaging youth, however, flexibility is also an expensive concept since it contributes to the high costs of engaging youth (Dunn *et al.,* 2018; Toraif *et al.,* 2021; Doyle *et al.,* 2022; Povey *et al.,* 2022; Thomson, Peasgood & Robertson, 2022).

Other important obstacles to note are the limited time youth have, usually due to other commitments such as school workload, sport, extracurricular activities, and family obligations; the logistical challenges of engaging youth including transport and suitable meeting places; and the lack of skills needed with academic forms of communication (Powers & Tiffany, 2006; Atkiss *et al.,* 2013; Pullmann *et al.,* 2013; Fletcher & Mullett, 2016; Kendal *et al.,* 2017; Ali *et al.,* 2020; Patchen *et al.,* 2020; Toraif *et al.,* 2021; Doyle *et al.,* 2022; Povey *et al.,* 2022).

Researchers themselves are also obstacles in successful youth engagement as they have different understandings, attitudes and perceptions of what youth engagement is; they fear losing control over the research process; and they might view youth through a deficit lens that can cause youth to doubt their own legitimacy (King *et al.*, 2015; Faithfull *et al.*, 2019; Hawke *et al.*, 2020; Sprague Martinez, Jones & Connolly, 2020; Asuquo *et al.*, 2021; Fletcher, 2022; McCabe *et al.*, 2023). Prati and Albanesi, who wrote a paper on why youth engagement is a right, requirement, and a value, stated that youth sometimes need to be included to answer research questions where they are the perceived problem, i.e., they are juvenile criminals, abuse different substances, dropped out of school, and are unemployed, therefore, it is seen as a reason to not engage them in the research or policy process (Prati & Albanesi, 2023). Similar obstacles were reported by McCabe and colleagues, who completed a systematic review on youth engagement in mental health research and stated that there is an increase in resources and time that is needed for the research (McCabe *et al.,* 2022). They also highlighted the potential negative impacts of youth engagement on the methodological rigour of the research, as youth often have an impact on the data collection and analysis (McCabe *et al.*, 2022).



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While youth engagement in health research and practice is crucial, obstacles like aging out, difficulties in building trust, financial constraints, time limitations, and researcher biases persist. Overcoming these obstacles demands a holistic approach addressing both practical aspects and underlying attitudes toward youth engagement in health research and practice development processes.

### 5.3. Conceptual framework for youth engagement in health research, policy, and practice

Although various conceptual and theoretical frameworks were mentioned in the included studies, two specific studies (Swist *et al.,* 2021; Doyle *et al.,* 2022) emphasised the role of three conceptual frameworks in youth engagement: the flower of participation; Lansdown's conceptual framework for measuring outcomes of adolescent participation; and the WH&Y engagement framework. The flower of participation aims to address the issue that programmes developed for youth are not developed by youth, while Lansdown's conceptual framework focuses on the environment and conditions that are needed to ensure effective participation (Youth Do It, n.d.; Lansdown, 2018). The WH&Y engagement framework aims to provide a set of values and questions on how to effectively engage youth (Swist *et al.,* 2021). These three frameworks consist of several similar key elements including the level of youth engagement and the youth's ability to contribute to certain decisions.

Several key concepts emerged from this review on youth engagement in health research and practice: active engagement, youth voices, and the role of key youth stakeholders. These key concepts, identified from this review, including from the three conceptual frameworks highlighted in Swist and colleagues and Doyle and colleagues, have informed the advancement of a youth engagement framework (see Figure 6). The starting point for the development of research projects and new policy documents is at the institutional level, such as governmental and academic institutions. It is therefore integral that youth are already included at the institutional level to ensure that the research, policy and practice is relevant and applicable to youth. Several key stakeholders are however needed to ensure that youth are effectively engaged in the research, policy, or practice development processes. Buy in from stakeholders such as health facilities, non-governmental organisations, colleges, schools, community groups, peers, and family members, will ensure active engagement of the youth in the research, policy, or practice development processes. Youth can be actively engaged on four different engagement levels. To ensure that youth are actively, yet ethically engaged, practical questions and values based on the three elements of equity and responsiveness, diversity and inclusion,



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and mutual trust and accountability, should be incorporated. When youth are actively engaged in the research, policy, and practice development processes, with the support of key stakeholders and institutions, their voices are more likely to be heard and therefore the research, policy, or practice outcomes are likely to be more successful.

