

Youth Engagement in Obesity and Chronic Disease
Prevention Research, Policy, and Guideline Development

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A thesis submitted to fulfil requirements for the degree of Doctor of Philosophy

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2024

STATEMENT OF ORIGINALITY

This is to certify that to the best of my knowledge; the content of this thesis is my own work.

This thesis has not been submitted for any degree or other purposes.

I certify that the intellectual content of this thesis is the product of my own work and that all the assistance received in preparing this thesis and sources have been acknowledged.

Mariam Mandoh

5th December 2023

ABSTRACT

Background: Adolescence (10-24years) is a foundational life stage in the development of behavioural and metabolic risk factors for chronic diseases such as cardiovascular disease and Type 2 Diabetes Mellitus. Current obesity and chronic disease prevention interventions, policies and guidelines focused on adolescents have not made sufficient progress to reduce chronic disease risk factors such as obesity, unhealthy diet, and physical inactivity. Youth engagement has the potential to support the design of relevant, acceptable, and tailored chronic disease prevention interventions, policies, and guidelines for adolescents. This thesis aims to examine how adolescents are currently being engaged, their experiences of engagement, and their preferences for engagement in obesity and chronic disease prevention decision making.

Methods: To address these aims multiple study designs were included in the chapters that form this thesis. Research methodologies employed include a systematic review, a scoping review, cross-sectional study (n=501), focus groups (n=19), and a pre-post mixed methods evaluation study (n=13). Outcomes of interest were based on the UNICEF- Lansdown conceptual framework for measuring outcomes of adolescent's participation. Primary outcomes included: mode and nature of youth engagement in obesity and chronic disease prevention decision-making. Secondary outcomes included: participatory markers of empowerment and influence comprising sense of self-efficacy, sense of being taken seriously, confidence in decision-making, and confidence in public and community engagement.

Results: Adolescent engagement in obesity and chronic disease prevention research, policy and guideline development is uncommon in empirical research, is predominantly consultative in nature and rarely extends throughout the research and development process. Demographic characteristics were not found to influence likelihood of engagement, however adolescents with experience volunteering were three times more likely to have been engaged in chronic

disease prevention activities. Largely, adolescents seek to be engaged, however face multiple barriers including accessibility, lack of opportunities, and time. Preferences for participation include hybrid or online and in-person activities, skill development opportunities, compensation for time and choice in the level and degree of engagement. Youth engagement improved adolescents' leadership and research skills and was associated with positive trends in participatory markers including influence, empowerment, and contribution. A youth advisory group exemplified a feasible method of engaging adolescents in chronic disease prevention research decision-making.

Conclusion: Overall, this thesis established that adolescent engagement in obesity and chronic disease prevention decision-making has the potential to empower adolescents by increasing skills and capabilities. Nonetheless, adolescents experience multiple barriers to youth engagement. Evidence outlined in the chapters of this thesis form the foundation for a youth engagement framework to guide researchers and policymakers on strategies to engage adolescents in a meaningful and ethical capacity in the obesity and chronic disease prevention field.

ACKNOWLEDGEMENTS

In this acknowledgement section, I extend my deepest gratitude to all who walked with me on this challenging but rewarding journey. This thesis would not have been possible without the support, encouragement, and guidance from my supervisory team, colleagues, and loved ones.

First, I thank my supervisory team, Doctor Stephanie Partridge, Professor Julie Redfern, and Associate Professor Seema Mahrshahi. Stephanie, thank you for taking me on as your student despite my lack of research experience. Your dedication to developing your students and allowing them to grow as independent researchers is remarkable. Your leadership and guidance have been invaluable, and I feel truly blessed to have had the opportunity to learn from you and work alongside you these past few years. Your positive attitude and empathy always made the most significant challenges seem small. Finally, your commitment to enhancing the health and well-being of young people is inspiring, and I look forward to seeing the direction and outcome of all the important work you do. Julie, you have been a remarkable mentor and leader. You are so generous in your commitment to building the capabilities of your team members. You have impressed me with the vision of what authentic leadership should look like. Seema, thank you for all your guidance and expertise during my PhD journey. I am so grateful for all your kindness, wisdom, and support, which were instrumental in helping me cross the finish line.

Caroline Wu and Julia Ning, thank you for all your administrative support. You are always cheerful and ready to assist, which helped make this journey smoother. Professor Philayrath Phongsavan and Dr. Helen Cheng, thank you for collaborating with me and the supervisory team on my research projects and imparting your knowledge, in-depth critique, and valuable

expertise. Thank you to all my colleagues in the ECHO hub. Being part of one of the most professional, kind, and dedicated teams has been a pleasure. A special mention to my colleagues Rebecca, Sisi, Allyson, Sara, Nashid, and Anna: thank you for being great friends and supporting me through this journey. Though I worked remotely during most of my PhD, I always looked forward to and enjoyed our chats and lunches. I would also like to acknowledge the HAPYUS youth advisory group members; you were a pleasure to work with and an inspirational group of young people. I am confident that you all have a bright future ahead and that at least one of you will become a future prime minister of Australia!

Next, I want to acknowledge my friends Hanine, Zahra, Hawraa and Samah. Your patience and staunch support during my most difficult times have been an infinite source of strength. I always looked forward to our therapeutic late-night café visits (aka. complaining sessions). I am grateful to my beautiful sisters Mona, Manal, and Laila for all your love and support. You are the best listeners, advisors, and critics. Our weekly movie nights with the kids were always a highlight of my week and something I have missed over the last few months. I am forever thankful to my incredible parents, Sobhi, and Fatima. Your love, encouragement, and support are unwavering. You instilled within my siblings and me a love of learning and self-development. You taught us resilience and perseverance, life skills that only now, as a parent myself, I appreciate how difficult they are to teach. I love you so much! To my biggest blessing, my children Fatimah, Zaynab, and Abbas. Thank you for the tight hugs and loving kisses. Thank you for the cheekiness and the laughter you fill our home with. Thank you for the fantastic shoulder rubs and homemade desserts (some of which are dangerously experimental). I love you so much and am glad you were part of my cheer squad as I crossed the finish line. Last but certainly not least, I would like to acknowledge and thank my wonderful husband, Hussein. You have always been my biggest cheerleader and supporter,

and on my PhD journey, you were my pillar of strength. Your motivational talks and breakfast dates kept me on track when I was overwhelmed and questioning myself. I love you and am so blessed to have had you by my side during this emotional roller coaster.

DEDICATION

This thesis is dedicated to my children Fatimah, Zaynab and Abbas whose laughter is my favourite sound and smile is my favourite view. You fill my heart with so much love and joy and inspire me to be the best version of myself every single day. *I love you!*

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LIST OF ABBREVIATED TERMS AND ACRONYMS

AA-HA!:	Accelerated Action for the Health of Adolescents
Add Health:	The National Longitudinal Study of Adolescent Health
AR:	Action Research
ASGS-RA:	Australian Statistical Geographical Standard Remoteness Areas
AT:	Allyson Todd
AUD:	Australian Dollar
BGL:	Blood Glucose Level
BMI:	Body Mass Index
CALD:	Culturally and Linguistically Diverse
CBPR:	Community-Based Participatory Research
CENTRAL:	Cochrane Central Register for Controlled Trials
CINAHL:	Cumulative Index of Nursing and Allied Health Literature
COVID-19:	Corona Virus Disease 2019
CVD:	Cardiovascular Disease
DALY:	Disability Adjusted Life Year
e-PAR:	technology-based Participatory Action Research
EDA:	Exploratory Data Analysis
EYTO:	European Youth Tackling Obesity
GBD:	Global Burden of Disease
GSE:	General Self-Efficacy scale
GSHS:	Global School-based Student Health Surveys
HAPYUS:	Health Advisory Panel for Youth at the University of Sydney
HDL-C:	High Density Lipoprotein Cholesterol
HIC:	High Income Country

HIV: Human Immunodeficiency Virus

IRSAD: Index of Relative Socio-economic Advantage and Disadvantage

IRSD: Index of Relative Socioeconomic Disadvantage

JB: Joanna Briggs Institute

JR: Julie Redfern

KNHANES: Korean National Health and Nutrition Examination Survey

LDL-C: Low Density Lipoprotein Cholesterol

LGBT: Lesbian, Gay, Bisexual, Transgender

LMICs: Low- and Middle-Income Countries

LSAC: Longitudinal Study of Australian Children

LTSES: Leadership, Teamwork Self-Efficacy Scale

MeSH: Medical Subject Headings

MM: Mariam Mandoh

NCD: Non-Communicable Disease

NeurOx YPAG: Oxford Neuroscience, Ethics and Society Young People's Advisory Group

NHANES: National Health and Nutrition Examination Survey

NHMRC: National Health and Medical Research Council

NICE: National Institute for Health Care Excellence

NIHR: National Institute for Health Research

P-BASIC: Promote, Build, Accessible, Supportive, Integrate, Compensate

PAR: Participatory Action Research

PCC: Population, Concept, Context

PE: Patient Engagement

PMNCH: Partnership for Maternal, Newborn and Child Health

PRISMA-ScR: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews

RCT: Randomised Control Trial

REDCap: Research Electronic Data Capture

SALSA: Students As LifeStyle Activists

SD: Standard Deviation

SDG: Sustainable Development Goal

SEIFA: Socioeconomic Indexes for Areas

SES: Socioeconomic Status

SRP: Stephanie Ruth Partridge

SSB: Sugar Sweetened Beverage

T2DM: Type 2 Diabetes Mellitus

UK: United Kingdom

UN H6+: A collaboration between UNFPA, UNICEF, UN Women, WHO, UNAIDS and World Bank Group

UN: United Nations

UNAIDS: The joint United Nations Programme on HIV/AIDS

UNCRC: United Nations Conventions on the Rights of a Child

UNESCO: The United Nations Educational, Scientific and Cultural Organization

UNFPA: United Nations Population Fund

UNICEF: United Nations International Children's Emergency Fund

US: United States

USA: United States of America

VIF: Variance Inflation Factor

WHO: World Health Organisation

YAG: Youth Advisory Group

YES: Youth Engagement Study

YLLSDS: Youth Leadership Life Skills Development Survey

YPAR: Youth-led Participatory Action Research

PUBLICATIONS AND PRESENTATIONS ARISING FROM THIS THESIS

This thesis contains material that has previously been published in peer-reviewed journals.

Peer reviewed publications

1. CHAPTER TWO of this thesis is published as:

Mariam Mandoh, Seema Mahrshahi, Hoi Lun Cheng, Julie Redfern, and Stephanie R. Partridge. Adolescent Participation in Research, Policies and Guidelines for Chronic Disease Prevention: A Scoping Review Protocol. *International Journal of environmental research and public health*. 2020; 17:21.

Authorship attribution statement: I developed the original concept of the protocol, was responsible for designing, refining, registering of the study protocol with the Joanna Briggs Institute (JBI) and Opens Science Framework (OSF), drafting manuscript and subsequent revisions, and leading submission for publication of the protocol paper. The convention of the *International Journal of Environmental Research and Public Health* is that the author with the principal contribution to the manuscript is the first author.

2. CHAPTER THREE of this thesis is published as:

Mariam Mandoh, Julie Redfern, Seema Mahrshahi, Hoi Lun Cheng, Philayrath Phongsavan, Stephanie Ruth Partridge. Shifting from tokenism to meaningful adolescent participation in research for obesity prevention: a systematic scoping review. *Frontiers in public health*. 2021; 9:789535.

Authorship attribution statement: I developed the original concept of the systematic scoping review, was responsible for performing the literature search, study inclusion and exclusion, data extraction, drafting the manuscript and leading submission for publication

of the original research paper. The convention of the journal *Frontiers in Public Health* is that the author with the principal contribution to the manuscript is the first author.

3. CHAPTER FOUR of this thesis is published as:

Mandoh M, Redfern J, Mhrshahi S Cheng HL, Phongsavan P, Partridge SR. How are adolescents engaged in obesity and chronic disease prevention policy and guideline development? A scoping review. *Global Health Research and Policy*. 2023; 8:9.

Authorship attribution statement: I developed the original concept of the scoping review, was responsible for performing the literature search, policy and guideline inclusion and exclusion, data extraction, drafting the manuscript and leading submission for publication of the original research paper. The convention of the journal *Global health research and policy* is that the author with the principal contribution to the manuscript is the first author.

4. CHAPTER SIX of this thesis is published as:

Mariam Mandoh, Rebecca Raeside, Allyson Todd, Julie Redfern, Seema Mhrshahi, Hoi Lun Cheng, Philayrath Phongsavan, Stephanie R Partridge. Evaluating the effect of a 12-month youth advisory group on adolescent's leadership skills and perceptions related to chronic disease prevention research: a mixed methods study. *BioMed Central Public Health*. 2023; 23:2344.

Authorship attribution statement: I developed the original concept of the evaluation study, interviewed participants, collected the data, analysed the data, interpreted the results, drafted the manuscript, and coordinated submission of the manuscript. The

convention of the journal *BioMed Central Public Health* is that the author with the principal contribution to the manuscript is the first author.

In addition to the statements above, in cases where I am not the corresponding author of a published item, permission to include the published material has been granted by the corresponding author.

Mariam Mandoh

5th December 2023

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statements above are correct.

Dr Stephanie R Partridge

5th December 2023

Published abstracts

1. [FIRST AUTHOR] **Mariam Mandoh**, Stephanie Ruth Partridge, Seema Mahrshahi, Helen Cheng, Julie Redfern. Youth engagement in nutrition research, policies, and guidelines for chronic disease prevention: scoping review results. *Nutrition and Dietetics: Journal of Dietitians Australia*. 2020; 77: S1.

Invited presentations

1. [INTERNATIONAL ORAL Workshop] **Mariam Mandoh**, Stephanie Partridge. Strategies to effectively engage young people in research and community initiatives for non-communicable disease prevention. Adolescent participation in obesity and chronic disease prevention research: a scoping review. International Association for Adolescent Health (IAAH) World Congress on Adolescent Health (November 2021).

Presentations selected from abstract

1. [INSTITUTIONAL ORAL] **Mariam Mandoh**, Seema Mahrshahi, Helen Cheng, Julie Redfern, Stephanie R. Partridge. Are adolescents engaged in meaningful participation in research for chronic disease prevention? CPC EMCR Symposium, Sydney, Australia (September 2020).
2. [INTERNATIONAL ORAL] **Mariam Mandoh**, Seema Mahrshahi, Julie Redfern, Hoi Lun Cheng, Philayrath Phongsavan, Stephanie Partridge. Shifting from tokenism to meaningful adolescent participation in research for obesity prevention: a scoping review of 71 studies. International Society of Behavioural Nutrition and Physical Activity Xchange Initiative (June 2021).
3. [INSTITUTIONAL ORAL] **Mariam Mandoh**, Seema Mahrshahi, Julie Redfern, Hoi Lun Cheng, Philayrath Phongsavan, Stephanie Partridge. Optimising adolescent consumer

engagement in co-designing research for chronic disease prevention. CPC EMCR symposium, Sydney Australia (September 2021).

4. [NATIONAL ORAL] **Mariam Mandoh**, Stephanie R. Partridge. Enhancing nutrition research: Evaluation of the Health Advisory Panel for Youth at University of Sydney. Dietitians Australia conference, Adelaide, Australia (August 2022).
5. [INTERNATIONAL POSTER] **Mariam Mandoh**, Stephanie R. Partridge. Adolescent participation in policy and guideline development for obesity and chronic disease prevention: a scoping review. International Congress on Obesity, Melbourne, Australia (October 2022).
6. [NATIONAL ORAL] **Mariam Mandoh**, Stephanie R. Partridge. The Youth Engagement Study (YES!) Optimising adolescent participation in chronic disease prevention research. Digital Health and Informatics Network (DHIN) Digital health week (February 2023).
7. [NATIONAL ORAL] **Mariam Mandoh**, Stephanie R. Partridge. Assessing the impact of a 12-month youth advisory group on empowering adolescents in chronic disease prevention research involvement: a mixed-methods evaluation. Australian Association of Adolescent Health (AAAH) (November 2023).

Other Presentations

1. [INSTITUTIONAL ORAL] **Mariam Mandoh**. Youth engagement in research, policies, and guidelines for chronic disease prevention. Westmead Applied Research Centre (WARC), the University of Sydney (2020).
2. [INSTITUTIONAL ORAL] **Mariam Mandoh**. Youth engagement in research, policies, and guidelines for chronic disease prevention. Higher degree milestones, the University of Sydney (2020).

3. [INSTITUTIONAL ORAL] **Mariam Mandoh**. Optimizing Adolescent Engagement in Co-designing Research for Obesity & Chronic Disease Prevention. Research bites seminar for higher degree research students and early career researchers, the Matilda centre, University of Sydney. Selected via competitive selection process (2022)
4. [INSTITUTIONAL ORAL] **Mariam Mandoh**. The Youth Engagement Study (YES!). Youth health workshop, the Charles Perkins Centre, the University of Sydney (2022).
5. [NATIONAL ORAL Webinar] **Mariam Mandoh**. Enhancing health research: Evaluation of the Health Advisory panel for Youth at The University of Sydney (HAPYUS) at the ‘Engaging consumers in health and medical research’ webinar hosted by Health Consumer NSW (HCNSW) and Sydney Health Partners (SHP) 2022).

MEDIA ARISING FROM THIS THESIS

To date our youth engagement research and development of the Health Advisory Panel for Youth at the University of Sydney (HAPYUS) has resulted in noteworthy media attention reaching greater than 1.2 million people:

- April 30, 2022: Sydney Morning Herald (SMH) [‘Left to our own devices’: Lockdown kids got two years of screens, influencers, and junk food ads](#). Featured on front-page of the SMH highlighting keys messages from our [Lancet essay](#).
- May 02, 2022: University of Sydney media press release: [‘Youth outline top health concerns on scientific stage’](#).
- May 03, 2022: Channel 7’S Sunrise: [Live interview](#) with HAPYUS youth.
- May 11, 2022: Stephanie Partridge, Rebecca Raeside, **Mariam Mandoh**, Hoi Lun Cheng. [‘Putting a spotlight on issues that affect the wellbeing of young people’](#). *Croakey Health Media*.

CHAPTER ONE: THESIS INTRODUCTION

ADOLESCENCE

Adolescence is defined by the World Health Organisation (WHO) as a transitional life stage between childhood and adulthood.¹ The WHO describes adolescence as spanning the ages 10 to 19 years, and although unique, the definition of adolescence intersects with the WHO designation of youth 15–24-year age group and young people aged 10-24 years.² This equivalence has resulted in the interchangeable use of the terms ‘adolescent,’ ‘youth,’ and ‘young people’ in the literature.³

Adolescence is characterised by significant biological, cognitive, social, and psychosocial changes.³ Adolescence typically begins with the onset of puberty and ends with the mental maturation, behavioural change, and financial independence characteristic of early adulthood.⁴ Differences between countries, cultures, and contexts are apparent, but overall, over the past century, adolescents have experienced a significant global shift in social role transitions.⁵ Contemporary social norms such as continuing formal education, later marriage, and delayed parenthood have contributed to a prolongation in the adolescent life stage and transition to adulthood.^{3,5} Consequently, there is growing consensus to expand the classification of adolescence to encompass the ages 10 to 24 years.⁵

Demographics

Adolescents (10-24 years) account for almost a quarter (22%) of the world population, comprising the largest generation in history.⁶ Adolescents today total 1.8 billion, of which 900 million identify as female.^{6,7} The vast majority (90%) of adolescents reside in Low and Middle-Income Countries (LMICs), representing a large percentage of the population.⁶ India

and China comprise a substantial proportion of global youth, with a population of 235 million and 225 million adolescents, respectively.⁶

Worldwide, the population of adolescents is expected to rise by at least 7% by 2030. Global trends indicate that the youth population has stabilised in size in all regions except Africa, where the number of adolescents continues to grow steadily. The population of adolescents in Africa is predicted to grow by 42% by the year 2030.⁸⁻¹⁰

In Australia, adolescents (10-24 years) total 4.6 million, representing 18.2% of the population and 30% of the First Nations population.¹¹ Males account for 51% of Australia's adolescents, while a quarter of Australia's adolescent population live in a regional or remote area.¹²

National prediction data suggests that the size of the adolescent population is expected to continue growing until the year 2066, with the number of 15-24-year-olds alone expected to increase to 5.1 million in 2066.¹²

Developmental milestones in adolescence

The complexity of adolescence is rooted in the intermediary nature of this life stage.