This framework (figure 6) does not supersede any of the concepts or the conceptual frameworks identified in this review, but it does aim to combine various elements of youth engagement in the literature.

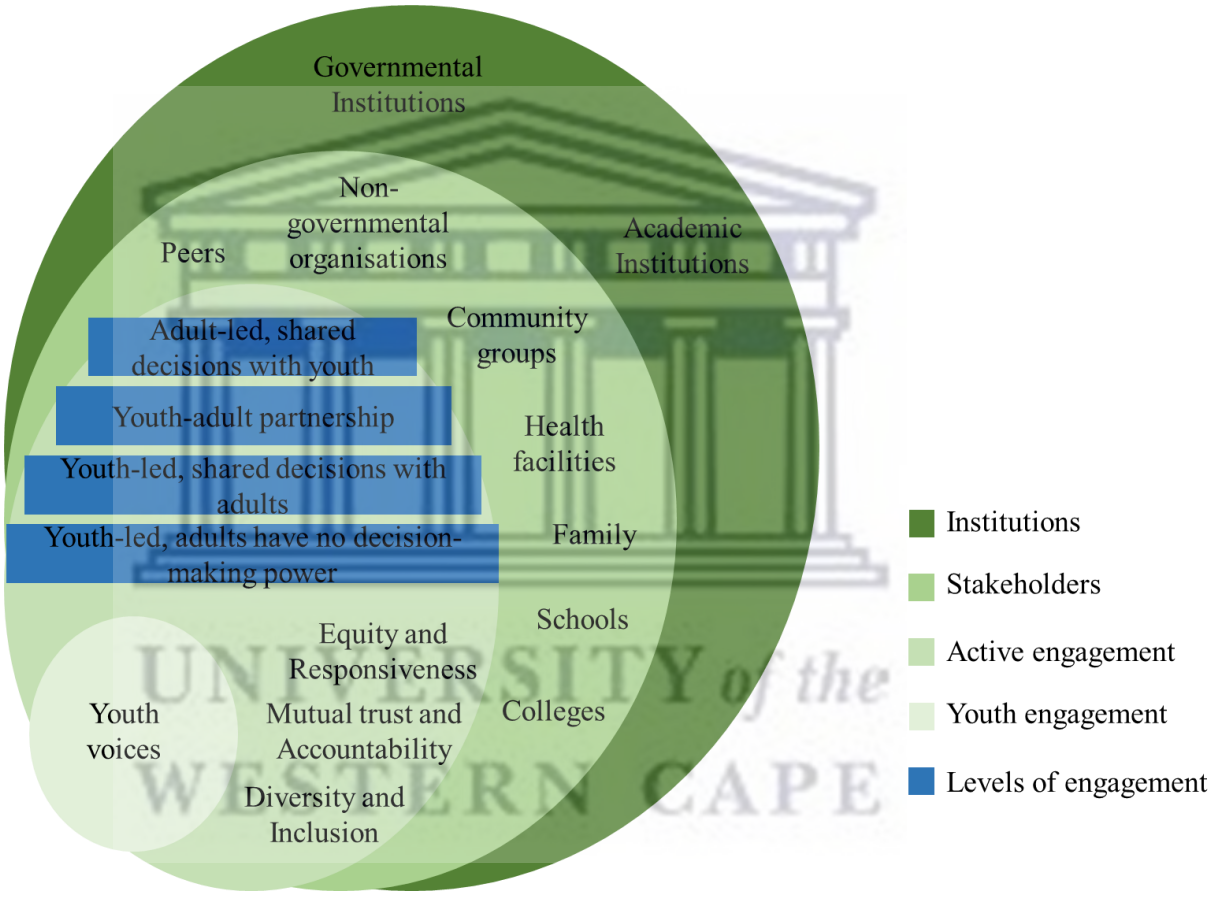


**Figure 6: Conceptual framework adapted from concepts and conceptual frameworks of youth engagement identified in this review, including the flower of participation, Lansdown's conceptual framework for measuring outcomes of adolescent participation, and the WH&Y engagement framework (Lansdown, 2018; Swist *et al.*, 2021; Doyle *et al.*, 2022)**



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## CHAPTER 6: CONCLUSION

This chapter provides a conclusion for this mini thesis, including limitations of this review and recommendations for successfully engaging youth in health research, policy, and practice.

### 6.1. Conclusion

Despite the growing body of research addressing youth-related challenges, a significant gap remains in actively engaging youth in the decision-making processes related to health research, policy, and practice. The reasons for, methods of, and conditions under which youth are engaged in health research, policy, and practice remain largely unexplored. Presently, there is also a disconnect between the intentions to engage youth in the research and practice development process and in policy decisions, and the actual implementation in practice (Prati & Albanesi, 2023).

From this review, it is evident that to do research "with", or have research done "by" youth, is more important than to do research "on", "about", or "for" them. When it comes to the challenges that youth face, they themselves are the experts on these challenges and the ideal is to have them be actively involved in the processes aimed at resolving these challenges. When youth are engaged in research activities and processes, for example, recruiting their peers or other relevant stakeholders to take part, the outcome will be more suited to their needs. This review showed that there are multiple benefits to including youth as partners in the process. Not only do the youth themselves gain new skills that will help them in future endeavours, but the research and practice development process is better as the quality improves due to research questions aligning more with the youth's priorities (Wilson *et al.*, 2020; Warraitch *et al.*, 2023), and the researchers having better access to the populations they are interested in (Powers & Tiffany, 2006; Hackett, Gillens-Eromosele & Dixon, 2015; Valdez, Valdez & Garcia, 2021). These improvements in the research and practice development process can then lead to a more suitable and sustainable outcome for the broader community as the interventions are more culturally sensitive (Powers & Tiffany, 2006; Hackett, Gillens-Eromosele & Dixon, 2015).

This review showed that there is a variety of conceptualisations regarding youth engagement, especially focussing on activities, processes, and strategies on how youth are, and can be engaged. When engaging youth to have their voices heard, it is crucial to consider several key elements. This include the institutions that are involved, whether youth engagement is on an



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academic level (research and practices) or a governmental level (in policies). Additionally, attention should also be given to the relevant stakeholders and the specific level of engagement designed for youth.

In conclusion, it is evident from this review that there are several conceptualisations regarding youth engagement focussing on activities, processes, outcomes, and strategies. Youth are the experts of their own lives and want to be engaged in matters affecting them. Addressing the gaps in youth engagement and actively engaging youth in health research, policy, and practice is essential for fostering meaningful and sustainable outcomes for both youth and the broader community.

### 6.2. Recommendations for youth engagement

For successful youth engagement in research, policy and practice, the following recommendations are provided for consideration:

#### 6.2.1. Implications for practice

##### 6.2.1.1. Early engagement in the process

Youth should be included in the research process as early as possible, i.e., they should already be part of the process when the formulation of the research question and concept of the study takes place to have their lived experiences form the direction of the study, policy, or health practice (Doyle *et al.*, 2022). It should also be clear from the start what the youth's expectations are, and what the expectations of the researchers are for the youth.

##### 6.2.1.2. Adult stakeholders

Adult stakeholders, such as researchers need to be trained on how to adapt the language and approaches that they use to make it more accessible and acceptable for young people (Powers & Tiffany, 2006; Doyle *et al.*, 2022). Youth often carry the burden of learning how to effectively communicate with the adult stakeholders, however, adults need to learn and understand how to effectively communicate with youth to engage them more successfully. Adult stakeholders should also develop structures through which youth can influence the design of the research throughout the duration of the research (Doyle *et al.*, 2022).



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6.2.1.3. Providing logistical support

To successfully engage youth takes proper planning, time, and financial investment. It is important to ensure that there are enough resources to provide maximum support to youth, e.g., a suitable and safe space for youth to meet, or transport for youth that live far away and who need to travel in the dark. The process should have a realistic timeframe but also be flexible to take the busy and changing schedules of youth into account (Powers & Tiffany, 2006; Ford, Rasmus & Allen, 2012; Swist *et al.*, 2021; Doyle *et al.*, 2022). Van Schelven and colleagues (2020) suggest that to reimburse youth for their involvement are a tangible and valuable way of showing appreciation.

6.2.1.4. Evaluation of the processes

After youth have been engaged in the processes, it is important to have them, as well as the other stakeholders involved, evaluate the processes, and provide input on how future studies or projects can be improved.