Adolescence is characterised by significant developmental milestones second only to the first 1000 days.¹³ Adolescence initiates at the onset of puberty and continues with the completion of physical growth and complex social and cognitive development.¹⁴ The ending of adolescence is marked by the development of identity as well as emotional, personal, and financial independence from parents and guardians.¹⁵ Understanding the developmental milestones of adolescence is critical to appreciating how adolescents interact, behave, think, and perceive the world around them concerning health and well-being.

Biological development

Adolescence is a developmental period defined by the onset of puberty and significant somatic growth.⁴ Puberty represents a complex sequence of events mediated by genetic, endocrinal, and environmental factors ending in physical maturity and attainment of reproductive capacity.⁴ Timing and tempo of puberty vary significantly between individuals; nonetheless, puberty is a gradual process that takes several years to complete.¹⁴ The biology of puberty is interconnected with adolescent well-being.¹⁴ Optimal nutritional intake during adolescence supports ideal growth and healthy pubertal development.¹⁶ Adolescence is a complex and dynamic stage of change.¹⁶ Sexually dimorphic adolescence marks a period of rapid transformation in body composition, size, and shape.¹⁶ An upsurge in gonadal steroid hormones during puberty is responsible for physical changes, including the build-up and distribution of body fat, particularly in girls, a growth spurt, and increased acne.¹⁶

Neurobiological development

Significant structural and functional neurological development occurs during the adolescent years.¹⁷ The degree of neurodevelopmental change follows only infancy in its magnitude and importance.¹⁴ Fundamental neurodevelopmental plasticity occurs during adolescence and includes significant changes to the structure, function, and connectivity of the brain.¹⁸ Further, adolescence represents a critical period in the development of higher-order cognition.¹⁹ Despite significant development in adolescence, the adolescent brain processes salient events differently from that of adults.¹⁷ Consequently, particular vulnerabilities exist during adolescence and are related to reduced neuronal synchronization and processing efficiency in adolescents, which can manifest as mental illness during this life stage.¹⁷ Additionally, developmental changes in the dopamine system of the brain are thought to influence adolescents' reward processing system and motivated behaviour.²⁰ Reward-

associated impulses in adolescence are typically heightened and linked to precarious behaviours such as binge drinking, substance abuse, and unsafe risk-taking.²⁰ Equally, changes in reward-linked impulses may also embolden adolescents to discover the world around them and challenge social structures or societal roles.²⁰ Therefore, understanding reward sensitivity in adolescents is imperative to appreciate the context of positive youth development.²⁰

Cognitive development

The adolescent life stage involves complex transformations in various cognitive domains.²¹ Mental development progresses with chronological age, knowledge acquisition, and epistemological sophistication.²²⁻²⁴ Cognitive growth in individuals is affected by various dynamics, including genetics, nutrition during gestation and infancy, and environmental exposure.²⁵⁻²⁸ Healthy cognition in adolescence is characterised by the attainment of formal operational thought,²² increased intelligence,²⁶ enhanced metacognition,²³ critical thinking,²⁴ reasoning skills,²⁷ intellectual amalgamation, analysis, and abstract thinking, which enables the expression of creativity.²⁹

Social development

Adolescence is a time of extensive social adjustment, including changes to family and interpersonal relationships.³⁰ Adolescents shift from being dependent on family support to becoming increasingly reliant on peers for help, approval, and validation.^{30, 31} Peer relationships become more salient and complex³² with increased peer influence,³¹ and the emergence of group dynamics and hierarchies.³² The progression through adolescence requires youth to socially adapt to changing societal contexts, academic development, transition to employment, tertiary education, and independent living arrangements.³³

Furthermore, the increasing autonomy gained during adolescence, combined with peer influence and evolving social norms, has meant that adolescents increasingly interact and communicate online via gaming platforms or social media, which may increase the risk of social isolation for some youth.³³ Further, adolescents with poor stress management and interpersonal skills are significantly more likely to be involved in violence, physical bullying, and aggression.³⁴ Social determinants, including economic, cultural, and political factors, influence the progression through adolescence and transition to adulthood.³⁰ The adolescent life stage is usually the time when disruptive behaviour disorders, substance abuse, and trauma disorders begin to emerge.³⁵

ADOLESCENT HEALTH

Adolescent health and well-being is fundamental in its influence on population health.^{36, 37}

The significance of adolescent health extends beyond a reduction in mortality rates.⁷ It is now universally recognised that investing in adolescent health yields a ‘triple dividend,’ promoting optimal adolescent growth and development, shaping a healthy trajectory into adulthood, and providing a foundation of good health for future offspring.^{36, 38}

Attention to adolescent physical and mental health needs is vital for optimal pubertal maturation, linear growth, body composition, cardiorespiratory fitness, neurodevelopment, and immune system development.³⁹ Nutritional intake, physical activity levels, and hormonal balance in adolescence are significant mediating factors impacting skeletal, muscular, and endocrine development and the capacity of individuals to achieve height potential and peak bone mass by early adulthood.³⁹⁻⁴¹ Furthermore, dietary intake and lifestyle exposure during adolescence directly and indirectly affect the maturing brain.³⁹ Severe energy restriction and nutrient deficiency²⁶ of anorexia nervosa⁴² and inactivity of screentime⁴³ are linked with

worse psychosocial health, poorer cognitive development, and lowered educational achievement.^{42, 43}

Health in adolescence lays the foundation for adult health.^{1, 21, 44, 45} However, morbidity in adolescence is often sub-clinical and may not manifest entirely until later in life.⁴⁶ Lifestyle factors and habits of young people are linked to chronic disease risk factor development and increased risk of chronic disease onset and subsequent ill health in adulthood.^{47, 48} Longitudinal studies^{44 49} have established key trends in adolescent health that have important implications for adult physical and mental health.^{50, 51} The progress of obesity among young people indicates worsening health and growing inequalities as they transition into adulthood.⁴⁵ Longer exposure to obesity during adolescence and young adulthood is correlated with an increased risk of severe obesity,⁵² type 2 diabetes (T2DM), high blood pressure, elevated cholesterol, and sleep problems in adulthood.⁴⁴ Furthermore, good adolescent health is associated with better mental health outcomes, academic achievement, good workforce participation, improved quality of life, and more significant contributions to society.^{36, 45, 53} Additionally, poor health in adolescence is associated with socioeconomic indicators, including increased financial disparity, disproportionate disadvantage, and lower educational attainment.^{26, 53, 54}

Health in adolescence has a profound effect on the health of future children.³⁹ Parental dietary intake and environmental exposure have epigenetic effects with intergenerational consequences on offspring growth, development, and metabolic disease risk in adulthood.⁵⁵ Stunting, inadequate micronutrient intake, and excess adiposity among adolescents impact the health of offspring by affecting foetal development, growth in infancy, and cardiometabolic health of children into adulthood.³⁹

Global advances in medicine and healthcare over the 21st century have resulted in more children surviving until adolescence.^{56, 57} In parallel, adolescent health and well-being is subject to the interplay of a vast myriad of unique and dynamic forces.³⁶ Climate change and sustainability, globalization, technological developments, rapid urbanization, and changing food production systems have transformed lifestyle patterns and the diet and nutrition landscape adolescents are emerging into.^{36, 58} Concurrently, national and international policy and practice have not kept pace with the shifting nutrition and health needs and challenges of today's adolescents.⁵⁹⁻⁶² Adolescence is commonly associated with optimal health and well-being; however, significant rates of morbidity and mortality affect today's young people.^{57, 58} Noncommunicable diseases are the leading cause of disease burden in adolescents, accounting for 56% (142 million) of global adolescent disability-adjusted life years (DALYs).⁶² The 2019 Global Burden of Disease (GBD) study found that worldwide 27% of preventable adolescent deaths were due to noncommunicable chronic diseases alone.⁷

Over the past decade, the significance of adolescent health in changing the trajectory of global population health has been realized.^{36, 37, 63} In 2015, the United Nations (UN) upgraded the 'Every Woman, Every Child' agenda with the new 'Global Strategy for Women's, Children's, and Adolescent's Health'⁶⁴⁻⁶⁶ and positioned adolescents at the centre of the UN Sustainable Development agenda.^{67, 68} Additionally, in October 2023 the Global Accelerated Action for the Health of Adolescents (AA-HA!) Guidance document⁶⁵ to support implementation of the 'Global Strategy for Women's, Children's, and Adolescent's Health'⁶⁶ was updated and a second edition released.⁶⁹ Still political commitment to the specific and multidimensional well-being needs of youth is inadequate.³⁸ Adolescents today experience multiple health problems that require a targeted response. However, investment in adolescent health is still substantially limited to specific health issues such as mental and sexual health.³⁸

Creating sustainable and adolescent-responsive health systems is essential to achieving health equity for adolescents³⁸ and central to achieving global health goals.^{66, 68, 70}

Chronic disease risk factors

A strong association exists between behavioural risk factor manifestation in adolescence, progress of metabolic risk factors, and development of chronic diseases like cardiovascular disease (CVD) and T2DM.^{47, 71-73} The relationship between behaviour and metabolic outcomes is demonstrated in the National Health and Nutrition Examination Surveys (NHANES) longitudinal study, which followed a cohort of more than 4000 adolescents over six years into early adulthood.⁵¹ The NHANES study determined that, generally, adolescents exhibited a low prevalence of ideal cardiovascular health behaviors.⁵¹ Overall, less than one percent of adolescents exhibited an ideal healthy diet score, and less than 50% of males achieved ideal physical activity levels.⁵¹ Signs of physiological change began to emerge in adolescence, with a low but present prevalence of high blood pressure and elevated cholesterol levels. An unhealthy diet, and low physical activity in adolescence contributed to the increasing prevalence of obesity, elevated blood pressure, unhealthy cholesterol levels and high blood glucose levels in adulthood.⁵¹ Overall, results from the NHANES study demonstrated that unhealthful behavioural and metabolic risk factors in adolescence track into adulthood.⁵¹

Behavioural risk factors

Behavioural risk factors are modifiable lifestyle choices that increase the risk of chronic disease development. Key behavioural risk factors for chronic disease include physical inactivity, unhealthy diet, excess screen time, poor sleep habits, alcohol consumption, and

smoking.⁷⁴ Physical inactivity and unhealthy diet are the most significant behavioural contributors to the chronic disease burden^{75, 76} and will be discussed in the following sections.

Regular physical activity promotes positive physical and mental health outcomes in adolescents.⁷⁷⁻⁷⁹ Worldwide, physical inactivity has been declared a global pandemic⁸⁰ and is the fourth leading risk factor for premature death,⁸¹ responsible for 7.2% and 7.6% of all-cause and CVD disease mortality, respectively.⁷² Major modern-day contributors to physical inactivity include increased dependence on inactive transportation, urbanisation, and increased screen time and technology usage for work, study, and recreation.^{82, 83}

The WHO Global Status Report on Physical Activity 2022⁸⁴ reports that more than 80% of the global adolescent population (aged 11-17 years) do not meet the WHO physical activity guidelines⁸⁴⁻⁸⁸ of at least 60 minutes of moderate to vigorous intensity physical activity per day.⁸⁶⁻⁸⁸ Adolescent females are more likely to be insufficiently active than their male counterparts, with 85% of girls not meeting physical activity guidelines.⁸⁸ High-income countries experience physical inactivity levels twice that of low-income countries.⁸⁸ In Australia, a mere 15% of 10-14-year-olds,⁸⁹ and 11% of 15-17-year-olds⁹⁰ meet national physical activity recommendations for their age.⁹¹

The Cardiovascular Risk in Young Finns longitudinal study followed a cohort of 2115 children for 31 years.⁹² Data from the study found a significant association between physical inactivity in youth and poor cardiometabolic health in adulthood.⁹³ Low physical activity levels in youth were associated with increased risk of obesity, high waist circumference, high triglycerides, and high blood glucose concentrations,⁹⁴ as well as low high-density lipoprotein cholesterol (HDL-C) concentration in adulthood.⁹³ Low physical activity levels in adolescence is a crucial risk factor for developing chronic disease later in life.⁹⁵ Evidence

suggests a strong dose-response relationship between physical activity levels and health.^{73, 96} Physical fitness in youth is correlated with reduced risk of the onset of chronic disease risk factors, including overweight, obesity, and metabolic syndrome in adulthood.⁹⁷ Small increases in physical activity were found to contribute to the reduction in chronic disease burden and improvement in health status.^{73, 96}

Physical inactivity is projected to account for 500 million new cases of preventable chronic disease between 2020 and 2030, incurring an economic cost of US\$ 27 billion annually if there is no change in the existing incidence of physical inactivity.^{84, 98} The WHO global action plan on Physical Activity 2018-2030⁸³ recognizes the opportunity and necessity of addressing physical inactivity in adolescents to support long-lasting health into adulthood⁸³ and hence achieve the health and well-being goal of the Sustainable Development Agenda 2030.⁹⁹

Greater than two decades after the declaration of physical inactivity as a global pandemic and recognizing the detrimental and long-term impact of physical inactivity on health,⁸⁰ little progress has been made on improving physical activity levels of populations worldwide.¹⁰⁰ Lack of priority, mixed messaging, uncoordinated efforts, under-resourcing, and poor implementation of policies and plans globally have resulted in unsuccessful physical activity promotion among adolescents over the past two decades.¹⁰⁰⁻¹⁰² If current trends continue, the Global Action Plan for the Prevention and Control of Noncommunicable Diseases (NCDs) 2013-2020 global physical activity target of “10% relative reduction in insufficient physical activity” by 2025^{103, 104} and the WHO global action plan on physical activity 2018-2030 target of “15% reduction in the global prevalence of physical inactivity in adolescents and adults by 2030”⁸³ will not be met. Failing to progress towards established physical activity

targets^{83, 103, 104} threatens population health and derails progress toward the 2030 sustainable development agenda.⁹⁹

A healthy diet and adequate nutrition play a vital role in mediating healthy adolescent growth and development.³⁹ Rapid physical growth, cognitive development, and physiological maturation demand increased energy, micronutrient, and macronutrient requirements.⁴⁰ Moreover, diet and nutrition in adolescence significantly influence the future risk of disease development as well as the health of future offspring.³⁹

A range of complex intrinsic and extrinsic factors converge to influence dietary intake and nutritional status in adolescence. The development of autonomy and agency during adolescence has substantial consequences on dietary patterns. Changing eating habits during adolescence is common. Youth gradually move away from family meal structure and parental control of food and meal choices to the increased influence of peers on dietary intake.^{45, 50} Adolescents are more likely to skip breakfast, eat fast food outside the home, and rely on snacking.^{40, 45, 50} Increased appetite during various stages of adolescence is an innate adaption to support the increased energy and nutrients required for growth and development.⁴⁰ However, increased appetite can result in excess energy intake if refined, energy-dense, nutrient-poor foods are over-consumed.⁴⁰

Rapidly changing food production systems, urbanisation, targeted marketing by the food industry, and a rise in food delivery services¹⁰⁵ have transformed adolescent food environments.^{63, 112} The increased exposure, choice, and ease of access to high-energy, nutrient-poor foods has resulted in a global nutrition transition, where adolescents are replacing traditional, often healthier dietary choices for more convenient modern foods.^{62, 106}

Food insecurity and poor-quality diets high in energy, refined sugars, unhealthy fats, and sodium during adolescence place young people at increased risk of nutrient deficiencies, overweight and obesity, and sub-optimal health.¹⁰⁷ The co-existence of malnutrition and the obesity epidemic demonstrates that the impact of overnutrition in the form of overweight and obesity has led to significant changes in adolescent health globally.¹¹²

A meta-analysis of Global School-based Student Health Surveys (GSHS) by Beal et al. examined the global dietary patterns of adolescents.¹⁰⁸ The study revealed high heterogeneity between countries and regions. Still, many adolescents fail to reach the WHO recommendations of five servings or 400g of fruit and vegetables daily.¹⁰⁹ This meta-analysis found that, on average, 34.5% of adolescents consumed fruit less than once per day, and 20.6% consumed vegetables less than once per day.¹⁰⁹ The lowest intakes were found in South and East Asia.¹⁰⁸ A cross-sectional study on Australian adolescents collected data from adolescents over two separate phases and found that less than 15% of adolescents at each time point met recommended vegetables guidelines, and 70% met recommended fruit intake guidelines at both time points.¹¹⁰ These findings align with the Well-being of Young Australians report card 2018,¹¹¹ however, they are alarming since fruits and vegetables represent a significant source of micronutrients and fibre necessary for optimal health and development.¹¹² Further, low fruit and vegetable consumption is linked to an increased risk of chronic disease.¹¹² The WHO Global NCD action plan specifically addresses the need to increase consumption of fruit and vegetables as a fundamental step to address objective three, which states 'to reduce modifiable risk factors for noncommunicable disease and underlying social determinants through the creation of health-promoting environments.'¹⁰³

Discretionary foods and drinks are energy-dense and nutrient-poor choices that do not help to meet nutrient requirements.¹¹³ Discretionary choices are primarily ultra-processed foodstuffs that are high in sodium, sugars, and saturated and trans fats.¹¹³ Rapidly changing food manufacturing systems and the increasing popularity of food delivery services have resulted in a surge in discretionary choices.^{105, 106} Fast food, SSBs, baked goods, and snack foods exemplify common discretionary choices made by adolescents.¹⁰⁶ Social influences, increased independence, and autonomous decision-making in adolescence make this cohort the largest consumer of discretionary foods worldwide.¹⁰⁶ Meta-analysis of the GSHS data found that 46.1% of adolescents globally consumed fast food at least once per week.¹⁰⁸ A study assessing data from the National Nutrition and Physical Activity Survey (n=2812) found that 74% of Australian youth, regardless of gender, socioeconomic status, or physical activity levels, exceeded the maximum recommended servings of discretionary food per day.¹¹⁴ Though this study examined data collected from children aged 2-18 years, analysis revealed a positive association was found between increasing age and energy intake from discretionary foods.¹¹⁴ Further, national data sources established that >40% of the energy intake of Australian adolescents aged 14-18 years is from discretionary foods alone.¹¹⁵ Longitudinal data suggests that unhealthy dietary habits such as fast food intake in adolescence are linked to higher fast food intake in adulthood and, therefore, increased risk of poor chronic disease outcomes.¹¹⁶

Meta-analysis of GSHS data established that 42.8% of adolescents consumed soft drinks at least once daily.¹⁰⁸ This finding was most evident in more affluent countries and regions with mixed food environments.¹⁰⁸ Furthermore, school-based data representing 107 countries found a statistically significant correlation between daily soft drink consumption and overweight and obesity.¹¹⁷ A review of sugar consumption from nationally representative

dietary surveys across the world found that, generally, intake of sugars is high in school-aged children and adolescents, comprising up to 19% of their total energy intake.¹¹⁸ The WHO recommends that <10% of energy intake is from simple sugars.⁷⁶ High intake of simple sugars such as fructose, glucose, and added sugars during adolescence is correlated with an increased risk of poor nutrition, excess adiposity, increased risk of chronic disease,⁷⁶ and colorectal cancer in adulthood.^{76, 119, 120} A systematic review of pooled national data from 73 countries found that sugar-sweetened beverages (SSBs) contribute a significant amount of added sugars to the diet of adolescents worldwide,¹²¹ with adolescents representing the biggest consumers of SSBs globally.¹²¹ The SSB intake of peers strongly influences adolescents' consumption of SSBs. The more SSB consumed by peers, the more an adolescent is likely to consume.¹²² A systematic review and meta-analysis of longitudinal studies investigating changes in added sugar intake between the ages of 13 and 30 found that sugar consumption habits track into adulthood, with a non-significant decrease in added sugar consumption or SSB consumption from adolescence to early adulthood.¹²³