6.2.2. Implications for research

There are several gaps present in the research. None of the included studies addressed youth engagement in policy development. This is a significant gap that needs to be addressed since there are several policies that focus on youth, but more often these policies do not include the experiences and perspectives of the youth. Majority of the studies were also conducted in HICs, therefore there is a gap on how youth are engaged in LMICs.

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**6.3. Limitations of the review**

For this review only three electronic databases were searched, which could have resulted in some studies being missed. However, a key strength of this review is that it provided depth in understanding of youth engagement rather than merely breadth of studies. Only studies published in English were searched for, which could also result in some studies being missed. However, it was not feasible (in terms of time and resources) to search for non-English studies and to translate them to English to assess eligibility for this review. The review and collection of the data were conducted by one researcher which may impact the comprehensiveness and depth of the analysis. However, efforts were made to ensure rigour and accuracy within the study. **Specific rigorous methodologies included registering the research protocol on**



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**PROSPERO, developing the search strategy with a UWC librarian, searching three databases to maximise the number of eligible studies, and supervisors performing quality checks on the data extraction, analysis, and synthesis.**






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**ANNEXURES**

## ANNEXURE 1: DATA EXTRACTION FORM

**Table 4: Data extraction form**

| | | | | | |
|---|---|---|---|---|---|
| Study title: | | | | | |
| Study no | Authors | Publication date | | Country of origin | Primary purpose / Study aim / Objectives |
| | | | | | |
| Study design | | Participants | | Methods | |
| Qualitative | Mixed methods | Gender | Age group | Data collection | Data analysis |
| | | | | | |
| Strategies (including interventions and models) | | Descriptions of youth engagement | | Framework (conceptual or theoretical)? | Comments |
| Conceptualisations of youth engagement | Activities | | | | |
| | Processes | | | | |
| | Outcomes | | | | |



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## ANNEXURE 2: SAMPLE OF THE EXTRACTED DATA

| Number | Authors | Publication Date | Study Title | Country | Aim / Purpose / Objectives | Study Design (Qual / MM) | Participants | | Methods | | Strategies (incl. interventions & models) |
|---|---|---|---|---|---|---|---|---|---|---|---|
| | | | | | | | Gender | Age | Data Collection | Data Analysis | |
| 1 | Ali, S., de Viggiani, N., Abzhaparova, A., Salmon, D. & Gray, S | 2020 | Exploring young people's interpretations of female genital mutilation in the UK using a community-based participatory research approach | United Kingdom | Explores how second-generation young people living in the United Kingdom (UK) - whether directly or indirectly affected by FGM - interpret and understand FGM | Qual | 8 F; 1 M | 15-18 | Focus Groups; Semi-structured Interviews | Six-phase reflexive thematic analysis process | Make decisions re. key stages of the project - conveying information about the project in appropriate and accessible languages |
| 2 | Altares, A., Hobbs, S., Sobel, D., Nelson, T., Serpa, M. & Bellows, L. L. | 2022 | Cultivating community change to promote food access and healthy eating through participatory action research with youth | United States of America | Youth CAN project goal - develop a community-engaged research collaboration between a university research team and GES community partners and youth; Project aimed to guide youth in investigation, critical thinking, and problem solving related to health issues within their community and to connect these youth with community leaders and policymakers to impact meaningful change within the community | Qual | Not specified | Not specified | Photovoice; Spoken word; Street art | Thematic analysis | Youth explored their built environment and shared their experiences with community leaders and policy makers - photovoice, spoken word, street art; directly involved in identifying facilitators and barriers; community assessment (photovoice, street art, spoken word) and collaboration on solutions-based workshops (World Café); assist in proposal and implement changes |
| 3 | Atkiss, K., Moyer, M., Desai, M. & Roland, M. | 2013 | Positive youth development: An integration of the developmental assests theory and the socio-ecological model | United States of America | To explore the efficacy of integrating the Developmental Assest (DA) and Socio-Ecological Model (SEM) in a pilot youth development program, the Youth Health Action Board (YHAB); Examines youth participant impressions of the effect of their participation on themselves and their community within the context of these two models | Qual | Not specified | 6 seniors (G12) & 5 juniors (G11) | Structured interviews | Classic content analysis - code-based technique | Models - Developmental Assests (DA) and Socio-Ecological Model (SEM); YHAB developed from two existing health programs - youth saw duplication and an opportunity to make a more significant impact by integrating into one program |