Globally, dietary risk factors have a significant impact on morbidity and mortality rates. In a 2017 GBD study, more than half of diet-related deaths and two-thirds of diet-related DALYs were due to excess sodium consumption (responsible for three million deaths and 70 million DALYs), inadequate consumption of whole grains (contributing to three million deaths and 82 million DALYs), and low intake of fruits (contributing towards two million deaths and 65 million DALYs).⁷¹ Overall, unhealthy dietary quality and patterns are linked with poorer mental health outcomes during adolescence.¹²⁴ Further, excess energy intake and an unhealthy diet are leading risk factors for obesity,^{45, 50} chronic diseases such as CVD and T2DM,^{125, 126} and mortality globally.^{71, 126}

Metabolic risk factors

Metabolic risk factors are physiological changes that increase the risk of developing chronic diseases.⁷⁵ Established metabolic risk factors for chronic diseases include overweight/obesity, hyperglycaemia, hypertension, and hyperlipidaemia.⁷⁵ A systematic analysis of the 2019 GBD study evaluated the extent of risk factor exposure, relative risk, and attributable disease of almost 90 risk factors in 204 nations between 1990 and 2019.¹²⁷ The analysis established a significant rise in metabolic risk factors over the past three decades.¹²⁷

Hyperglycaemia and high body mass index (BMI) presented the most significant increases in risk exposure.¹²⁷ In 2019, the leading level 2 risk factor globally for attributable death was hypertension, which accounted for almost 11 million deaths and 19% of all deaths in 2019.¹²⁷ Similarly, analysis of the Australian GBD dataset established hypertension, hyperglycaemia, and high BMI to be the leading metabolic risk factors affecting the Australian population, and accounting for more than half of all deaths in 2019.¹²⁸ GBD data specific to adolescents and young adults aged 15-39 years, established hypertension, high BMI, and hyperlipidaemia to be the main risk factors attributable to DALYs of CVDs worldwide.¹²⁹

Overweight and obesity are states of excess accumulation of adipose tissue (body fat) that increase the risk of ill health.¹³⁰ Overweight and obesity are often measured using the BMI, which classifies weight status based on a weight-for-height index.¹³⁰ Overweight and obesity are often a consequence of a complex interaction of biological, behavioural, and environmental factors.¹³⁰ Behavioural and environmental factors often affect body weight by influencing energy balance.¹³⁰ Excessive intake of energy-dense foods, high in refined sugars and fats, in addition to inadequate physical activity levels, results in an energy imbalance, which triggers the deposition of excess fat around the body.¹³⁰ Data from the GBD study indicate that the incidence of overweight and obesity has increased over the past 30 years,

rising at a rate that is faster than the increase in associated chronic disease burden.^{131, 132} Data projections report that if the current trend of weight gain continues, almost 268 million children and adolescents worldwide will be overweight, and 124 million will be obese by the year 2025, with a further almost 75% increase in related chronic disease morbidity and mortality.^{131, 132} Furthermore overweight and obesity disproportionately affect adolescent males across all regions.⁸⁵ In the Australian context, the incidence of obesity continues to increase, with 31.6% of children and young people aged 5-24 years classified as obese in 2014-2015, up from 29.6% in 2007.¹¹¹ In parallel, rates of obesity for Indigenous youth are higher at 40.1% in 2012-13.¹¹¹

Overweight and obesity have additional implications for chronic disease risk. A cross-sectional study of 924 overweight and obese Malaysian youth established a significant correlation between higher BMI-z-score, waist circumference, percentage body fat, and prevalence of metabolic risk factors, including hyperglycaemia, hypertension, hyperlipidaemia or metabolic syndrome in which a combination of risk factors co-exist.¹³³ Furthermore, a systematic review and meta-analysis of 15 prospective cohort studies with greater than 200,000 participants found that eight out of ten obese adolescents will remain obese into adulthood.¹³⁴ The National Longitudinal Study of Adolescent Health (Add Health) is an ongoing cohort study involving over 20,000 adolescents aged 12-19 years and living in the United States of America.⁴⁴ Add Health gathered data over the past three decades and determined a relationship between exposure to obesity during adolescence and increased chronic disease-related morbidity in adulthood.⁴⁴ Obese adolescents were significantly more likely to develop T2DM, hypertension, hyperlipidaemia, and sleep disturbances during adulthood compared to their non-obese peers.⁴⁴

Hyperglycaemia is a physiological change characterized by higher than normal blood glucose levels (BGLs).¹³⁵ Hyperglycaemia is diagnosed if fasting BGLs are greater than 125mg/dL and 2-hour postprandial BGLs are greater than 180mg/dL.¹³⁵ Further, abnormalities in glucose metabolism can manifest as impaired glucose tolerance or pre-diabetes, which is diagnosed with a fasting glucose of 100mg/dL to 125mg/dL.¹³⁵ A patient is termed diabetic with a fasting BGL of greater than 125mg/dL.¹³⁵

Major risk factors for hyperglycaemia include genetic predisposition or family history of T2DM, presence of hyperlipidaemia or hypertension, and obesity.¹³⁵ Obesity is an independent risk factor for hyperglycaemia.¹⁴⁰ Excessive abdominal fat in obesity triggers metabolic changes, which lead to insulin resistance, glucose intolerance, hyperglycaemia, and ultimately T2DM.^{135, 136} Furthermore, hyperglycaemia is a predisposing factor to CVD and cognitive decline.¹³⁵ The Korea National Health and Nutrition Examination Study (KNHANES) 2007-2018 sought to assess the risk of T2DM in adolescents 10-18 years.¹³⁶ KNHANES determined that the prevalence of fasting hyperglycaemia has risen over the past two decades.¹³⁶ Further, adolescents who exhibited hyperglycaemia were also more likely to have hypertension and elevated triglycerides.¹³⁶

Hypertension or high blood pressure is a physiological condition in which blood is pumped through the blood vessels with consistently elevated pressure.¹³⁷ Higher blood pressure requires the heart to exert extra pressure to pump blood around the body, and therefore is a significant risk factor for CVD, brain and kidney disease, and is a significant cause of premature death worldwide.¹³⁷ Hypertension is often attributed to older age,¹³⁷ however, a systematic review and meta-analysis of 47 articles by Song et al. found that the prevalence of hypertension in youth globally has increased over the past two decades.¹³⁸ The examination

of the literature found a pooled prevalence of 4% for hypertension and 9.67% for prehypertension in youth younger than 19 years.¹³⁸ However, subgroup analysis determined that a higher BMI was linked with an increased prevalence of hypertension (higher in overweight (15.27%) and obese (4.99%) youth).¹³⁸ Other risk factors for hypertension include high sodium intake (highly processed foods, takeaway foods), low physical activity, genetics, and smoking.¹³⁷ Hypertension and prehypertension are frequently undiagnosed in the paediatric population.¹³⁹ However, an increase in age and an obesity-related diagnosis increased the frequency of abnormal blood pressure diagnoses.¹³⁹ Of a cohort of more than 14,000 3–18-year-olds, 507 had hypertension, and only 26% of these had a documented diagnosis.¹³⁹ Another 485 had prehypertension, and 11% had an appropriate diagnosis documented.¹³⁹

Hyperlipidaemia describes several hereditary and acquired metabolic conditions characterized by raised blood lipid concentrations. Hyperlipidaemia can be defined as low-density lipoprotein cholesterol (LDL-C), triglyceride levels, total cholesterol, or lipoprotein levels above the 90th percentile in comparison to the general population or HDL-C levels lower than the 10th percentile when compared to the general population.¹⁴⁰ Risk factors for hyperlipidaemia include genetic factors, unhealthy diet, high saturated fat intake, central adiposity, uncontrolled diabetes, and an unhealthy lifestyle.^{47, 140} The 2019 GBD study identified hyperlipidaemia among the top three risk factors for CVDs in adolescents and young adults aged 15-19 years.¹²⁹ Independently, hyperlipidaemia was attributed to 28.21% of the proportion of DALYs of CVD.¹²⁹ Hyperlipidaemia is rarely diagnosed in youth due to having no symptoms in the early stages; therefore, reported prevalence data in Australian adolescents is potentially under-representative.¹⁴¹ Still, persons aged 18 years and over who

were obese were twice as likely as adults in the normal weight range to have high cholesterol (11.2% compared to 4.5% respectively).¹⁴¹

CHRONIC DISEASE PREVENTION

The Ottawa Charter 1986 outlined the fundamental action areas necessary for promoting health and preventing chronic disease, including: ‘reorienting health services,’ ‘developing personal skills,’ ‘strengthening community action,’ ‘creating supportive environments,’ and ‘build healthy public policy.’¹⁴² The need for targeted multi-level prevention strategies to minimize the burden of chronic disease risk factors for specific populations such as adolescents is reiterated in the AA-HA! Guidance⁶⁹ to support implementation of the Global Strategy for Women’s, Children’s, and Adolescent’s Health (2016-2030).⁶⁶ Nevertheless, this level of broad cooperation across sectors requires commitment and investment in adolescent health priorities by governments and policymakers.

Chronic disease prevention in adolescents is commonly oriented at primordial and primary prevention strategies, which aim to address social determinants of health and manage specific behavioural chronic disease risk factors such as diet and physical activity or metabolic risks such as obesity prevention.¹⁴³ Primordial and primary prevention strategies are often enforced through laws and nationwide policies and include regulations on advertising to children.¹⁴³ Policies relating to the built environment include the safety of walking paths, cycle paths, and access to healthy food options.¹⁴³

Chronic disease prevention strategies usually target one or more ecological levels as outlined in the AA-HA! guideline.⁶⁹ Structural and environmental strategies may include nutrition labelling programs and urban planning policies. Examples of community or organisational

approaches include healthy food environments in schools and public awareness programs on physical activity.⁶⁹ While individual/family-focused strategies could involve guidance or education on a healthy diet and physical activity.⁶⁹

Adolescence represents a critical life stage in the establishment of health and prevention of chronic disease risk factors, which have serious consequences into adulthood.¹⁴⁴

Chronic diseases such as CVD and T2DM have common risk factors. Morbidity and mortality due to CVD and T2DM can be significantly reduced by addressing behavioural risk factors. Unhealthy dietary choices and low physical activity levels are directly associated with increasing metabolic risk factors for CVD and T2DM, including overweight/ obesity, hyperglycaemia, hypertension, and hyperlipidaemia. Addressing the chronic disease burden and its impact on adverse health outcomes in adulthood requires confronting the shared impact of behavioural and metabolic risk factors in adolescence.^{51, 85} A collaborative effort is required to transform health behaviours and will have positive repercussions on the disease burden caused by CVD and T2DM.¹⁴⁴

A lack of awareness and knowledge of chronic disease risk factors and their implication on future health is evident in adolescents.⁷⁴ An Australian study of more than 680 adolescents determined that despite adolescents exhibiting multiple chronic disease risk factors, they mostly perceive themselves and their environments to be healthy.⁷⁴ These findings underscore the importance of multifaceted approaches to addressing chronic disease prevention in adolescents, which include nutrition and health education.^{69, 145}

Effectiveness of chronic disease prevention interventions targeted at adolescents

An abundance of chronic disease prevention research examines the effect of various health promotion strategies on chronic disease risk factor reduction. Behavioural risk factors like low physical activity, unhealthy diet, or a combination of both are the most common intervention targets while preventing metabolic risk factors such as obesity is the most described chronic disease outcome.

A systematic review of social media-based nutrition interventions assessed 16 studies that targeted adolescents. Although social media interventions were, in some instances, a component of a larger study design, e.g., an educational or support component, 11/16 studies reported at least one significant short-term nutrition-related, clinical, or behavioural outcome. However, limited measures of the feasibility or efficacy of social media individually were included in the studies. The effectiveness of social media interventions for chronic disease prevention is limited but encouraging.¹⁴⁶ Some evidence suggests that empowering adolescents through increased food literacy can improve their dietary intake.¹⁴⁷ An evidence synthesis of mobile health (mHealth) intervention literature determined that individualisation produced significant positive effects on reducing insufficient physical activity levels compared to studies that did not individualise. Another review of digital interventions assessing 27 studies found that significant diet and physical activity behaviour changes were apparent when interventions included education, goal setting, self-monitoring, and parental involvement.¹⁴⁸ Nevertheless, longer-term chronic disease outcomes were not evaluated.¹⁴⁸

A scoping review of food environment-based interventions concluded with inconsistent findings. Varying degrees of benefit and association with nutrition, improved diet, or improved food choices were described, although statistical significance could not be

established.¹⁴⁹ Nevertheless, systematic reviews assessing the impact of food labelling strategies on food choices in the general population exhibited some positive outcomes.^{150, 151} A meta-analysis by Croker et al. 2020, found that front-of-pack labelling led to a reduction in the purchase of high sodium, high sugar, high energy, and high saturated fat foods.¹⁵⁰ Still, the trend to purchase healthier food was only demonstrated in interrupted time series studies.¹⁵⁰ Similarly, a review and meta-analysis by Cecchini & Warin 2016, assessed food labelling systems studied via a randomized control trial study design.¹⁵¹ Results revealed that food labelling had a helpful effect on the selection of healthier food choices; however, overall results were not statistically significant.¹⁵¹

An updated Cochrane review assessed primary care-relevant behavioural interventions such as diet, physical activity, or lifestyle strategies in 90 studies.¹⁵² A meta-analysis found that 16 studies showed a small but significant improvement in BMI.¹⁵² Features of effective intervention strategies included those conducted in educational institutions (14/16), those involving group-based features (15/16), and those that included a combination of exercise and dietary components.¹⁵² Limitations identified were short duration, mixed-weight youth, and high age variability (0-18-years).¹⁵² Another review and meta-analysis of 139 obesity prevention programs in high-income countries assessed various adiposity-related outcomes in children and adolescents aged 2-18 years.¹⁵³ Greater than 80% of studies included were predominantly school-based and demonstrated moderately strong evidence of effectiveness. 2/10 community-based or environmental level interventions produced a statistically significant result, and 1/7 consumer health informatics studies produced a significant reduction in BMI.¹⁵³ Further, a review of reviews on primary prevention of overweight and obesity in adolescents examined 13 systematic reviews.¹⁵⁴ Individual and school-based interventions were most common; however, little to no effect on BMI or physical activity

levels was detected.¹⁵⁴ Two reviews with mixed diet and physical activity-based intervention exhibited small but significant positive effects on SSB consumption. Further, these reviews demonstrated some benefits of combinations of multi-level strategies such as school-based policies, governmental and environmental strategies, and counselling and dietary education.¹⁵⁴ Nonetheless, overall, the certainty of evidence was low for all outcomes.¹⁵⁴ Similarly, a meta-synthesis of 26 meta-analyses established that obesity reduction interventions have more impact on chronic disease outcomes than obesity prevention programs in children and adolescents.¹⁵⁵

Overall, the literature on chronic disease prevention interventions targeted at adolescents is broad, and although some intervention designs show potential, results are still inconclusive and require further investigation. Some moderately strong evidence in the chronic disease prevention literature supports multi-level strategies incorporating a school-based component^{152, 154} as recommended by the 2023 AA-HA! guideline.⁶⁹

Examination of the literature revealed many limitations that reduced the strength and validity of the results. Limitations to the literature included small study sample sizes, which impacted the generalisability of study findings, and short study duration, which made it difficult to establish a preventative effect. Systematic reviews were found to often group interventions targeted at infants, preschool and elementary school children, and adolescents together, undermining the unique biological, social, and cognitive stages each age group is at and limited comparability of chronic disease prevention outcomes between these groups.

YOUTH ENGAGEMENT

Meaningful youth ‘engagement’ or ‘participation’ in adolescent health agendas has gained increasing visibility and significance over the last few decades.^{156, 157} The United Nations Children’s Fund (UNICEF) defines meaningful youth engagement as “adolescent girls and boys (individually and/or collectively) form and express their views and influence matters that concern them directly or indirectly.”¹⁵⁸ Youth Participatory Action Research (YPAR) is a theoretical framework that seeks to develop the skills and capacity of youth and views meaningful youth involvement as an asset and resource in research and intervention development.^{159, 160} A fundamental tenet of YPAR is that youth engagement entails a methodological approach to research and intervention development that recognizes and prioritizes the vital role adolescents play as active participants in addressing evolving modern-day challenges.^{162, 165}

The rationale for youth engagement in adolescent health is justified by both rights-based and empirical reasoning.^{156, 161} Article 12 of the United Nations Conventions on the Rights of the Child (UN CRC) 1989 states that every adolescent has the right to express their views and be heard on matters of importance to them.¹⁶² Participatory opportunities such as youth leadership and engagement in decision-making processes strengthen young people’s influence and foster adolescents’ health-based rights.¹⁶³ Additionally, the UNICEF conceptual framework for measuring outcomes of adolescent participation recognises that, unlike passive and tokenistic involvement, meaningful participation changes with the developing capacities of young people and is empowering while simultaneously being universal and multidimensional in its relevance to adolescents’ needs and context.^{158, 162} Nevertheless, the participatory rights of adolescents are often constrained by intersecting complexities,

including traditional social structures and inequalities, which restrict opportunities for participation.¹⁶⁴

At a foundational level, youth engagement involves considering the unique lived experience, insight, and concerns of adolescents in decision-making processes that affect their lives.¹⁵⁸ More universally, youth engagement is dynamic in its potential to advance adolescent-specific health and social services and policies and ensure greater accountability within communities,³⁶ and of policymakers and leaders more broadly.¹⁵⁸ Further, meaningful youth engagement nurtures positive youth development, extending adolescents' skills, capacity,¹⁵⁹ confidence, and social and emotional growth.³⁶

Youth engagement has the potential to generate tangible change for adolescents and their communities at a local, national, and global level.¹⁵⁷ 'Youth lead the change: participatory budgeting Boston' exemplifies a community-level initiative that engages youth to guide budget spending community initiatives and tailor youth-specific resources.¹⁶⁵ Though this project was not targeted at health and well-being, the youth engagement process ensured youth priorities were central to future community agenda planning, fostered community partnerships, and empowered youth.¹⁶⁵ Furthermore, on a national level, youth consultations via Canada's prime minister's youth council¹³⁰ and the development of Nepal's youth audit tool¹³¹ in partnership with adolescents demonstrated the capacity and willingness of adolescents to contribute to decision-making impacting their societies meaningfully.^{166, 167} Youth engagement opportunities provide youth with a platform to advocate for global and regional issues of importance to them, such as gender equality¹⁶⁸ and climate change,¹⁵⁷ demanding their rights for representation and influencing global agendas.^{157, 168} Though these projects were not explicitly targeted at health and well-being, the youth engagement process

ensured youth priorities were central to agenda planning, enabled the cultivation of adolescent-adult partnerships, and upskilled and empowered youth.^{130, 131, 157, 165, 168}

Youth engagement in adolescent health

The WHO's 2023 adolescent well-being investment interim report positions adolescent engagement as a central element for transformative investment in adolescent health and well-being.¹⁶⁹ The report outlines that for responsive global health and well-being programs and initiatives, planning must be in consultation with adolescents and consider adolescent needs and contextual realities.¹⁶⁹ Furthermore, the report highlights the need for significant and urgent investment to improve the capabilities of youth, underscoring the importance of capacity building and empowerment in overcoming adolescent-specific challenges and enabling adolescents' health and well-being to flourish into adulthood.^{157, 169} Meaningful youth engagement is equity-focused, ensuring adolescents' voices are heard and enabling the creation of tailored health promotion and prevention programs, thus improving health and well-being trajectories for young people.^{158, 159}

The Lancet Commission on Adolescent Health and Well-being (2016) clearly articulates the vital role youth engagement plays in influencing adolescent health outcomes now and into the future.^{36, 170} This message is reiterated by the WHO in its global strategy for women's, children's and adolescent's health; a framework for attaining sustainable development goal (SDG) targets, in which adolescents are recognized as critical partners, whose involvement is necessary for the attainment of health and well-being targets by the year 2030.^{66, 68} Still, overall, adolescents are frequently overlooked in health initiative planning.¹⁶³

Health equity is a central element for healthy and fair societies.⁴⁰ Youth engagement promotes sustainability and equity in societies,¹⁶³ results in more efficient adolescent serving organizations^{38, 170} and improves adolescent health outcomes.¹⁶³ Further, adolescent participation and empowerment have the potential to transform old-fashioned models of health promotion to create more adolescent-responsive health systems that are tailored to the unprecedented challenges affecting adolescents today.³⁶ The 2016 Lancet Commission on Adolescent Health identified adolescent engagement as essential to address the inequalities in health and well-being, which are particularly apparent in socially and economically marginalised adolescents, including ethnic minorities, refugees, young offenders, indigenous, and LGBT adolescents.³⁶

Modelling of the costs and benefits of health interventions found that investment in adolescent health, skill, and capability development was significantly associated with a high rate of economic and social return in the future.¹⁷¹ Building capacity through youth engagement in solution generation underpins sustainable development.^{68, 171, 172} Youth engagement has become a widely recommended methodology for enhancing adolescent health-specific research, intervention, and policy development.^{66, 59, 65} Though youth engagement is increasingly employed in the health domain, evidence syntheses are primarily concentrated on mental health, substance abuse, and sexual and reproductive health.¹⁷³⁻¹⁷⁶

A systematic review investigating the impact of youth engagement on mental health research found that 14 studies engaged adolescents in a meaningful capacity in the research process.¹⁷³ This review established that adolescent engagement had a positive influence on the research process, enhanced the relevancy of the research topics, enhanced dissemination, and generated a positive influence on the health system.¹⁷³ Furthermore, the review documented

that adolescent engagement resulted in positive impacts on youths' personal development, empowerment, and capacity building.¹⁷³ This systematic review also established that adolescents are willing and capable of engaging across the research cycle.¹⁷³ Nevertheless, this assessment found that resources and funding hinder youth engagement in mental health research.¹⁷³ Effective mental health and substance use interventions were described in another review examining 40 studies that reported utilizing youth engagement during the research development.¹⁷⁴ Youth engagement strategies in the studies assessed within this review varied in methodology and the degree of adolescent engagement.¹⁷⁴ Nonetheless, youth participation in decision-making was determined to be beneficial in its impact on the research process, intervention development, and mental health outcomes.¹⁷⁴

A systematic synthesis and meta-analysis of fifteen studies examined the effect of adolescent participation in youth-led approaches to sexual health education in developed nations.¹⁷⁵ Overall, youth engagement via peer leadership was found to enhance knowledge of sexual health and attitudes to sexual health interventions.¹⁷⁵ Moreover, a scoping review of youth engagement in HIV prevention interventions in sub-Saharan Africa examined 74 interventions.¹⁷⁶ Adolescents were reported to exhibit “strong decision-making power” or “shared decision-making power,” designated as ‘substantial’ or ‘moderate’ levels of youth engagement, respectively, in nine of the studies.¹⁷⁶ Youth engagement activities such as youth-led research and crowdsourcing were determined to be feasible activities that enabled further youth engagement in multiple low-resource settings and were of particular relevance to LMICs.¹⁷⁶

Youth engagement in chronic disease prevention

Chronic disease prevention represents a comprehensive field of study. The significance of adolescent engagement in chronic disease prevention research and intervention decision-making is widely recognized.³⁸ Nevertheless, evidence syntheses assessing this body of literature vary in their inferences. Variations in conclusions primarily depend on outcomes of interest, whether they report chronic disease risk factor outcomes, participatory outcomes, or a combination of both.

An interpretive literature review by Larsson et al. broadly investigated youth participation in the health and well-being literature, targeting children and young people aged less than 25 years.¹⁷⁷ Twelve studies focused on healthy diet, obesity, or physical activity in youth, all based in the school or community setting.¹⁷⁷ Findings of this review determined that youth were engaged within the limited capacity of a consultative role, where they expressed their views and had their opinions taken seriously.¹⁷⁷ Conversely, Frerichs et al. examined the literature on ‘functional participation’ and excluded consultative participatory methods such as interviews and focus groups.¹⁴³ Frerichs et al. assessed the obesity prevention literature and identified eighteen studies that utilized participatory strategies to engage children and adolescents (5-19 years) in intervention decision-making.¹⁴³ The analysis established that thirteen studies reported at least one statistically significant chronic disease risk factor outcome, such as weight, physical activity, or dietary change.¹⁴³

Overall, evidence syntheses assessing youth engagement in chronic disease prevention decision-making are uncommon. However, specific interventions show promise of the potential engaging adolescents can impart in the chronic disease prevention domain. The European Youth Tackling Obesity (EYTO)-kids project established the capacity of youth to

lead the design and implementation of a health-promoting social marketing campaign targeted at younger peers.¹⁷⁸ The EYTO-kids program was a 10-month parallel-cluster randomized control pilot trial based in schools in underprivileged communities in Spain.¹⁷⁸ The youth-led social marketing campaign produced a significant increase in the physical activity level of girls, while a significant decrease in the intake of sweets, soft drinks, and fast food was found in girls, and a significant reduction in daily screen time was established in boys.¹⁷⁸ The Students As LifeStyle Activists (SALSA) program underpinned by a peer education model did not engage adolescents in program development decision-making; however, it employed a youth-led approach to implementing the program.¹⁷⁹ Youth leaders demonstrated the capacity of adolescents to facilitate, educate, and influence their peers to make healthy lifestyle choices.¹⁷⁹ Further, the SALSA program empowered youth with skills to advocate for healthy changes within their school setting.¹⁷⁹

The capacity of adolescents to grow from participatory experiences and be instrumental in enriching chronic disease prevention agendas is demonstrated in the CO-CREATE project.¹⁸⁰ The CO-CREATE project engaged youth collaboratively in a pan-European systems-based investigation.¹⁸⁰ Adolescents informed the co-production of knowledge syntheses, multiple context-specific policy-based tools and frameworks, obesity prevention measures, and resources.¹⁸⁰ Moreover, engaging adolescents in co-designing digital obesity prevention tools supports the production of adolescent-tailored and accepted smartphone applications and wearable devices for weight management and health support.¹⁸¹

Today, global commissions, action plans, and calls to action have explicitly designated meaningful engagement of youth or ‘people with lived experience’ as a fundamental action point and critical driver of progress and change in addressing chronic disease risk factors

such as physical inactivity, unhealthy diet, and obesity in adolescents.^{69, 99, 132, 182} Over the past two decades, there has been inadequate political commitment and insufficient resource allocation directed at chronic disease prevention.¹⁸⁷ Subsequently, the Global Action Plan for the Prevention and Control of NCDs 2013-2020 did not achieve the stated chronic disease mortality reduction goals.^{103, 182} Consequently, this chronic disease action plan¹⁰³ was extended, aligned with the 2030 SDG agenda,¹⁷¹ and a new implementation roadmap developed to guide implementation from 2023-2030.¹⁸² Similarly, the integral role adolescents play in the global adolescent health agenda is clearly articulated in the Global Strategy for Women's Children's and Adolescent's health (2016-2030).⁶⁶ Nonetheless, an update of the AA-HA! guidance⁶⁹ in alignment with the 2030 SDGs¹⁷¹ has been developed to accelerate progress on adolescent health outcomes. Overall, updated international policies and guidelines have increased clarity on the significance and requirement for youth informed practice. Incorporation of participatory methods and youth engagement is acknowledged as fundamental to the development of relevant and innovative health-promoting strategies and interventions for adolescents.⁶⁹

KNOWLEDGE GAPS

Adolescents today face unprecedented and compounding challenges to their health and well-being, placing them at increased risk for the early development of chronic diseases such as CVD and T2DM.^{30, 36} Additionally, current approaches to chronic disease prevention have not been effective in reducing the burden of behavioural or metabolic chronic disease risk factors in the adolescent population.¹¹¹

Over the past decade, adolescents have challenged the status quo and demanded their rights to be heard and engaged on matters of importance to them. Through advocacy and activism,

adolescents have influenced transformational global agendas in climate change and planetary health.^{30, 157} Effective progress in reducing the burden of chronic disease now and into the future requires increased investment in adolescent capacity building and engagement to promote relevant, contemporary, and adolescent-responsive solutions to the chronic disease problem in adolescents.^{169, 171}

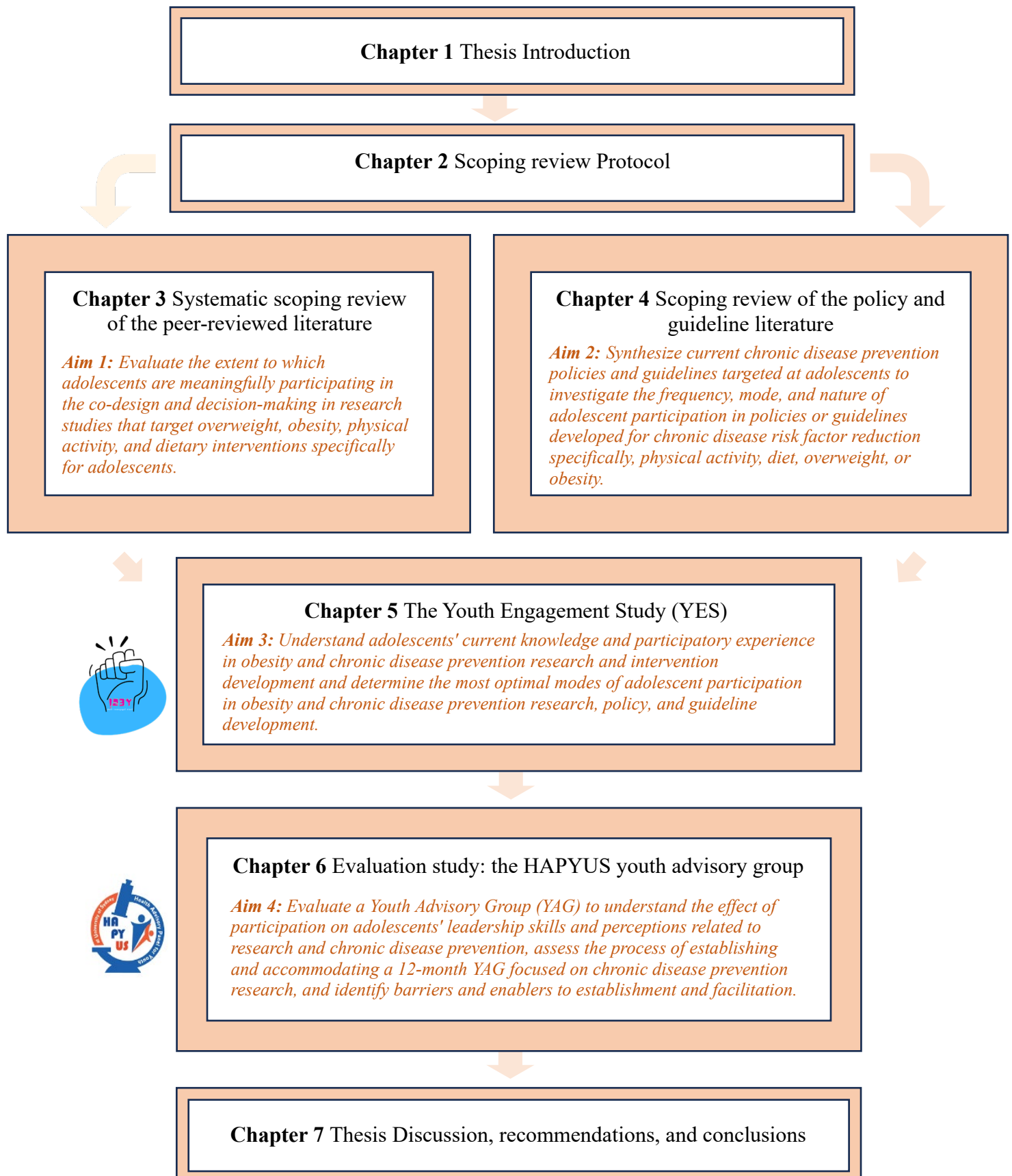
An increasing number of national and international frameworks have promoted youth engagement as a necessary component in intervention planning for improved adolescent health outcomes.^{65, 68, 69} However, explicit guidance on how to best engage adolescents in chronic disease prevention activities in an ethical and meaningful capacity is still unclear.³⁶

THESIS AIMS

This thesis aims to address this knowledge gap and provide recommendations for meaningful adolescent engagement by understanding how adolescents are currently being engaged, their experiences of engagement, and their preferences for engagement in chronic disease prevention decision-making. Specific aims are to:

1. Evaluate the extent to which adolescents are meaningfully participating in the co-design and decision-making in research studies that target overweight, obesity, physical activity, and dietary interventions specifically for adolescents.
2. Synthesize current chronic disease prevention policies and guidelines targeted at adolescents in a scoping review to investigate the frequency of incorporation of adolescent engagement in policy and guideline development and to assess the mode and nature of adolescent participation in policies or guidelines developed for chronic disease risk factor reduction specifically, physical activity, diet, overweight, or obesity.
3. Understand adolescents' current knowledge and participatory experience in obesity and chronic disease prevention research and intervention development and determine the most optimal modes of adolescent participation in obesity and chronic disease prevention research, policy, and guideline development.
4. Evaluate a Youth Advisory Group (YAG) to understand the effect of participation on adolescents' leadership skills and perceptions related to research and chronic disease prevention, assess the process of establishing and accommodating a 12-month YAG focused on chronic disease prevention research, and identify barriers and enablers to establishment and facilitation.

Schematic Representation of Thesis Outline



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CHAPTER TWO: SCOPING REVIEW PROTOCOL

Chapter 1 Thesis Introduction

Chapter 2 Scoping review Protocol

Chapter 3 Systematic scoping review of the peer-reviewed literature

Aim 1: Evaluate the extent to which adolescents are meaningfully participating in the co-design and decision-making in research studies that target overweight, obesity, physical activity, and dietary interventions specifically for adolescents.

Chapter 4 Scoping review of the policy and guideline literature

Aim 2: Synthesize current chronic disease prevention policies and guidelines targeted at adolescents to investigate the frequency, mode, and nature of adolescent participation in policies or guidelines developed for chronic disease risk factor reduction specifically, physical activity, diet, overweight, or obesity.

Chapter 5 The Youth Engagement Study (YES)

Aim 3: Understand adolescents' current knowledge and participatory experience in obesity and chronic disease prevention research and intervention development and determine the most optimal modes of adolescent participation in obesity and chronic disease prevention research, policy, and guideline development.



Chapter 6 Evaluation study: the HAPYUS youth advisory group

Aim 4: Evaluate a Youth Advisory Group (YAG) to understand the effect of participation on adolescents' leadership skills and perceptions related to research and chronic disease prevention, assess the process of establishing and accommodating a 12-month YAG focused on chronic disease prevention research, and identify barriers and enablers to establishment and facilitation.



Chapter 7 Thesis Discussion, recommendations, and conclusions

Schematic Representation of Thesis Outline

Preface to Chapter Two

Chapter one explained the significance of adolescence as a critical life stage in the onset and progression of chronic disease risk factors such as obesity. Chapter two presents the protocol for a systematic scoping review of adolescent participation in research, policies, and guidelines for chronic disease prevention. The protocol provides rationale and a clear framework for evidence synthesis in the adolescent participation in chronic disease prevention peer-reviewed and grey literature. It was conducted in accordance with best practice guidelines for conducting a systematic scoping review. The protocol was registered with Joanna Briggs Institute and Open Science Framework, doi:10.17605/OSF.IO/E3S64 and is published in the International Journal of Environmental Research and Public Health (IJERPH).

Published peer reviewed manuscript

Mariam Mandoh, Seema Mahrshahi, Hoi Lun Cheng, Julie Redfern, and Stephanie R. Partridge. Adolescent Participation in Research, Policies and Guidelines for Chronic Disease Prevention: A Scoping Review Protocol, *International Journal of Environmental Research and Public Health*. 2020; 17:21. This work is licensed under a Creative Commons Attribution 4.0 International License (CC BY 4.0)

Authorship attribution statement: This statement is to stipulate that contribution made by Mariam Mandoh in the preparation and submission of the following manuscript “Adolescent Participation in Research, Policies and Guidelines for Chronic Disease Prevention: A Scoping Review Protocol.” The convention is that the author with the principal contribution to the manuscript is the first author.

Mariam Mandoh during her PhD candidature developed the original concept of the protocol, Mariam Mandoh was responsible for designing, refining, registering of the study protocol with the Joanna Briggs Institute (JBI) and Opens Science Framework (OSF), drafting manuscript and subsequent revisions, and leading submission for publication of the protocol paper.

The individual roles of co-authors are listed below:

Task	Role of co-author
Conceptualization	MM, SM, HLC, JR, SRP
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As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement is correct.

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Protocol

Adolescent Participation in Research, Policies and Guidelines for Chronic Disease Prevention: A Scoping Review Protocol

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Received: 17 August 2020; Accepted: 4 November 2020; Published: 9 November 2020



Abstract: Adolescents (10–24 years old) account for 23% of the global population. Physical inactivity, suboptimal dietary intake, overweight, and obesity during adolescence are risk factors associated with chronic disease development into adulthood. Research, policies, and guidelines that seek to prevent chronic disease risk factor development rarely engage adolescents in planning and decision-making processes. The aims of this review are to investigate (i) how adolescents currently participate in research, policy, and guidelines for reduction of chronic disease risk factors, and (ii) provide recommendations to optimize adolescent participation in future research, policy, and guideline decision making for chronic disease prevention. A systematic scoping review of the health peer-review research, policy, and guidelines, using Arksey and O'Malley's six-stage framework, will be conducted. Participatory outcomes will be assessed based on the Lansdown-UNICEF conceptual framework for measuring adolescent participation. Classified as consultative, collaborative, or adolescent-led according to the degree of influence and power adolescents possess in the decision-making processes. Consultation with adolescents via digital surveys and focus groups will provide further information, perspective, and insight. Qualitative data will be analyzed by descriptive numerical summary and qualitative content analytical techniques. The title of this protocol is registered with Joanna Briggs Institute and Open Science Framework, doi:10.17605/OSF.IO/E3S64.

Keywords: youth; adolescent; engagement; participatory action; health policy; decision-making; chronic disease; non-communicable diseases (NCD); prevention

1. Introduction

Adolescence is a unique stage of life connecting childhood to adulthood, characterized by rapid cognitive development and accelerated physical growth [1,2]. In conjunction with physiological changes,

adolescents exhibit increased autonomy, identity formation, and the development of critical social skills, knowledge and networks that enable them to engage with broader society [3–5]. Adolescence plays a critical role in laying the foundations necessary for the development of a productive future workforce, and the next generation of decision makers and leaders [6–8]. Today rapid social and technological transformations are directly impacting the understanding of the duration of adolescence [9]. It is now recognized that adolescence encompasses a longer portion of the life course than in any other time in history (10 to 24 years of age) [9]. It is therefore imperative that adolescents are empowered in the decision-making process to make informed health choices at this life stage in order to improve their health and quality of life trajectory.

Chronic disease risk factors, such as physical inactivity, suboptimal dietary behaviors, and overweight or obesity often cluster in adolescence. In 2018 the World Health Organization (WHO) reported that 81% of adolescents aged 11–17 years are insufficiently physically active [10]. Adolescents display a simultaneous increase in obesogenic dietary behaviors as they progress through adolescence, such as reduced fruit and vegetable intake and increasing intake of sugar sweetened beverages [11–13].