**Figure 7: Sample of the extracted data**



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## ANNEXURE 3: CONCEPTUAL FRAMEWORKS

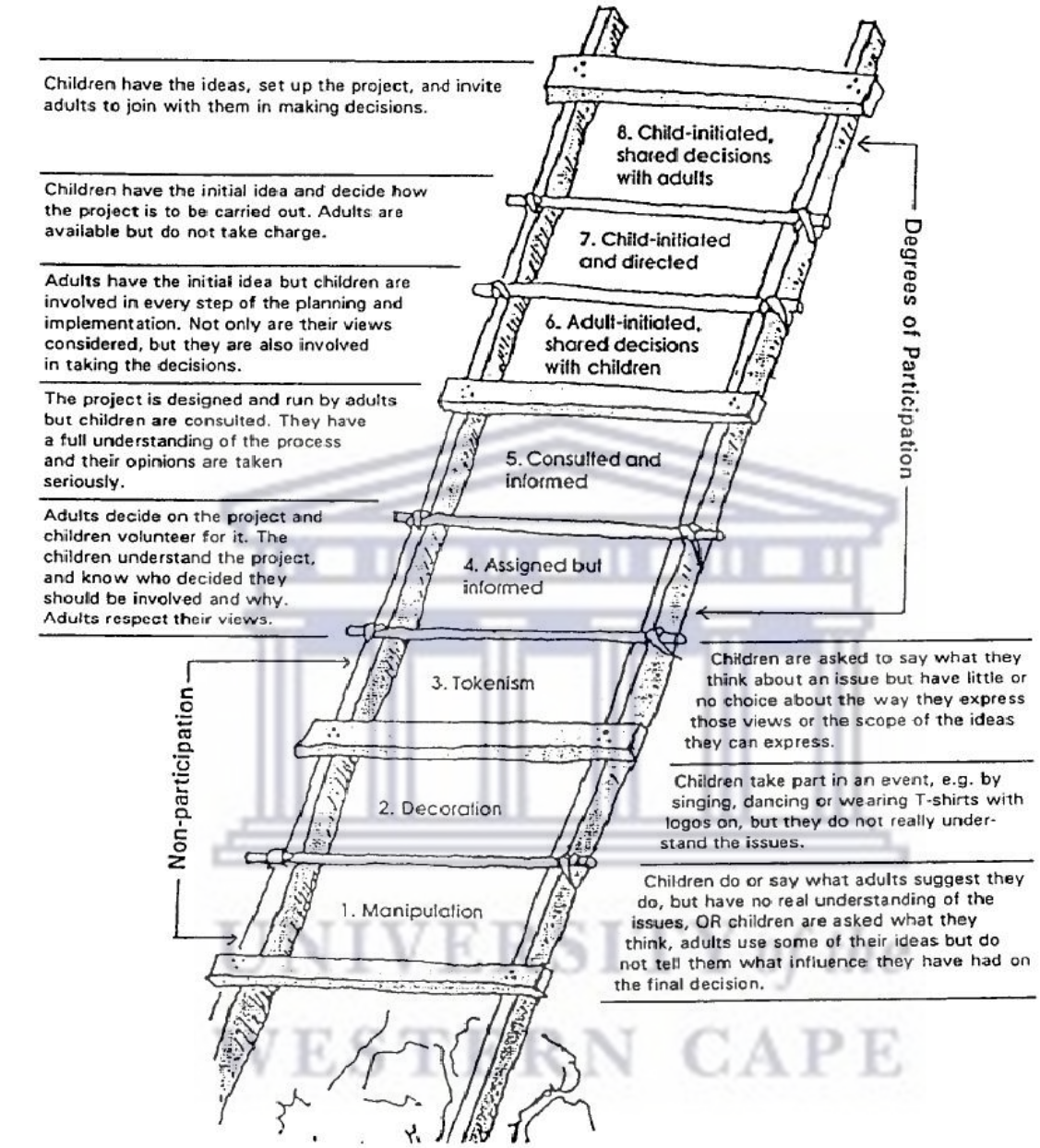