The association between physical activity, diet, overweight, and obesity in adolescence and chronic disease outcomes as well as quality of living in later life has been well established [14–18]. Seventy percent of preventable adult deaths from chronic diseases are linked to lifestyle risk factors that start during adolescence [19]. Moreover, an inequitable distribution of chronic disease risk factors exists, with a higher prevalence of overweight and obesity among adolescents of low-socioeconomic status in both developing and developed countries [20–23]. These phenomena are of paramount concern for not only the adolescents themselves and their families, but also governments who face lost productivity associated with chronic diseases as well as an increased strain on health systems to manage chronic diseases. A shift in paradigm of approaches to prevent chronic disease in adolescents is required [24].

The United Nations Convention on the Rights of the Child (UN CRC), declares that “Governments should ensure that children survive and develop healthily” and “Children have the right to good quality health care, clean water, nutritious food, and a clean environment so that they will stay healthy.” The UN CRC also maintains that “participation” in decision-making that affects the life of an adolescent is their legal right [25,26]. The UN CRC treaty has been ratified by all except one country globally [27]. Most participating countries have not achieved their obligations. For example, adolescents are rarely engaged in the health and medical research cycles that shape the chronic disease prevention interventions, guidelines, and policies that serve them [28–30]. A 2020 report by the WHO-UNICEF-Lancet Commission addressed the lack of effective and cohesive measures taken by governments globally to tackle adolescent engagement issue successfully [31].

Ineffectively engaging and empowering adolescents in research about their health and the health of their peers will potentially result in unsustainable and unsuccessful chronic disease prevention interventions, policy, and guideline development. This will subsequently result in adverse long-term health consequences for adolescents and their future offspring [31]. The importance of consumer and community engagement in research is widely acknowledged [26,32]. Adolescents represent a key stakeholder group [33], with untapped potential to benefit societies socially, politically, and economically. When given a voice and opportunity adolescents have demonstrated considerable value for meaningful contributions to issues of importance to them, their community and beyond [29]. Still, current evidence suggests that adolescent participation in research is often ad hoc and tokenistic [34].

Definitions of participation in health research vary considerably. Common terminology includes but are not limited to youth-led participatory action research (Y-PAR), community-based participatory research (CBPR), participatory action research (PAR), e-PAR (technology-based PAR), action research (AR), participatory practices, youth engagement, and youth involvement. Furthermore, systematic reviews on participatory methods in adolescent populations vary largely in their scope, in terms of context, age range, demographics or outcomes measured [35–41]. For example, some reviews

are specific in their inclusion criteria of age such as “0–18 years” [36] while other reviews investigate broad definitions of “youth” or “child” participation [40] with health outcomes infrequently evaluated. Adolescent health is a fundamental element necessary to promoting better quality of life and reduced chronic disease risk across the life course. Yet, despite extensive focus on youth participation methods more broadly [42,43], there remains limited research demonstrating effective strategies for adolescents’ participation in research and interventions for chronic disease prevention.

The current body of chronic disease prevention research is lacking in effective and inclusive research, policies, and guidelines which support all adolescents to improve chronic disease risk factors and lead healthy lives [18]. There is a need to synthesize the peer review and grey literature to evaluate adolescents as a unique demographic and assess their current role in health research, policy, and guideline development for chronic disease prevention. The aims of this scoping review protocol are two-fold. First, to conduct a scoping review to analyze the mode of adolescent participation in health peer-reviewed primary research studies, policies, and guidelines for co-designing or decision making for chronic disease risk factor reduction, specifically, physical activity, diet, overweight, and obesity research. Second, to determine, through adolescent participation, recommendations for the most optimal modes of participation for research, policy, and guideline decision-making for chronic disease prevention.

2. Materials and Methods

2.1. Protocol Design

The approach to be taken to systematically review the knowledge base on our topic of interest was determined by considering the purpose of this review and nature of the data sought. It was determined that a systematic scoping review would best address the study aims. A scoping review is a valid method to broadly “map” the existing literature on a particular topic. For the purpose of this review, it will permit for a broad and thorough examination of the emerging field of research into adolescent participation in research, policies, and guidelines for chronic disease prevention. This will allow for the identification and analysis of key outcomes and knowledge gaps on this topic, whereas a traditional systematic review is narrower in scope, guided by an explicit research question with the purpose to inform clinical practice or policy [44,45].

The scoping review will be informed by Arksey and O’Malley’s six stage framework for scoping reviews [46], with Levac et al.’s recommendations (Figure 1) [45,47]. This framework enables a flexible and iterative approach to systematically scope and interpret a range of peer-reviewed primary research studies and grey literature. The Arksey and O’Malley framework is a published methodology for scoping reviews, which has been further advanced and iterated since inception [47,48]. This framework provides the foundation for the Joanna Briggs Institute (JBI) manual for evidence synthesis scoping review guidelines [45] and provides clear guidance at each stage of the scoping review process to ensure a clear and rigorous review process.

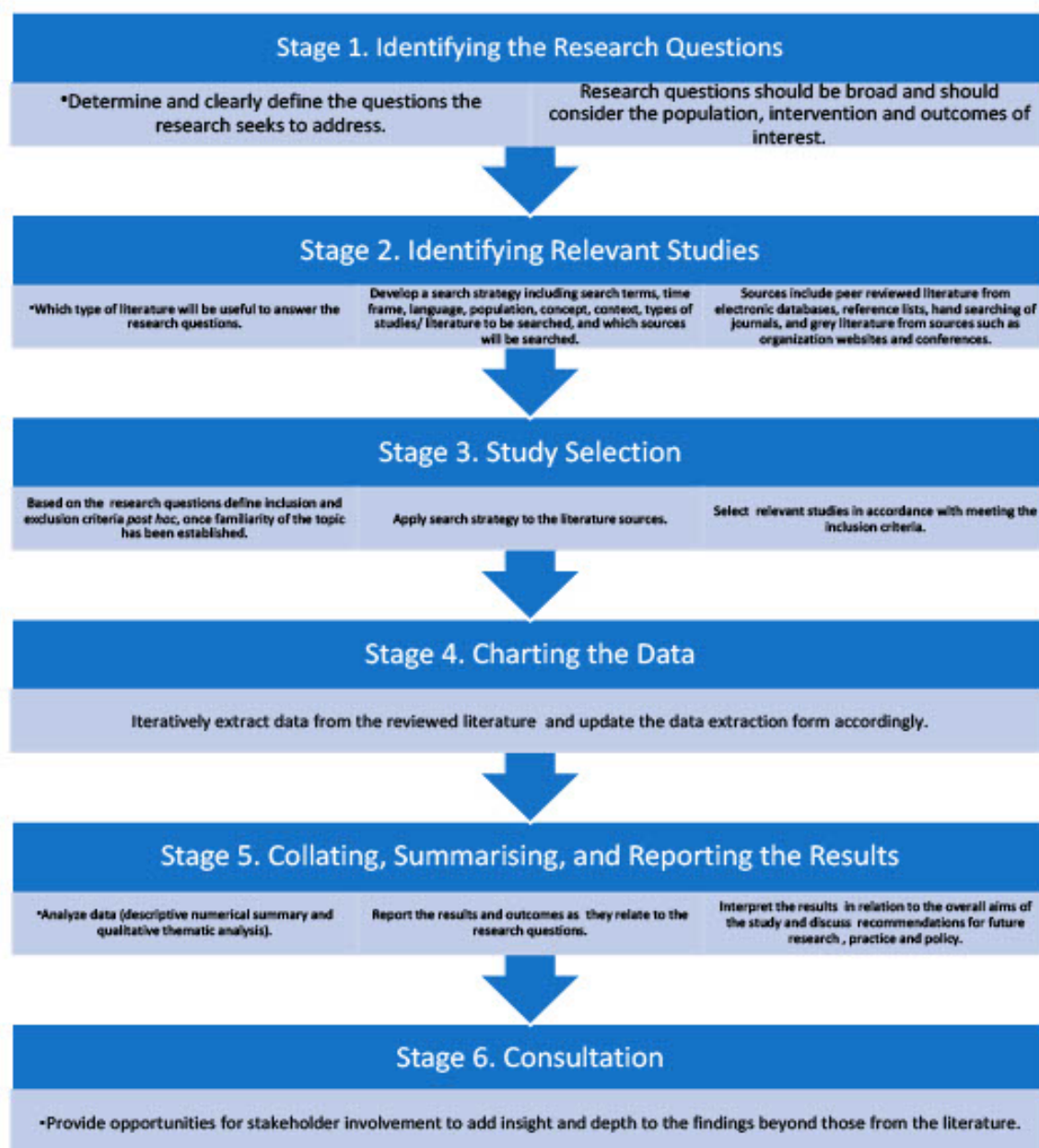


Figure 1. Methodological framework for conducting a scoping review adapted from the Arksey and O'Malley six stage framework.

The Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist [49] will be used to ensure the scoping review meets necessary quality standards of practice and reproducibility.

2.1.1. Identifying the Research Questions

Preliminary search of the peer-reviewed primary research studies and grey literature aided in refining the research questions. The research questions aim to provide evidence and critical insight into how adolescents can effectively participate in co-designing, and in decision making related to research, guidelines, and policies for chronic disease prevention. The main chronic disease risk factors to be included are physical inactivity, suboptimal diet, overweight, and obesity, given their prevalence in adolescence and similarities in primary prevention approaches. The research questions are (i) is there evidence of effectiveness of adolescent participation in reducing chronic disease risk factors

in peer-reviewed primary research studies, policies, and guidelines? (ii) what are the components, processes, or conceptual frameworks of effective peer-reviewed primary research studies, policies, and guidelines involving adolescent participation in chronic disease risk factor reduction? and (iii) are there any identifiable barriers or facilitators or evidence gaps for adolescent participation in the chronic disease prevention space?

2.1.2. Identifying Relevant Studies and Study selection

Peer-reviewed primary research studies, policies, and guidelines for inclusion will be identified by systematic and comprehensive searches of electronic health and medical research databases as well as grey literature databases and registers. First, to identify primary research studies, a systematic search of the peer-reviewed literature using medical subject headings (MeSH) terms, keywords, and database categorization will be conducted. This iterative process will involve broad search terms, including combinations, truncations, and synonyms of “nutrition,” “diet,” “physical activity,” “overweight,” “obesity,” “lifestyle risk factors,” “non-communicable diseases,” “adolescents,” “youth,” “teenagers,” “guidelines,” “co-design,” “decision-making,” “youth engagement,” “youth involvement,” “participatory research” (will cover Y-PAR, CBPR, PAR, e-PAR), “action research” and “participatory practices.” Second, to identify relevant policies and guidelines, grey literature sources will be searched using the keywords mentioned above as well as the population (adolescence, youth), concept (adolescent engagement, participation), and context (chronic disease prevention) classification where necessary.

2.1.3. Search Strategy

As recommended by the Joanna Briggs Institute (JBI) for scoping reviews, a three-step search strategy will be utilized. Both peer-reviewed published primary research studies and grey literature will be evaluated. First, a preliminary search of Medline (through PubMed) and Cumulative Index of Nursing and Allied Health Literature (CINAHL) databases will be conducted. Key search terms will be refined by analysis of keywords contained in the title and abstract of the retrieved articles, and of the index terms used to describe the articles.

Second, a systematic and comprehensive search of the peer-reviewed literature will be conducted. All identified keywords and index terms will be searched across all included databases. Six major databases will be examined: Medline (through PubMed), Embase, the Cochrane Central Register for Controlled Trials (CENTRAL), CINAHL, Global health and Scopus. In addition, grey literature will be consulted from the National Health and Medical Research Council (NHMRC) Guideline Index (Australia), the National Guideline Clearinghouse (U.S), the Disease Prevention and Control Guidelines (Canada), the National Institute for Health and Care Excellence-Evidence Search (UK), and the United Nations (UN). A universal internet search engine (Google) advanced search function will be utilized to identify additional policies or guidelines. The grey literature search will be conducted in incognito mode on the search engine to restrict ads and cookies. The search results will be limited to the first five pages of search. The final grey literature source will be Tripdatabase.com which will be examined using the population, concept, context (PCC) search option as described above.

Next, the database results will be pooled, and duplicates removed. A two-part study selection process will be applied to minimize opportunity for errors and reviewer bias. In part one, a title and abstract review will take place by one reviewer (MM), articles that do not meet defined inclusion criteria will be excluded. Part two will involve a full text review of remaining articles by two reviewers (MM and SRP) independently. Articles that do not meet inclusion criteria by both reviewers will be excluded. In cases of disagreement a third reviewer (JR) will adjudicate the final decision.

Finally, reference list examination and citation chaining (both forward and backward where necessary) will be conducted for full text articles that meet all the inclusion criteria as well as those of any identified reviews. Duplicates will be removed and studies that are found via this method will likewise undergo a two-part selection process (as above) to determine eligibility for inclusion in the final scoping review.

2.2. Inclusion Criteria

Peer reviewed and grey literature will be subject to inclusion and exclusion criteria defined after preliminary searching, agreed upon by study coordinators. Details of the criteria on which the scoping review will be based are outlined below in accordance with the Joanna Briggs's Institute (JBI) Manual for evidence synthesis [45]. The population, concept, context, types and sources of literature of interest are defined.

2.2.1. Population

The WHO defines an “adolescent” as a person aged between 10–19 years old, and “youth” as a person aged between 15 and 24 years old [3]. WHO also recognizes that “youth” is a fluid term that varies depending on country and experience [33]. The Lancet Child and Adolescent Health describes an adolescent as one between the age of 10–24 years [9]. Within the published peer-reviewed literature these two terms are used loosely and interchangeably. For a comprehensive analysis of the peer-reviewed literature this scoping review will assess published and grey literature involving “adolescents” or “youth” defined as ages 10–24.

2.2.2. Concept

The fundamental concept to be examined and considered for inclusion is all forms of adolescent participation, engagement, and decision-making in peer-reviewed primary research studies, policy, and guideline development related to physical activity, dietary behaviors, overweight, obesity, and chronic disease prevention. This will include but is not limited to Y-PAR, CBPR, PAR, e-PAR, AR, participatory practices, youth engagement, and youth involvement.

2.2.3. Context

The review will encompass a broad context. All genders and all languages with the exclusion of papers without an abstract published in English will be considered. Published peer-reviewed literature from all countries will be examined, while policies and guidelines will be limited to those from Australia, the United Kingdom (UK), the United States of America (USA), Canada, and the United Nations (UN), reflecting similar demographics and health ethos. Material published prior to 1995 will be excluded to reflect literature, policies, and guidelines likely to impact the current generation of youth, the Generation Y (or “millennials,” born between 1981 and 1996) and Generation Z (born between 1995 and 2015). These generations have in common that they are more technologically savvy and more “connected” than the generations before them [50]. Constant internet access and accessibility of devices have made these generations more conscious of social, environmental, and global political issues than previous generations. This demographic is also unique in that they solve problems in dynamic and innovative ways, they value being involved in decision making and disengage when decisions are imposed upon them, challenging traditional norms [51].

2.2.4. Types and Sources of Literature

This scoping review seeks to capture the current state of adolescent participation in the chronic disease prevention space. Published peer reviewed primary studies, guidelines, and policies are the documents which have the most impact on the chronic prevention processes. These documents are accepted by academic professionals and policy makers and are the basis for driving future program development. Therefore, all published peer-reviewed literature of primary studies as well as published policies and guidelines involving adolescent participation in chronic disease prevention will be assessed for inclusion.

2.2.5. Charting the Data

Interest in measuring and evaluating meaningful youth engagement in projects for research is not a new concept. In 1969 Arnstein developed a “ladder” [52] to metaphorically represent and categorize citizen participation in projects [53]. In 1992 Roger A. Hart, in association with the United Nations Children’s Fund developed the “ladder of participation” (also known as “HART’s ladder”), which involved eight levels or rungs of the ladder, each representing a differing level of young people’s participation [54]. Furthermore, in 2001 Harry Shier proposed an alternative model, “Pathways to participation,” which involved 5 levels of children’s participation and 15 questions spread throughout the pathway. Shier recognized that it is possible to be at more than one stage of the pathway at any one given time. Hence, it does not completely replace Hart’s ladder but acts as an adjunct [53].

More recently, Gerison Lansdown (2018), in association with UNICEF, further built on these models and developed a more comprehensive “Conceptual Framework for Measuring Outcomes of Adolescent Participation,” comprising three modes of meaningful participation: collaborative, consultative, and adolescent-led. This framework, instead of using an approach based on “stages,” emphasizes that true participation which leads to empowerment and influence can be achieved through differing approaches which are valid but suitable for different contexts and subject to evolving capacities [55].

The data will be charted by categorizing the qualitative data according to key concepts using the Lansdown UNICEF (2018) model. Two researchers (MM and SRP) will extract the data to ensure categories are consistent with the research questions. The data extraction form will be iteratively updated and fine-tuned during data collection to ensure all relevant data are obtained.

2.2.6. Collating, Summarizing and Reporting the Results

Data will be analyzed by descriptive summary using a scale to assess research, policies, and guidelines against the key concepts and by qualitative content analytical techniques. The results will be reported considering gaps in the evidence for adolescent engagement in co-design and decision making related to chronic disease prevention and the implications of the findings will be considered within the broader context of adolescent health and non-communicable chronic disease prevention. Since, the results of this scoping review are essentially qualitative, the results will be discussed in narrative form.

2.2.7. Participatory Consultation Exercise

Stage six of the Arksey and O’Malley framework involves a participatory consultation exercise with adolescent stakeholders. This is necessary to provide further depth and context to the results obtained from the literature. This process will be informed by the results of the scoping of published and grey literature.

3. Timeline

Our research is in progress. A draft of the scoping review is currently underway and will be submitted before the end of 2020.

4. Discussion

Although systematic in nature, this scoping review is not without potential challenges. Despite a comprehensive search, relevant literature could potentially be missed due to terminology differences within this field. Nonetheless, this review will present a summary of adolescent participation in the chronic disease prevention space. It will identify gaps in the literature and specifically analyze the current state of adolescent participation in the health and medical research cycle as well as policy and guideline development processes. This research will provide new insight and solutions to effectively tackle chronic disease risk factor development in communities of low, middle, and high

socioeconomic status and varying demographics. Findings will inform advanced resource development, providing a robust foundation for innovative chronic disease prevention research, policy, and guideline development. Electronic resources and tools will be developed and form a tool kit to guide and support researchers, industry, and policy makers on how to effectively engage adolescents at all stages of the research, policy, and guideline development process. This will promote efficient and effective interventions to support the adoption of healthy lifestyle behaviors during adolescence and subsequently reduce the risk of chronic disease onset throughout the life course.

5. Conclusions

Youth participation in the research, policy, and guideline development and decision-making processes for chronic disease prevention is a novel approach to the global challenge of chronic disease. By partnering with adolescents to address the root causes of chronic disease risk factor development, this research will aid in finding solutions to overcome facets of chronic disease burden.

Author Contributions: Conceptualization, M.M., S.M., H.L.C., J.R. and S.R.P.; methodology, M.M., S.M., H.L.C., J.R. and S.R.P.; investigation, M.M., S.M., H.L.C., J.R. and S.R.P.; writing—original draft preparation, M.M.; writing—review and editing, M.M., S.M., H.L.C., J.R. and S.R.P.; supervision, J.R. and S.R.P. All authors have read and agreed to the published version of the manuscript.

Funding: This research was funded by a National Health and Medical Research Council/National Heart Foundation Early Career Fellowship, grant number APP1157438 award to S.R.P.; and J.R. is funded by a National Health and Medical Research Council Career Development Fellowship, grant number APP1143538.

Acknowledgments: The authors wish to thank the academic liaison librarians at the University of Sydney, Tess Aiken and Kanchana Ekanayake, for their support developing the search strategy.

Conflicts of Interest: The authors declare no conflict of interest.

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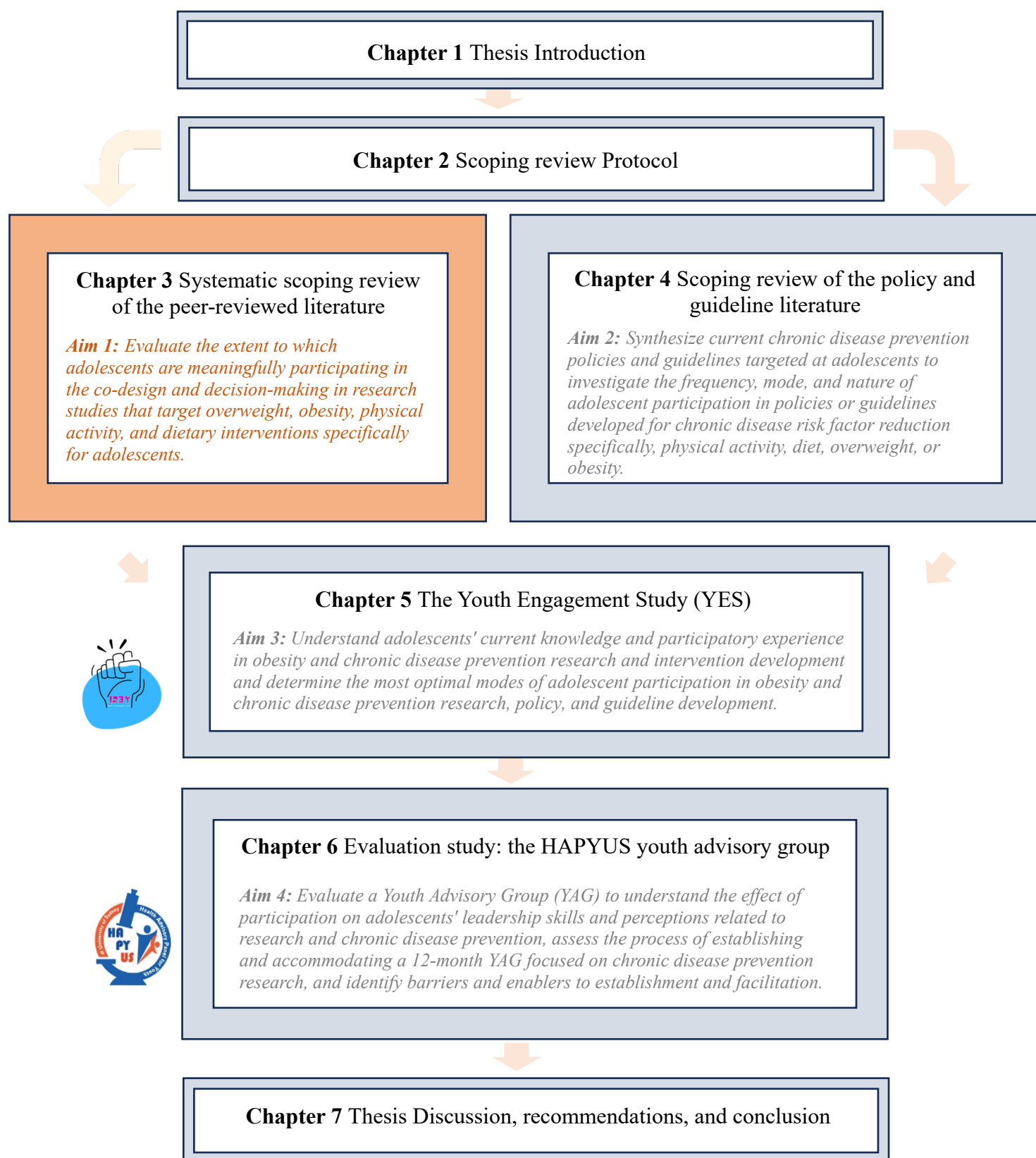
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CHAPTER THREE: SYSTEMATIC SCOPING REVIEW OF THE PEER-REVIEWED LITERATURE



Schematic Representation of Thesis Outline

Preface to Chapter Three

Chapter two presented the rationale for and framework to systematically scope the peer-reviewed and grey literature related to adolescent participation in research, policy, and guideline development for chronic disease prevention. Chapter three presents the results of a systematic scoping review of adolescent participation in the obesity and chronic disease prevention peer-reviewed literature. Overall, this scoping review addressed aim one of this thesis and established that meaningful adolescent participation in the obesity and chronic disease prevention research cycle is limited.

This scoping review has been peer-reviewed (submitted 5th October 2021, resubmitted with corrections according to reviewer comments 24th November 2021, accepted for publication on 24th November 2021) and published on 23rd December 2021 in *Frontiers of Public Health* Journal, which forms this chapter. Author's contributions to this paper are outlined in the authorship attribution statement. Chapter three has been disseminated as follows:

Published peer reviewed manuscript

Mandoh M, Redfern R, Mahrshahi S, Cheng HL, Phongsavan P and Partridge SR. Shifting from Tokenism to Meaningful Adolescent Participation in Research for Obesity Prevention: A Systematic Scoping Review, *Frontiers in Public Health*. 2021; 9:789535. This work is licensed under a Creative Commons Attribution 4.0 International License (CC BY 4.0).

Conference presentations

1. [INTERNATIONAL ORAL] **Mariam Mandoh**, Seema Mahrshahi, Julie Redfern, Hoi Lun Cheng, Philayrath Phongsavan, Stephanie Partridge. Shifting from tokenism to meaningful adolescent participation in research for obesity prevention: a scoping review of 71 studies. International Society of Behavioural Nutrition and Physical Activity Xchange Initiative (June 2021).
2. [INTERNATIONAL ORAL Workshop] **Mariam Mandoh**, Stephanie Partridge. Strategies to effectively engage young people in research and community initiatives for non-communicable disease prevention. Adolescent participation in obesity and chronic disease prevention research: a scoping review. International Association for Adolescent Health (IAAH) World Congress on Adolescent Health (November 2021).

Authorship attribution statement: This statement is to stipulate that contribution made by Mariam Mandoh in the preparation and submission of the following manuscript “Shifting from Tokenism to Meaningful Adolescent Participation in Research for Obesity Prevention: A Systematic Scoping Review.” The convention is that the author with the principal contribution to the manuscript is the first author.

Mariam Mandoh during her PhD candidature developed the original concept of the scoping review, Mariam Mandoh was responsible for performing the literature search, study inclusion and exclusion, data extraction, drafting the manuscript and leading submission for publication of the original research paper.

The individual roles of co-authors are listed below:

Task	Role of co-author
Conceptualization	MM, SM, HC, PP, JR, SRP
Methodology	MM, SM, HC, PP, JR, SRP
Investigation	MM, SM, HC, PP, JR, SRP
Writing- original draft preparation	MM
Writing- review and editing	MM, SM, HC, PP, JR, SRP
Supervision	JR, SRP
Management of manuscript submission	MM

Mariam Mandoh

Date: 05.12.2023

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement is correct.

Dr Stephanie R Partridge

Date: 05.12.2023



Shifting From Tokenism to Meaningful Adolescent Participation in Research for Obesity Prevention: A Systematic Scoping Review

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Specialty section:

This article was submitted to
Public Health and Nutrition,
a section of the journal
Frontiers in Public Health

Received: 05 October 2021

Accepted: 30 November 2021

Published: 23 December 2021

Citation:

Mandoh M, Redfern J, Mhrshahi S,
Cheng HL, Phongsavan P and
Partridge SR (2021) Shifting From
Tokenism to Meaningful Adolescent
Participation in Research for Obesity
Prevention: A Systematic Scoping
Review.
Front. Public Health 9:789535.
doi: 10.3389/fpubh.2021.789535

Background: Traditionally, adolescent participation in research has been tokenistic. Adolescents are rarely afforded the opportunity to influence decision-making in research designed to prevent obesity. Engaging adolescents in meaningful decision-making may enhance research translation. This review aimed to analyze the current modes and nature of adolescent participation in obesity prevention research decision-making.

Methods: A systematic scoping review was conducted using Arksey and O'Malley's six-stage framework. Six major databases were searched for peer-reviewed primary research studies with adolescent participation related to obesity, physical activity, and diet. Modes of adolescent participation were categorized based on the Lansdown-UNICEF conceptual framework for measuring outcomes of adolescent participation. The framework outlines three modes of meaningful participation: (i) consultative, which involves taking opinions and needs into consideration; (ii) collaborative, where adolescents are partners in the decision-making process; and (iii) adolescent-led participation where adolescents have the capacity to influence the process and outcomes. The degree of involvement in research cycles was classified based on the National Health and Medical Research Council consumer engagement framework. Five stages of the research cycle were determined: identify, design and develop, conduct, analyze and disseminate.

Results: In total, 126 papers describing 71 unique studies were identified. Of these, 69% (49/71) took place in the USA, and 85% (52/61) were conducted in minority or underserved communities, while males were more likely to be under-represented. In 49% (35/71) of studies, participation was consultative and 9% (6/71) of studies involved an adolescent-led approach. Furthermore, 87% (62/71) of studies incorporated adolescent participation in one or more of the research cycle's formative phases, which involve eliciting views, opinions and idea generation. Only 11% of studies engaged adolescents

in all five stages of the research cycle where adolescents could have more influence over the research process.

Conclusion: Meaningful adolescent participation in the obesity prevention research cycle is limited. Empowering and mobilizing equal partnership with adolescents should be at the forefront of all adolescent-related obesity prevention research.

Keywords: adolescent, youth, participation, engagement, decision-making, obesity, overweight, prevention

INTRODUCTION

Overweight and obesity is a global health crisis affecting 340 million young people (5–19 years) worldwide (1). Despite common misconceptions and gender-based stereotypes, obesity is more likely to affect adolescent boys than girls in 60% of countries, with this trend most apparent in high and upper-middle-income nations (2). The prevalence of overweight and obesity in young people continues to increase and has quadrupled in this cohort from 4 to 18% in the last three decades (3). The incidence of overweight and obesity has plateaued in several high-income countries while simultaneously escalating at a 10-fold rate in lower-income countries across Asia and Africa (4). Overweight and obesity are significant risk factors for developing lifestyle-related chronic diseases such as cardiovascular disease, diabetes mellitus, hypertension, some cancers, muscular-skeletal, and mental health disorders (5).

An unhealthy diet and insufficient physical activity are modifiable risk factors for obesity. Social equity challenges, such as income, education, and food insecurity strongly influence these risk factors (6, 7). An increasing body of evidence demonstrates the relationship between diet and physical activity behaviors in adolescence and the association between obesity and chronic disease development in adulthood (8–11). Yet, globally, there is inconsistent evidence regarding the effectiveness of diet or physical activity interventions or a combination of both to reduce the risk of obesity and its related co-morbidities in adolescents (12–14). Obesity prevention research is further complicated by ethical and psychosocial health concerns such as weight stigmatization, eating disorder risk, low self-esteem, body dissatisfaction, anxiety, and depression (15–18). Emerging research demonstrates how supervised obesity treatment can improve psychosocial health for adolescents; however, there is limited research regarding obesity prevention initiatives (19). Engaging adolescents in the design and development of obesity prevention interventions can address social equity challenges and ethical and psychosocial health concerns (20). It is therefore

crucial that adolescents from all backgrounds are engaged in obesity prevention research (21).

Current evidence syntheses have focused on determining the efficacy and effectiveness of obesity prevention interventions (12, 14); the conclusions are limited mainly to factors related to intervention outcomes (22). This finding suggests little attention has been given to understanding meaningful adolescent participation in the research decision-making process beyond passive engagement as research participants. Currently, no review has focused on understanding adolescents' engagement in the research cycle and relationships to intervention efficacy and effectiveness.

In recent years, there has been a growing call to prioritize the voice of adolescents in societal decision-making (23). Meaningful adolescent participation is a fundamental human right as articulated in the Convention on the Rights of the Child (24). The importance of adolescent participation is further expanded on in the Lansdown-UNICEF framework for adolescent participation (25). The framework acknowledges that meaningful participation involves adolescents articulating their views and being involved in the decision-making process to impact matters of importance to them. Meaningful participation varies in mode and is subject to the evolving capacity of adolescents as they transition from early adolescence through to young adulthood.

Theoretical youth engagement models such as UNICEF's Adolescent and Youth Engagement Strategic Framework (26), Hart's Ladder (27), and Shier's pathway (28), among others, have been developed to guide organizations on the components of effective and ethical consumer or stakeholder engagement. Such models aim to amplify adolescent voices and improve their confidence and feelings of empowerment, which are fundamental to meaningful participation and decision-making in research and ultimately to research translation (25, 26).

Additionally, practical and transparent frameworks allow researchers to monitor meaningful participation where stakeholders and consumers can be involved effectively throughout the research process. Examples of such are the United Kingdom's National Institute for Health Research (NIHR) INVOLVE Public and Patient Involvement Framework (29, 30), and the Australian National Health and Medical Research Council (NHMRC) Consumer Engagement Framework (31), which provide a detailed outline of the stages and strategies necessary to achieve meaningful participation. Such frameworks offer foundational measures for researchers to assess the degree of engagement expected throughout the research cycle.

Despite the increasing call to effectively engage adolescents in society and consumers in research, there is yet to be

Abbreviations: USA, United States of America; UNICEF, United Nations Children's Fund; NIHR, National Institute for Health Research; NHMRC, National Health and Medical Research Council; PAR, Participatory Action Research; PE, Patient Engagement; CBPR, Community Based Participatory Research; PRISMA-ScR, Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews; MeSH, Medical Subject Headings; CINAHL, Cumulative Index of Nursing and Allied Health Literature; CENTRAL, Cochrane Controlled Register of Trials; RCT, Randomized Control Trial; SES, Socioeconomic Status; BMI, Body Mass Index; WHO, World Health Organization; SDGs, Sustainable Development Goals; YAG, Youth Advisory Group; LMICs, Low- and Middle-Income Countries.

meaningful convergence. To date, reviews in the field of participatory research have tended to focus specifically on specific methodological approaches such as Participatory Action Research (PAR) (32, 33), Youth advisory (34), Patient Engagement (PE) (35), or Community Based Participatory Research (CBPR) (36). The demographic of interest also varies significantly between published reviews with researchers specifically investigating children (37) or children grouped with adolescents, youth, or young people and results for such populations analyzed together despite their significantly different needs and abilities (32, 33, 36, 38). Moreover, current evidence syntheses are looking broadly at participatory approaches (32, 33, 36), how they influence social determinants (32), general health and well-being (34, 35, 38), or health policy (39). Currently, comprehensive evidence syntheses are lacking to evaluate the participatory approaches for adolescent consumers in obesity prevention research.

Mental health researchers have recognized that engaging adolescents in meaningful participation is a crucial component of effective research and intervention development (40, 41). Adolescents have unique insight into their own lived experiences and needs; therefore meaningful participation involving adolescent consumers in the decision-making is a potentially vital link to tailor obesity and chronic disease prevention interventions to this demographic. In this scoping review, we aim to address this gap in the literature by broadly assessing how and to what extent adolescents are meaningfully participating in the co-design and decision-making in research studies that target overweight, obesity, physical activity, and dietary interventions specifically for adolescents. Secondly, we aim to provide recommendations on optimal modes of participation in obesity and chronic disease prevention research.

The following research questions guided this scoping review:

- i) Is there evidence of the effectiveness of adolescent participation in peer-reviewed primary research studies?
- ii) What are the components, processes, or conceptual frameworks of effective peer-reviewed primary research studies involving adolescent participation?
- iii) Are there any identified barriers or facilitators, or evidence gaps for adolescent participation?

METHODS

A scoping review was determined to be the most suitable form of evidence synthesis for the research question as it allowed for a broad and thorough examination of the existing literature (42). The scoping review methodology was informed by the Arksey and O'Malley six-stage framework (43), Levac et al.'s (44) recommendations, and the Joanna Briggs Institute (45–47) guidelines for scoping reviews. The review was reported based on the Preferred Reporting Items for Systematic Reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist (see **Supplementary File 1**) (48). As per scoping review guidelines, no quality assessment is required (47, 48). The research questions were formulated, followed by the

identification of criteria for the inclusion of relevant studies. Next, studies were selected based on the pre-defined criteria, and relevant data from the included studies were extracted. Collating, summarizing, and reporting the results followed. The scoping review protocol contains full details of the study methodology and search strategy (49). The protocol is registered with Joanna Briggs Institute and Open Science Framework, doi: 10.17605/OSF.IO/E3S64. A brief description of the methods is provided below.

Key Definitions

The term “adolescent” is defined by the World Health Organization (WHO) as a person aged 10–19 years old, and “youth” as one between the age of 15–24 years old (50). However, within the published peer-reviewed literature, these terms are used synonymously. To broadly examine the literature and in line with the Lancet Child and Adolescent health definition of an adolescent (51), this scoping review assessed published peer-reviewed literature engaging adolescents or youth aged 10–24 years.

Meaningful participation refers to participation in which adolescents have some level of influence over the research and development decision-making. The mode of meaningful participation is dependent on the degree of influence adolescents impart on the research process (**Table 1**). Furthermore, meaningful participation is dependent on the methods and strategies used at various points within the research cycle (31). All modes of participation can be valid and effective if conducted within an enabling environment where participatory outcomes are based on empowerment and the degree of influence is measured and achieved (25).

Search Strategy and Study Selection

Based on key concepts emerging from the research questions, the research team developed a search strategy in consultation with an academic liaison librarian. All qualitative and quantitative peer-reviewed primary research studies published from 1995 to December 2020 were considered for inclusion; reviews were excluded. Peer-reviewed papers of all languages with an abstract in English were considered. Studies involved participants aged 10–24 years involved in obesity or chronic disease prevention, nutrition or physical activity research decision-making. Youth participation was the primary outcome sought hence inclusion of broad search terminologies such as Youth-PAR, CBPR, youth involvement, and youth engagement. Medical subject heading (MeSH) terms were selected accordingly. An example search strategy is presented in **Supplementary Table 1**.

Systematic searches of six scientific databases, Medline (PubMed), Embase, CINAHL, Scopus, Global health, and CENTRAL, were conducted. Publications identified up to the first of December 2020 were considered. Additional sources were identified through hand searching, reference list examination, and citation chaining. Results were pooled and duplicates removed, remaining results were uploaded to the Covidence systematic review software. A two-part study selection process followed, first a title and abstract review by one reviewer (MM) and secondly a full-text review by two reviewers (MM and

TABLE 1 | Working definitions to classify mode and degree of adolescent participation.

Mode of adolescent participation	
Consultative	Adolescents contribute opinions, perspectives, knowledge, and experience
Collaborative	Adolescents are involved as partners in the decision-making process
Adolescent-led	Adolescents identify the issues and control the process and outcomes
Other	Adolescents are involved in an important role, but their opinions are not considered, they play no part in the decision-making and have no influence over the research process or outcomes
Adolescent participation in stages of the research cycle	
Identification of topic	The consumers views, opinions or aspirations are sought. Consumers are involved in the identification and development of the research idea and/or topic
Design and Development	The consumer is engaged in methods selection and development
Conduct	Consumers lead or facilitate research methods and gather data
Analyses	Consumers are involved in consolidating and reporting the findings
Dissemination	Consumers are involved in presenting and/or circulating the findings. Consumers are involved in implementing findings by developing strategies to translate research findings

Definitions adapted from the Lansdown-UNICEF conceptual framework for measuring outcomes of adolescent participation (25) and Australia's National Health and Medical Research Council (NHMRC) framework for effective consumer and community engagement in research (31).

SRP). Any discrepancies were resolved by consensus with a third reviewer (JR).

Data Extraction

Data extraction table variables were iteratively developed to broadly encompass the scope of adolescent participation in the obesity and chronic disease research cycle. Relevant data were extracted and tabulated by one reviewer (MM) (see **Supplementary Table 2**). Key outcomes extracted included social and environmental variables, the degree of adolescent participation in the research cycle, modes of participation, participatory outcomes, and chronic disease-associated outcomes. Corresponding authors were contacted *via* email where necessary data was missing or not reported. A second reviewer (SRP) cross-checked 20% of studies for consistency in data extraction.