**Figure 8: Hart's ladder of participation (Shier, 2001)**



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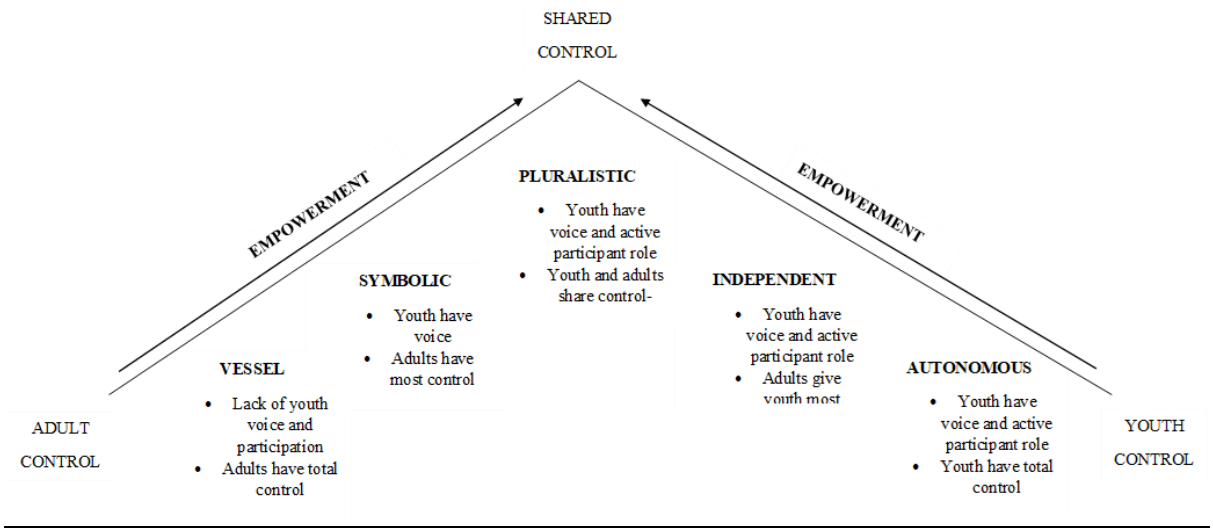