Synthesis and Analysis of the Results

Data presented were based on active (meaningful) adolescent participation in the research and decision-making process, where adolescents were engaged as consumers rather than passive study participants. Data were assessed based on key modes of participation (consultative, collaborative and, adolescent-led) and alignment with participatory outcomes from the Lansdown-UNICEF conceptual framework for adolescent participation

(25). After the protocol publication, the NHMRC framework for effective consumer and community engagement in research was selected to contextualize the data within the phases of the research cycle (31). The framework was deemed necessary for data analysis and was the only protocol deviation.

Chronic disease outcomes associated with improved health status or obesity and chronic disease risk factor prevention were established based on emerging categories founded on preliminary searching. Reported chronic disease outcomes were classified into the following categories: (i) increased awareness of family, peers and adolescents; (ii) program or intervention development; (iii) policy change; (iv) environmental change, relating to changes in the physical surroundings in which adolescents live; (v) behavior change specifically changes in diet and physical activity behaviors; and (iv) health status or risk factor change, including but not limited to change in body mass index, weight status, waist circumference, and blood pressure. Qualitative analysis of the data revealed emerging trends and themes. Data were reported by descriptive numerical analysis and in narrative form.

RESULTS

Descriptive Numerical Analysis

The search strategy generated a total of 1,212 results, including an additional 53 papers through hand searching, which were subsequently pooled, and duplicates removed, leaving 902 unique papers (**Figure 1**). The 902 papers were assessed by title and abstract screening for inclusion; 736 were excluded. The full text of the remaining 166 papers were reviewed, and a further 40 papers were excluded and reasons documented. In total, 126 full-text peer-reviewed papers (52–175) describing 71 unique studies were included in the review.

Study Characteristics

The studies identified varied broadly in their target demographic and scope. Various socioeconomic and ecological characteristics were analyzed (**Table 2**).

Study Design

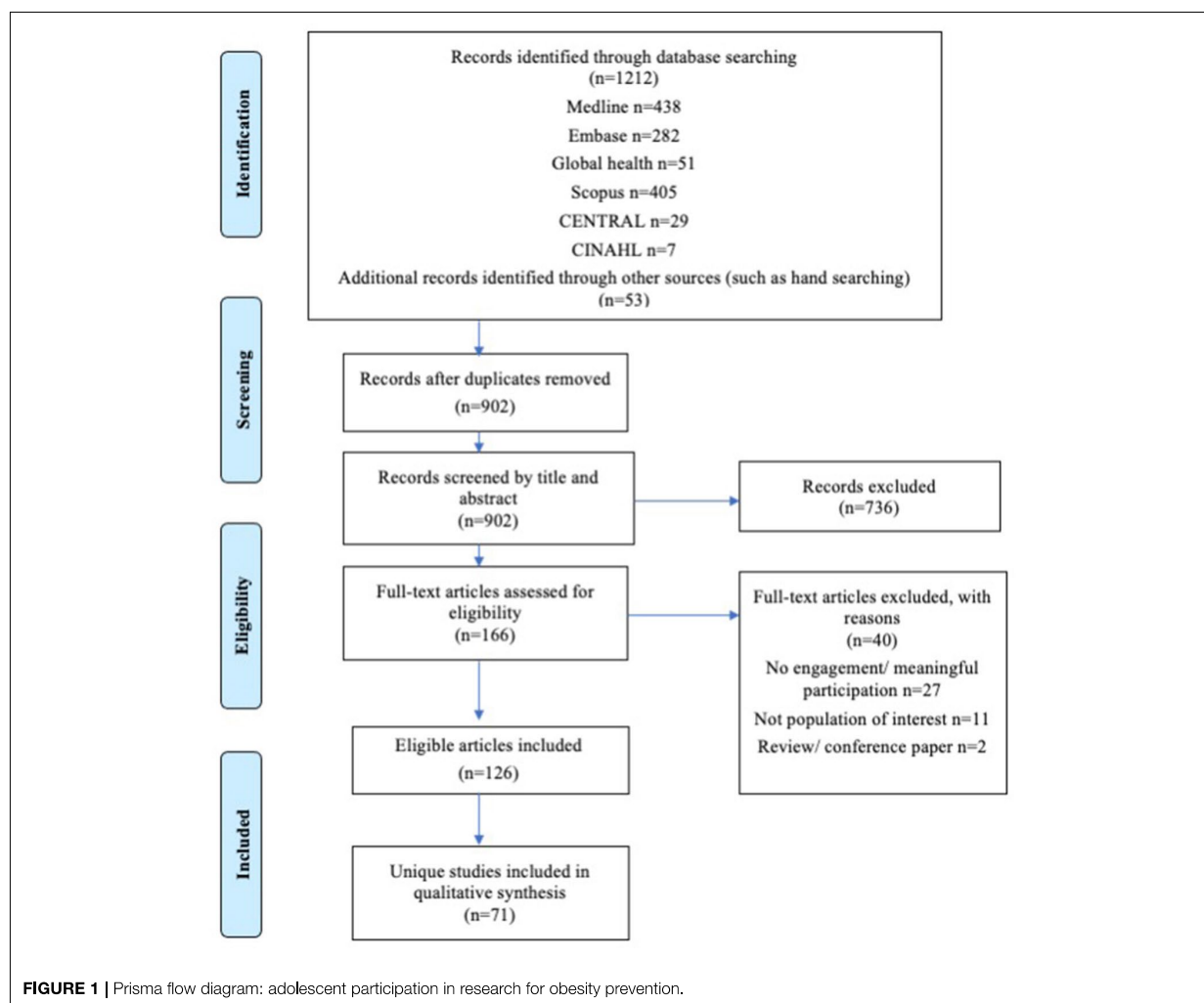
Of the 71 unique studies identified, 65% (46/71) were qualitative, and a further 30% (21/71) employed a mixed-methods approach. Thirteen studies (18%, 13/71) were randomized controlled trials (RCT).

Year of Publication and Study Duration

Publication dates ranged from 2003 to 2020, with >50% ($n = 36$) of studies publishing their first paper between 2015 and 2020. Studies varied in duration from 30-min to 6 years, the mean study duration being 3 months or less in duration (23/71), followed by intervention durations >12 months (12/71).

Country of Origin

Most studies (76%, 54/71) were conducted in North America, with a total of 49 in the USA and five in Canada. Eight studies took place in Europe (Netherlands, United Kingdom, Belgium, Spain, France) and five studies in Australia. Furthermore, two studies were conducted in Asia (Republic of Korea, Vietnam), one



in South America (Peru), and one multi-country (Australia, New Zealand, Fiji, and Tonga) study.

Socioecological Setting

The most common socioecological setting targeted was the local community (54%, 38/71), followed by secondary education institutions (30%, 21/71). Eight studies targeted the adolescent (individual), and one study specifically targeted the family unit. Peer leadership, mentoring, or education were components of 18 studies, with six targeting the local community and 12 targeting secondary education institutions. Similarly, youth or peer advocacy was a component of nine studies, eight of which targeted the local community and one targeting a secondary education institution.

Socioeconomic status (SES) was described in 61/71 studies (86%), of those reporting SES, 52 studies (85%) were conducted in a minority or underserved community, and one study took place in an affluent (high SES) setting.

Study Purpose

Overweight and obesity was the most common chronic disease or chronic disease risk factor targeted in the included studies, with 89% (63/71) of studies reporting this to be the main purpose for the study. The remaining eight studies investigated the prevention of obesity-related co-morbidities such as type 2 diabetes and cardiovascular disease.

Participants

Of the 71 studies, the total number of participants involved in a meaningful participatory method ranged from 5 to 14,000 participants (**Supplementary Table 2**), with a median of 43 participants. Thirty-one studies (46%) had between 11 and 50 participants; three studies did not report the number of adolescent participants. The gender of adolescent participants was not reported in 24% of studies (17/71). In 26 (48%) of the studies which reported gender, gender was evenly distributed. Still, in the studies that remained, males were more likely to be

TABLE 2 | Summary of study characteristics.

	Sub-category of study characteristics	N (%)
Study design <i>n</i> (%)	Mixed methods*	21 (30%)
	Qualitative	46 (65%)
	RCT only	4 (6%)
Publication year** <i>n</i> (%)	2001–2005	2 (3%)
	2006–2009	8 (11%)
	2010–2014	25 (35%)
	2015–2020	36 (51%)
Duration of intervention <i>n</i> (%)	≤3 months	23 (37%)
	>3 to <6 months	2 (3%)
	6 to <12 months	7 (11%)
	12 to <18 months	9 (15%)
	18–24 months	9 (15%)
	>24 months	12 (19%)
	Not reported	9 (13%)
Continent/country <i>n</i> (%)	USA	49 (69%)
	Canada	5 (7%)
	Europe/United Kingdom	8 (11%)
	Other***	9 (13%)
Socio-ecological setting <i>n</i> (%)	Local community <i>n</i> (%)	38 (54%)
	Institution's total (schools, hospitals, courts, workplaces) <i>n</i> (%)	24 (34%)
	Secondary education <i>n</i> (%)	21 (30%)
	Tertiary education	2 (3%)
	Hospital	1 (1%)
	Family	1 (1%)
	Peers**** (alone)	0
	Youth/peer leadership/mentoring or education total	18 (25%)
	Local community	6 (8%)
	Institution (secondary school)	12 (18%)
	Youth/peer advocacy/activism total	9 (13%)
	Local community	8 (11%)
	Institution (secondary school)	1 (1%)
	Adolescent (Individual)	8 (11%)
Main chronic disease or risk factor of interest	Overweight/obesity	63 (89%)
	Type 2 Diabetes	3 (4%)
	Cardiovascular disease	1 (1%)
	Wellness/determinants of health/NCD***** prevention	3 (4%)
	Physical inactivity	1 (1%)
Number of participants <i>n</i> (%)	1–10	6 (9%)
	11–50	31 (46%)
	51–100	11 (16%)
	>100	20 (29%)
	Not reported	3 (4%)
	Total number	39079

(Continued)

TABLE 2 | Continued

	Sub-category of study characteristics	N (%)
Gender	Mean	575
	Median	43
	Range	5–14000
	Majority female (>60%)	24 (44%)
	Majority male (>60%)	4 (7%)
	Mixed (almost equally)	26 (48%)
	All female	6 (11%)
	All male	2 (4%)
Socioeconomic status (SES)/participant representation	Not reported	17 (24%)
	Minority/underserved community/low-income	52 (85%)
	Mixed high and low SES	8 (13%)
	High SES	1 (2%)
	Not reported	10 (14%)

*Nine studies were RCT's with qualitative components.

**Year of publication of the first paper if multiple papers published regarding the same study.

***Five studies in Australia, two in Asia, One in South America and One Multi-country.

****Peer mentoring which took place within an institutional or local community setting was classified under those categories.

*****Non-Communicable Disease (NCD).

under-represented [24 (44%) or not represented at all six (11%), while females were under-represented in four (7%) studies and not represented in a further three (4%)].

Adolescent Participation Degree and Mode of Participation

In 87% (62/71) of studies, adolescents participated in at least one of the two formative phases of the research cycle (identification of the topic or design or development), and in 11% (8/71) of studies, participation took place in all five stages of the research process (Table 3). The mode of participation was almost equally distributed between consultative (49%, 35/71) and collaborative (41%, 29/71) approaches. An adolescent-led mode of participation was identified in six studies (9%).

Participatory Methods

The number and type of participatory methods used by researchers in the included studies significantly varied. Results revealed that a combination of methods was commonly employed in each study. Approaches ranged from one participatory method per study to a maximum of four methods, with a mean of two participatory methods per study. Adolescent-led participatory approaches were more likely to employ a greater number of participatory methods (mean of three methods per study) to achieve their outcomes.

Components of Participatory Methods

Overall, the most common single method used was focus groups in 55% (39/71) of studies, followed by questionnaires and surveys (38%, 27/71) and interviews (38%, 27/71). These were more

TABLE 3 | Adolescent participation, theoretical frameworks used and outcomes of participation in the research cycle.

		N (%)
Adolescent participation in the research cycle <i>n</i> (%)	1. Identification of topic (building relationships or developing research idea)	49 (69%)
	2. Design or development	45 (63%)
	3. Conduct	35 (49%)
	4. Analyses	10 (14%)
	5. Dissemination	28 (39%)
	Participation in at least one of the two formative stages (stages 1 or 2)	62 (87%)
	Participation in all 5 stages	8 (11%)
Mode of participation	Consultative	35 (49%)
	Collaborative	29 (41%)
	Adolescent-led	6 (9%)
	Other*	1 (1%)
Participatory outcomes (PO) measured	Sense of self-worth or self-esteem or efficacy	5 (7%)
	Being taken seriously	2 (3%)
	Making decisions	2 (3%)
	Public civic engagement	0%
	No. of studies which measured at least one PO	5 (7%)
	No. of studies which measured all four PO	1 (1%)
Chronic disease related outcomes (CDO)**	Increased Awareness	49 (69%)
	Program or intervention development	45 (63%)
	Policy change	8 (11%)
	Environmental change	16 (23%)
	Behavior change (diet and physical activity)	18 (25%)
	Health status or risk factors change*** (wt. = 6, BP = 1)	7 (10%)
	No. of studies which reported four or more CDO	10 (16%)
Models, theories or conceptual frameworks <i>n</i> (%)	Participatory****	34/71 (48%)
	Social*****	34/71 (48%)
	Complex models or multiple theories	35/71 (49%)
	Other*****	21/71 (30%)
	Not reported	9/71 (13%)

*Adolescents played a key role as facilitators, however they did not play any part in decision-making or influencing the process.

**These were not always reported or aimed for.

***Six studies reported change in weight, one study reported a change in blood pressure.

****Participatory alone (13), participatory included in multi-theory (21).

*****Social theory alone (5), Socio-ecological theory (7), Socio-cognitive theory (22, 31%).

*****Behavioral (3), Ecological (3), Environmental (1), Psychological (2), Empowerment (7).

commonly employed in consultative studies either alone or combination with other methods. Furthermore, other methods such as photovoice ($n = 10$), needs and community assessments ($n = 5$), discussion groups, and community forums ($n = 3$) were also used in a smaller proportion of studies. These methods have

in common that they elicit views, opinions and uncover the needs of adolescents and their community which is a fundamental element of formative work. Youth advisory groups ($n = 2$) and peer leadership and advocacy activities were a component of 25% of studies (18/71). The studies that used these approaches were typically studies that employed a collaborative ($n = 13$) or adolescent-led ($n = 3$) mode of participation. A social marketing approach was used in six studies (8%), four of which were collaborative, and two were adolescent-led. Additionally, co-design or co-creation activities (sessions) were specified in 7% ($n = 5$) of studies; these were a component of one consultative study and four studies that used a collaborative approach.

Models, Theories, and Conceptual Frameworks

Overall, studies varied significantly in their theoretical basis, with 9 theoretical models and 15 complex models and frameworks reported. **Table 3** presents the most common models, theories and frameworks used. A significant number of studies used multiple theories or models (49%, 35/71). Overall, 48% (34/71) of studies reported a participatory design, of which 74% (25/34) used CBPR principles to guide their project. Moreover, other theories which complement but do not explicitly promote a participatory approach were identified. Thirty-four (48%) studies reported a social component, with social-cognitive theory reported to inform 22/71 (31%) of studies, and socio-ecological theories informed seven studies. Of the multi-theory models employed, which did specifically involve a participatory component, the transtheoretical model of behavior change ($n = 5$) and the PRECEDE-PROCEED model ($n = 4$) were the most reported. Empowerment theory was used in seven studies; however, participatory outcomes which measure empowerment and influence were only measured in five studies. Of the studies labeled participatory, 32% (11/34) involved adolescents in at least four research cycle stages. A collaborative approach was employed in more than half (18/34, 53%) of participatory studies.

Chronic Disease Outcomes

Chronic disease outcomes were largely based on outcomes of obesity prevention research. The most common chronic disease-related outcomes of adolescent participation were “increased awareness among family and peers” (49/71, 69%) and “program or intervention development” (45/71, 63%). It is also important to note that two studies (69, 135) were in progress, and therefore, information on outcomes was not available or incomplete.

Characteristics of Studies Reporting Four or More Chronic Disease Outcomes

Overall, 12 studies (17%, 12/71) reported four or more chronic disease outcomes; these studies tended to be 12 months or longer in duration, and five of these studies (41%) involved adolescents in four or more stages of the research cycle. Nine of the 12 studies (75%) used a mixed-methods interventional design, with seven studies (58%) involving an RCT component and another two (17%) studies using a quasi-experimental design. Of these 12 studies, 11 (92%) employed a collaborative mode of adolescent participation. Moreover, seven studies (58%) were

supported by multiple theoretical frameworks, and six (50%) had a participatory agenda. While 8/12 (67%) studies used youth or peer leadership or advocacy practice, only 33% (4/12) were also described as participatory. In contrast, all seven RCTs involved youth or peer-leadership or advocacy regardless of whether they declared the usage of a participatory model or not. Overall, participatory outcomes were measured in 5/71 (7%) studies but were more likely to be reported in studies with four or more chronic disease outcomes measured 3/12 (25%).

Characteristics of Studies Reporting Three or Fewer Chronic Disease Outcomes

Due to the broad range of study designs and aims, chronic disease outcomes as per the established categories were not within the aim or scope of many of the studies reviewed and, as such, were not reported. This was particularly the case in qualitative studies that employed a consultative participatory mode, usually focus groups, discussion groups, questionnaires, surveys, or interviews. In these instances, the researchers were seeking opinions and preferences. Therefore changes in weight, diet, or physical activity levels were not measured as they would be outside the scope of the study. A total of 91% (29/32) of consultative studies described <3 chronic disease outcomes. Similarly, all six studies (82, 86, 114, 133, 173) that used an adolescent-led participation mode achieved no more than three chronic disease outcomes despite all except one (145) meeting the aims of their respective projects. Furthermore, adolescent-led studies described outcomes related to increased awareness (82, 86, 133, 173), program/intervention development (86, 114, 133, 173), or environmental changes (86, 133) and did not report anthropometric, behavioral changes, or changes in health status associated with obesity and chronic disease development.

Effectiveness of Studies Involving Adolescent Participation in Improving Obesity and Chronic Disease Risk Factors

Differences in the study designs and methodologies of the studies analyzed meant that data reporting differed. Quantitative measures were often not measured/ or sought in many studies included within this review. Still, 22 studies (31%) reported an improvement in one or more obesity risk factors. Data on anthropometric measures as well as behavioral measures such as physical activity and dietary intake were analyzed.

Anthropometric Measures

Eight studies (11%) reported an improvement in one or more anthropometric measures such as BMI (57, 62, 76, 91, 158, 169), weight (161), waist circumference (158), or adiposity (142) albeit not always statistically significant (161, 169). Methodological components which were common between these studies included use of an RCT (57, 62, 76, 91, 142, 169) in 75% (6/8) of studies, a collaborative (62, 76, 91, 158, 161, 169) mode of adolescent participation in 75% (6/8) of studies and inclusion of a peer-component (57, 62, 76, 91, 169) in 63% (5/8) of studies.

Physical Activity and Fitness

Improvements in physical activity and fitness behaviors were reported in 12 studies (54, 93, 96, 101, 105, 126, 142, 149, 161, 164, 165, 169), five of these involved an RCT (101, 142, 164, 165, 169), seven employed a collaborative (54, 93, 96, 105, 161, 165, 169) mode of adolescent participation and seven involved a peer-component (93, 96, 105, 126, 149, 164, 169).

Dietary Behaviors

Encouraging changes in dietary behaviors were reported in 17 studies, as an improvement in dietary intake or nutrition behaviors (61, 91, 96, 101, 105, 112, 126, 149, 161, 164, 165, 169), increased fruit (93) and vegetable consumption (121), reduced caloric intake (99), reduction in sugar sweetened beverage intake (108) or an increase in water consumption (54). Overall studies involving improvements in dietary behaviors had in common that they were more likely to be collaborative (9/17) (54, 91, 93, 96, 105, 108, 161, 165, 169) and involve a peer-component (10/17) (61, 91, 93, 96, 105, 108, 126, 149, 164, 169). Studies which reported an improvement in dietary behaviors were almost evenly of qualitative (7/17) (54, 93, 105, 112, 121, 126, 149) or RCT (6/17) design (91, 101, 108, 164, 165, 169).