**Figure 9: TYPE pyramid (Wong, Zimmerman & Parker, 2010)**

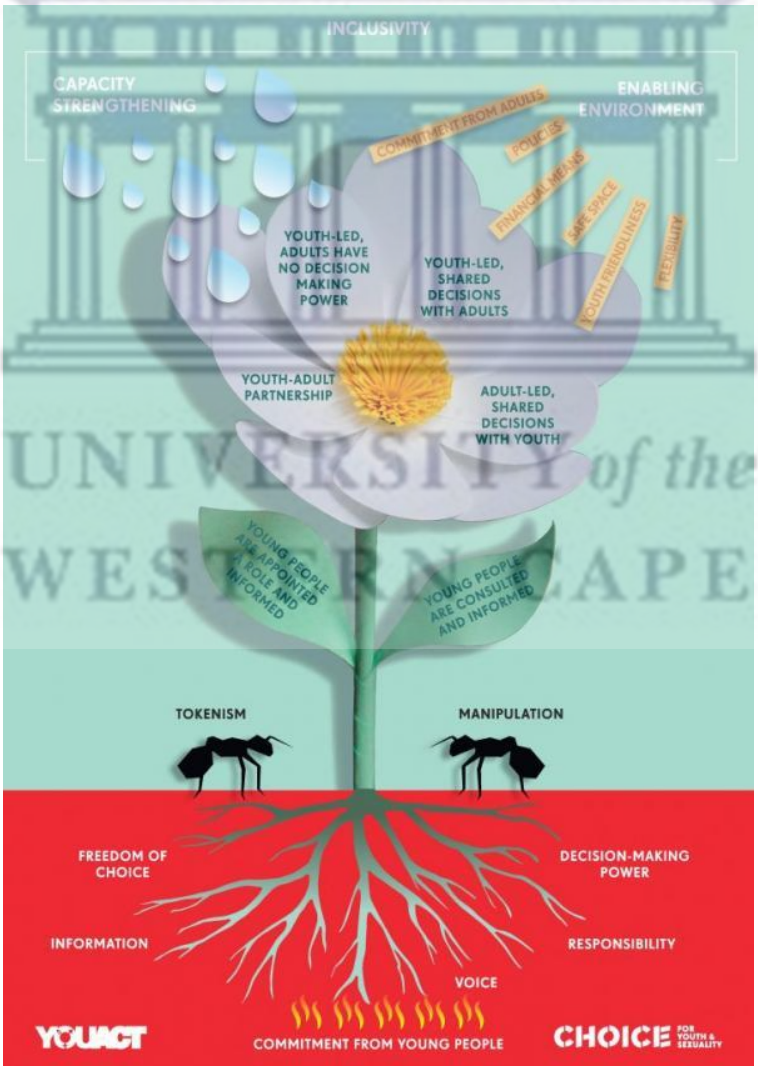


**Figure 10: Flower of participation (Youth do it, n.d.)**



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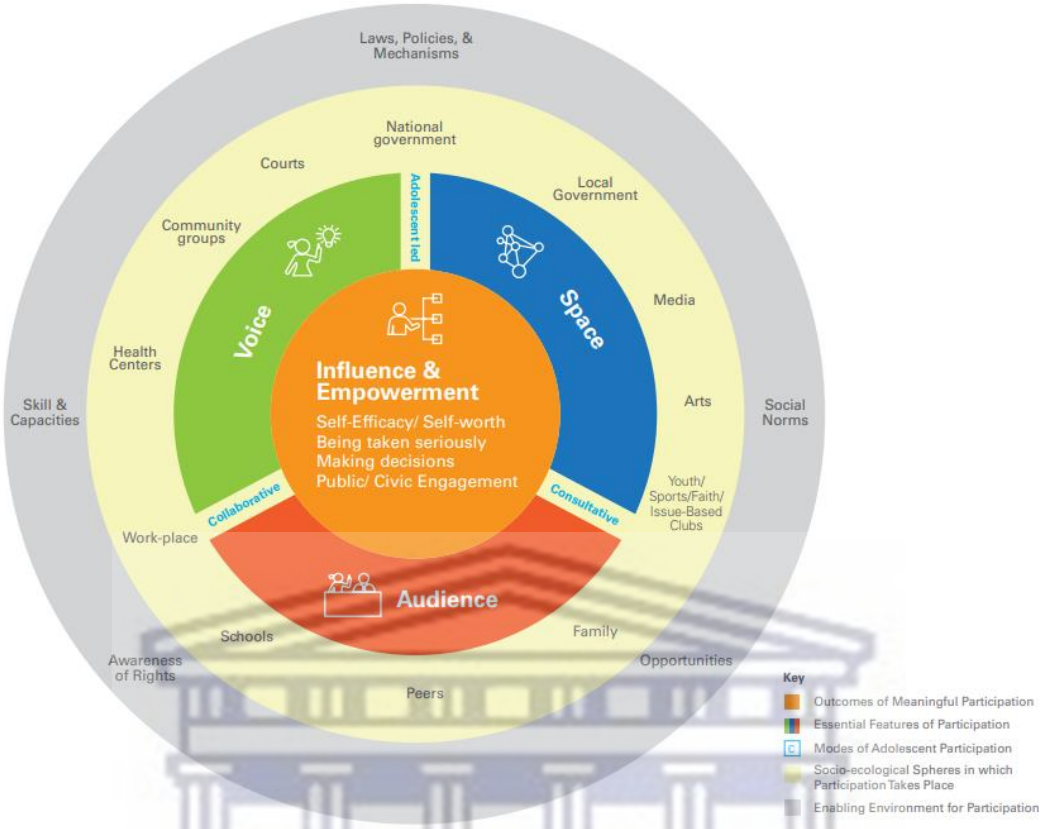


**Figure 11: Lansdown's conceptual framework for measuring outcomes of adolescent participation (Lansdown, 2018)**

| Idea | Themes – "to be able to... |
|---|---|
| People and relationships | • develop trusted adult to young person relationships.<br>• develop peer relationships.<br>• have someone listening, somewhere. |
| Places, spaces and time for me | • have our own private space for 'me time'.<br>• be fit and physically active.<br>• visit places that are fun inspire us.<br>• be able to pursue hobbies<br>• help others through volunteering opportunities<br>• get around easily and cheaply |
| Learning and skills | • develop social skills to negotiate with people online and in person<br>• develop life skills (time management, confidence, access to advice and direction)<br>• overcome challenges<br>• have access to content to help understand our experiences (content availability and means to access via technology) |
| Freedoms rights and responsibilities | • speak up and be listened to<br>• have our views taken seriously and treated in confidence<br>• be accepted and loved for you are.<br>• be 'authentically yourself'<br>• be safe from harms (people, safe spaces) |
| Health and wellbeing | • be physically and mentally well<br>• have access to information about how to stay well and where to get support. |

**Figure 12: Capabilities framework (Shearn *et al.*, 2021)**



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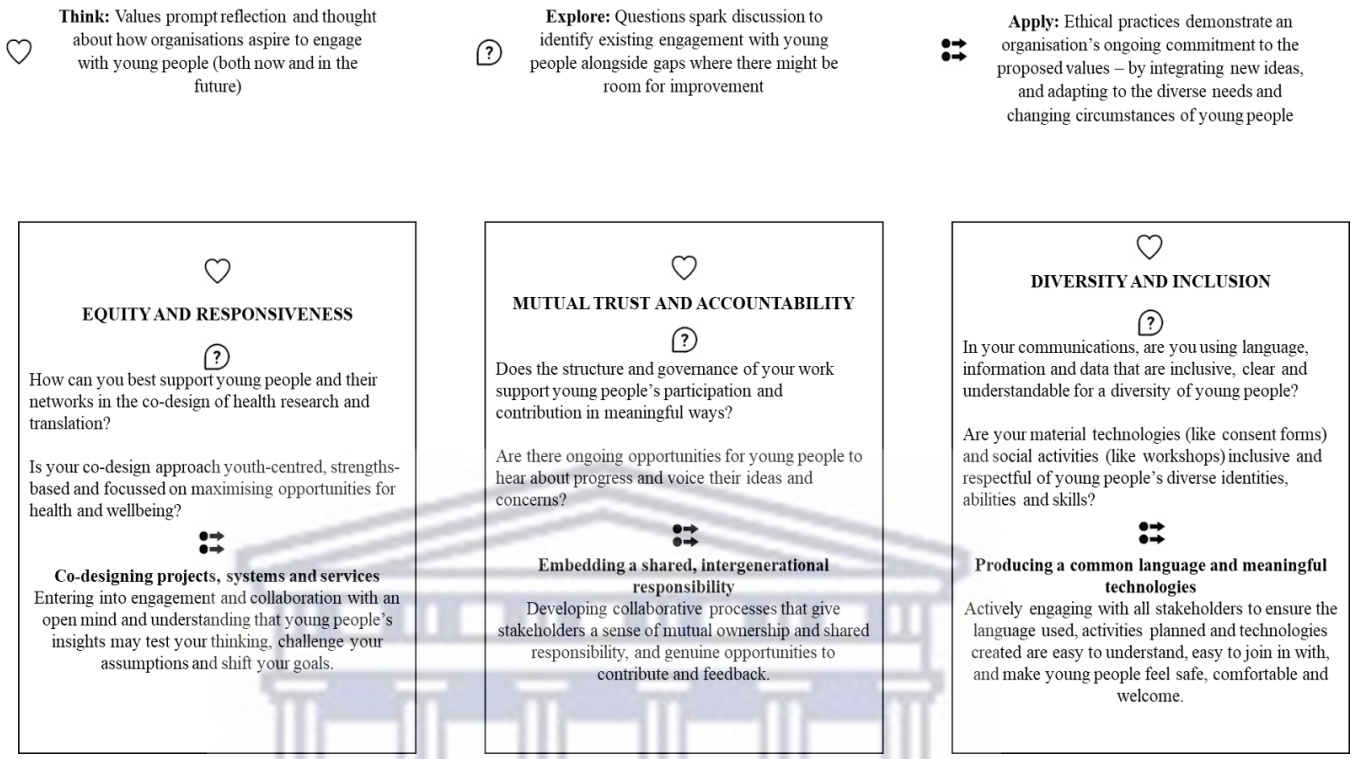


**Figure 13: Adapted WH&Y Engagement framework (Swist *et al.*, 2019)**

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