Barriers and Facilitators to Adolescent Engagement

Understanding barriers and facilitators to adolescent engagement are essential in improving meaningful adolescent participation in the obesity prevention research cycle. Of the studies analyzed, school, family, and work commitments were the most common barriers suggested. Facilitators to participation included compensation for the time spent participating, peer-support, leaderships opportunities, and adolescent-led participatory methods (such as photovoice and youth advisory groups), which gave the youth a voice and influence. Furthermore, incorporating meaningful participation into supportive and trusted environments such as the local community or school setting was suggested to facilitate engagement.

Overall, barriers and facilitators to adolescent participation when documented were usually reported as general observations rather than concrete data. Barriers and facilitators to participation were seldom an outcome measured in the studies reviewed and is in line with lacking measurements of participatory outcomes in general.

DISCUSSION

This is the first review investigating adolescent participation in the obesity prevention literature to the best of our knowledge. Overall, findings from our review indicate that adolescent participation in research is a complex yet adaptable construct that may be a vital link between obesity prevention research and practice.

Our review detailed the new and emerging field of adolescent participatory research in obesity prevention, with more than 50% of the studies identified having published their first paper in the last 5 years. We found that despite obesity and its associated co-morbidities affecting populations broadly

(176), the use of participatory research methods were not equitably deployed. Of the studies which reported socioeconomic characteristics, we found that 85% targeted minority or underserved communities in mostly affluent western nations. Only four studies took place in middle-income nations, where adolescents represent a greater proportion of the total population (177) and where obesity has surpassed undernutrition as a leading cause of morbidity (4). The lack of participatory research for adolescents in LMICs may be attributable to low resources and challenges in health research allocation and implementation. Funders and the global community often expect LMICs to direct research and funds to the most acute public health challenges (178). Furthermore, our finding suggests adolescent participation in obesity prevention research appears to be gender-biased with studies involving predominantly adolescents identifying as female. Adolescents identifying as male were either not represented at all or underrepresented in 55% of the included studies, while “no representation” or underrepresentation of adolescents identifying as female-only occurred in only 11% of studies. This finding may be explained by sociocultural factors and gender-based ideals, particularly in higher-income countries, with females more likely to be concerned with weight compared to their male counterparts (2). Girls are also more likely to partake in disordered eating behaviors and calls for further public health attention (179).

Our review revealed that over the last decade there has been a gradual increase in the awareness of the need to involve adolescents in the dialogue and decision-making processes to make progress on matters affecting youth, such as the global obesity crisis. This finding is consistent with the WHO-UNICEF-*Lancet* commission report (180), which recommends that youth be placed at the center of Sustainable Development Goals (SDGs). The commission states that “children should be given high-level platforms to share their concerns and ideas and to claim their rights to a healthy future” (180). Insights from our review indicate that meaningful participation not only upholds adolescents’ fundamental right to participation but also allows for the development of interventions that are tailored to the unique needs of this demographic.

Results of our review suggest that meaningful adolescent participation is limited within obesity and chronic disease prevention research. Our results indicate that when adolescents are engaged, they are more likely to be involved in the formative stages of the research cycle in activities such as relationship building, needs assessment, research idea development, and project design (34). Nevertheless, only 11% of the included studies reported meaningful participation in all stages of the research cycle. Further, our review determined that to date, participatory research with young people has been predominantly consultative in nature, using methods such as surveys, focus groups, and interviews to elicit views and opinions. At the same time, an adolescent-led mode of participation was described in only 9% of the 71 studies examined. We found that methods that engage adolescents more meaningfully in research such as YAGs, youth advocacy,

and peer leadership were a common component of the few adolescent-led participatory studies. Furthermore, studies that involved a youth-led component reported improvements in capacity building markers of empowerment and influence, enhanced confidence, and gave adolescents a voice in research that concerns their lives. The use of YAGs exemplifies a novel (181) yet practical and effective strategy to meaningfully engage adolescents in an adolescent-led approach throughout the entirety of the research cycle (114, 130). Similarly, in a recent scoping review investigating the use of YAGs in health research, Sellars et al. determined that YAGs are a valuable yet underutilized method of involving young people in effective research development and translation globally (34). Moreover, Sellars et al. also found an underutilization of YAGs was more apparent in research conducted in low and middle-income countries (LMICs), where socioeconomic and cultural factors such as lack of resources and age discrimination limited the use of such engagement strategies (34). This finding is consistent with the findings of our review, which found few participatory-focused research studies for adolescent obesity prevention in LMICs.

Findings from our review indicate significant variability in the scope of reported outcomes of meaningful adolescent participation. We found that participatory outcomes are rarely evaluated, and chronic disease outcomes are inconsistently reported. Nevertheless, similarly to Larsson et al. (38), our review provided evidence that increasing adolescent involvement in the advisory, co-design, and decision-making processes contributed to more meaningful obesity and chronic disease prevention associated outcomes. Chronic disease outcomes described within the studies analyzed included increased awareness of obesity, its risk factors and prevention, obesity prevention interventions and program development, environmental modifications to promote healthier lifestyle habits, behavioral changes including diet and physical activity, and improvements in anthropometric measures such as BMI and weight. Furthermore, we identified that meaningful participation contributes to the development of research and leadership skills as well participatory outcomes of empowerment and influence (82, 86). Although participatory outcomes were rarely evaluated in the 71 studies included within this review, there were reports of improved outcomes for the participating youth (97) and their peers (57, 62, 96). Additionally, DeBar et al. reported in their multi-center RCT, that meaningful participation alone (regardless of the amount) was the main factor driving a positive effect on outcomes, with peer-leadership and commitment contributing to a significant improvement in dietary behavior outcomes as well as a reduction in BMI compared to controls (76).

Our review revealed that current research is failing to take into consideration the dynamic context in which adolescents live, participate and the associated social, economic, cultural, political and health policy influences (182). Most included studies in our scoping review (87%) involved adolescent participation within a single socio-ecological setting, namely, local communities and secondary education institutions. However, studies that also included a “peer” context component in the form of YAGs, leadership, advocacy, or peer education were found to

be more likely to achieve a wider range of positive chronic disease outcomes. Moreover, findings from our review reinforced that adolescents as individuals live within a complex and intertwined socio-ecological sphere, which often impacts their opportunity for health equity (6, 25). In each context, adolescents experienced barriers and facilitators to their diet and lifestyle choices, and decision-making (183). Engaging adolescents in meaningful obesity prevention research across socio-ecological domains may allow for more efficient identification of risk factors that contribute to global adolescent health inequalities resulting in more dynamic intervention development and implementation (184–186). A study by Livingood et al. provided an exemplar model of how to engage adolescents in meaningful participation in research (114). Youth were engaged in a multi-method adolescent-led approach throughout the entirety of the research cycle. Youth developed and facilitated a youth advisory board and used methods such as photovoice and focus groups to identify needs, concerns and preferences. Youth analyzed and presented their findings, which ultimately led to the development of a digital communication (mHealth) obesity prevention intervention that was tailored to the specific needs of youth. However, although obesity prevention was indicated as an objective of the aforementioned study, chronic disease-related outcomes such as anthropometric measures were not taken and hence it is unclear what impact the development of this youth-led intervention will have on obesity incidence within the community (114).

Limitations

Despite our best efforts, this scoping review has several limitations and challenges to note. Overall, it was recognized that due to the lack of standardized measures and reporting, measuring and documenting participatory and chronic disease outcomes were predominantly subjective in nature. Furthermore, the term “participation” is routinely used to refer to participants taking part in a study and not necessarily participating in a meaningful way as per participatory frameworks (25). This made it difficult to decipher if meaningful participation was a component of the research processes. Additionally, participatory approaches were often included in methodology sections of reported studies and hence were often not components of the outcomes measured.

Furthermore, scoping reviews have innate limitations of importance to consider. By design scoping reviews are broad in scope and aim to map the literature therefore, the included studies were heterogeneous in range of study methodologies and designs. This made direct comparisons between studies challenging. Furthermore, although search terms used were broad and the search strategy was systematic, as with any review, it is possible that some studies were missed. Moreover, studies were limited to those with abstracts published in English; this self-selection limitation may have inadvertently excluded perspectives from non-English speaking countries. Finally, as per the scoping review guidelines, it is not necessary to rate the quality of the data or conduct a critical appraisal of the evidence used in scoping reviews; this may have implications for practice (47).

Recommendations

For research to translate effectively into practice and to address health equity challenges faced by minority and underserved communities, more effort needs to be placed on making participatory research gender-balanced and inclusive. Future research should endeavor to identify why high-risk groups such as males in high and high-middle-income countries are underrepresented in obesity prevention participatory research and work toward facilitating equal representation between genders. Furthermore, future participatory obesity prevention research should aim for a broad representation of young people from different socio-economic backgrounds as well as cultural and social groups. Additionally, funding bodies and researchers should direct attention and resources to the growing adolescent obesity concerns in LMICs, where meaningful adolescent participation in obesity prevention research is remarkably lacking. Also, for participatory research to truly capture the voice and needs of adolescents, it is necessary for researchers to engage young people in an increasingly collaborative or adolescent-led capacity throughout all stages of research and development processes. Researchers should also take into consideration the diverse and dynamic socio-ecological settings in which adolescents and their peers connect. Finally, to adequately measure participatory outcomes and make comparisons between studies we recommend standardized and universal tools to measure participatory outcomes in adolescent obesity-related participatory research.

CONCLUSION

Findings from our review indicate that adolescents globally are not being engaged sufficiently in obesity prevention research decision-making to uphold the recommendations of the WHO-UNICEF-Lancet commission. The limited number of studies identified from this review that engaged adolescents to a greater capacity within the research process highlights a key opportunity for enhancing obesity prevention research and practice. Meaningful engagement of adolescents in an inclusive and fair manner builds their capacity to contribute throughout the obesity prevention research process. Addressing the unique needs of adolescents requires adolescents to be afforded increased opportunities to collaborate and lead stages of the decision-making, research and translation process.

AUTHOR CONTRIBUTIONS

MM, SM, HC, PP, JR, and SP: conceptualization, methodology, investigation, and writing—review and editing. MM: writing—original draft preparation. JR and SP: supervision. All authors have read and agreed to the published version of the manuscript.

FUNDING

This research was supported by a National Health and Medical Research Council/National Heart Foundation Early

Career Fellowship (Grant Number APP1157438) awarded to SP. While JR was funded by a National Health and Medical Research Council Career Development Fellowship (Grant Number APP1143538).

ACKNOWLEDGMENTS

This research was conducted as part of MM's PhD project and supervised by SP and JR. The authors wish to thank the academic liaison librarians at the University of Sydney, Tess

Aiken and Kanchana Ekanayake for their support developing the search strategy.

SUPPLEMENTARY MATERIAL

The Supplementary Material for this article can be found online at: <https://www.frontiersin.org/articles/10.3389/fpubh.2021.789535/full#supplementary-material>

Supplementary File 1 | Prisma Scoping Review Checklist.

Supplementary Table 1 | Medline Search Strategy.

Supplementary Table 2 | Data extraction table of included studies.

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CHAPTER FOUR: SCOPING REVIEW OF THE POLICY AND GUIDELINE LITERATURE

Chapter 1 Thesis Introduction

Chapter 2 Scoping review Protocol

Chapter 3 Systematic scoping review of the peer-reviewed literature

Aim 1: Evaluate the extent to which adolescents are meaningfully participating in the co-design and decision-making in research studies that target overweight, obesity, physical activity, and dietary interventions specifically for adolescents.

Chapter 4 Scoping review of the policy and guideline literature

Aim 2: Synthesize current chronic disease prevention policies and guidelines targeted at adolescents to investigate the frequency, mode, and nature of adolescent participation in policies or guidelines developed for chronic disease risk factor reduction specifically, physical activity, diet, overweight, or obesity.

Chapter 5 The Youth Engagement Study (YES)

Aim 3: Understand adolescents' current knowledge and participatory experience in obesity and chronic disease prevention research and intervention development and determine the most optimal modes of adolescent participation in obesity and chronic disease prevention research, policy, and guideline development.



Chapter 6 Evaluation study: the HAPYUS youth advisory group

Aim 4: Evaluate a Youth Advisory Group (YAG) to understand the effect of participation on adolescents' leadership skills and perceptions related to research and chronic disease prevention, assess the process of establishing and accommodating a 12-month YAG focused on chronic disease prevention research, and identify barriers and enablers to establishment and facilitation.



Chapter 7 Thesis Discussion, recommendations, and conclusions

Schematic Representation of Thesis Outline

Preface to Chapter Four

Chapter three presented findings from a systematic scoping review of peer-reviewed literature examining adolescent participation in obesity and chronic disease prevention research. This review found meaningful adolescent participation in the obesity and chronic disease prevention research cycle was limited. Chapter four presents the results of a scoping review investigating adolescent participation in obesity and chronic disease prevention policy and guideline development. Overall, this scoping review addressed aim two of this thesis and established a paucity of adolescent engagement in obesity and chronic disease prevention policy and guideline development. Overall, adolescent participation was consultative in nature and seldom extended across the policy and guideline development and implementation process.

This scoping review has been peer-reviewed (submitted 24th August 2022, resubmitted with corrections according to reviewer comments 15th February 2023, accepted for publication on 5th March 2023) and published on 27th March 2023 in *Global Health Research and Policy* Journal, which forms this chapter. Author's contributions to this paper are outlined in the authorship attribution statement. Chapter four has been disseminated as follows:

Published peer reviewed manuscript

Mandoh, M., Redfern, J., Mahrshahi, S., Cheng HL., Phongsavan P., and Partridge SR. How are adolescents engaged in obesity and chronic disease prevention policy and guideline development? A scoping review. *Global health research and policy*. 2023; 8:9. This work is licensed under a Creative Commons Attribution 4.0 International License (CC BY 4.0) <http://creativecommons.org/licenses/by/4.0/>

Authorship attribution statement: This statement is to stipulate that contribution made by Mariam Mandoh in the preparation and submission of the following manuscript “How are adolescents engaged in obesity and chronic disease prevention policy and guideline development? A scoping review.” The convention is that the author with the principal contribution to the manuscript is the first author.

Mariam Mandoh during her PhD candidature developed the original concept of the scoping review, Mariam Mandoh was responsible for performing the literature search, policy and guideline inclusion and exclusion, data extraction, drafting the manuscript and leading submission for publication of the original research paper.

The individual roles of co-authors are listed below:

Task	Role of co-author
Conceptualization	MM, SM, HC, PP, JR, SRP
Methodology	MM, SM, HC, PP, JR, SRP
Investigation	MM, SM, HC, PP, JR, SRP
Writing- original draft preparation	MM
Writing- review and editing	MM, SM, HC, PP, JR, SRP
Supervision	JR, SRP
Management of manuscript submission	MM

Mariam Mandoh

Date: 05.12.2023

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement is correct.

Dr Stephanie R Partridge

Date: 05.12.2023

REVIEW

Open Access



How are adolescents engaged in obesity and chronic disease prevention policy and guideline development? A scoping review

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Abstract

Background Adolescent consumer engagement is widely accepted, with global calls to meaningfully involve adolescents for effective and tailored policy and guideline development. However, it is still unclear if and how adolescents are engaged. The aim of this review was to determine if and how adolescents meaningfully participate in policy and guideline development for obesity and chronic disease prevention.

Methods A scoping review was conducted guided by the Arksey and O'Malley six stage framework. Official government websites for Australia, Canada, United Kingdom, and United States including intergovernmental organizations (World Health Organisation and United Nations) were examined. Universal databases Tripdatabase and Google advanced search were also searched. Current and published international and national obesity or chronic disease prevention policies, guidelines, strategies, or frameworks that engaged adolescents aged 10–24 years in meaningful decision-making during the development process were included. The Lansdown-UNICEF conceptual framework was used to define mode of participation.

Results Nine policies and guidelines (n = 5 national, n = 4 international) engaged adolescents in a meaningful capacity, all focused on improving 'health and well-being'. Demographic characteristics were poorly reported, still most ensured representation from disadvantaged groups. Adolescents were primarily engaged in consultative modes (n = 6), via focus groups and consultation exercises. Predominantly in formative phases e.g., scoping the topic or identifying needs (n = 8) and to a lesser extent in the final stage of policy and guideline development e.g., implementation or dissemination (n = 4). No policy or guideline engaged adolescents in all stages of the policy and guideline development process.

Conclusion Overall, adolescent engagement in obesity and chronic disease prevention policy and guideline development is consultative and rarely extends throughout the entire development and implementation process.

Keywords Adolescent, Youth, Engagement, Decision-making, Participation, Obesity, Chronic disease, Prevention, Policy, Guideline

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Background

New and evolving diet and physical activity risk factors such as COVID-19 lockdowns [1], changing food environments and digitalisation and virtual entertainment have made adolescents (10–24 years) more susceptible to obesity and its chronic disease co-morbidities [2–4] compared to previous generations. Increasing evidence is emerging to support consumer engagement in health policy and guideline development to optimise public health solutions for those who they intend to benefit [5]. Consumer engagement is now recognised as a vital component in the development of relevant, effective and evidence informed strategies to tackle public health issues [6, 7].

The importance of engaging adolescents is widely documented, the United Nations (UN) has placed adolescents at the centre of Sustainable Development Goals (SDGs), recognising the importance of engaging young people in decision-making that affects their life and their health [8]. A number of UN and World Health Organisation (WHO) guidelines and guidance documents [9–12] acknowledge the value of and advocate for the inclusion of adolescents in decision-making, design and delivery of interventions. Adolescent participation in chronic disease prevention decision making, affirms not only adolescents potential to improve public health interventions but also the fundamental role adolescents play in social systems, economic growth, and technological development [13, 14].

Similarly, national health strategies have accepted the importance of engaging consumers in obesity and chronic disease prevention policy design and implementation [15, 16]. The United Kingdom's (UK) National Institute for Health Care Excellence (NICE) guidance [17] and Australian National Health and Medical Research Council (NHMRC) [7] have imbedded consumer engagement within the policy and recommendation development process. Though, not specific to adolescents, the emphasis on engaging relevant consumers from broad walks of life is linked to the development of evidence-based recommendations such as the Australian Dietary Guidelines [18]. Nevertheless, it is still unclear how and to what extent adolescents are engaged in obesity and chronic disease prevention policy and guideline development. The aim of this review is to 1) investigate the frequency of chronic disease prevention policies and guidelines that incorporate adolescent engagement and, 2) to assess the mode and nature of adolescent participation in policies or guidelines developed for chronic disease risk factor reduction, specifically, physical activity, diet, overweight, or obesity.

Methods

Study design

The Arksey and O'Malley six-stage framework [19] and Levac et al.'s [20] recommendations were used to guide this review to ensure the vast body of grey literature was thoroughly and iteratively mapped. The review is described based on the Preferred Reporting Items for Systematic reviews and Meta-analysis extension for Scoping Reviews (PRISMA-ScR) checklist (Additional file 1) [21]. The protocol is registered with the Joanna Briggs Institute and Open Science Framework, doi:19.17605/OSF.IO/E3S64, and is published elsewhere [22].

Eligibility criteria

This review sought to uncover the extent of adolescent participation in policies and guidelines aimed at preventing obesity and chronic lifestyle diseases in adolescents. The review was not intended to provide an assessment of quality of the individual policies or guidelines. The inclusion criteria were defined based on the PCC (Population, Concept, Context) framework as recommended by the Joanna Briggs Institute [23].

Population

Adolescents aged 10 to 24 years old [24]. This age range was selected to encompass the range of definitions present within the scientific literature. WHO defines an 'adolescent' as a person between the age of 10–19 years, 'youth' as 15–24 years old, and 'young people' as individuals between 10 and 24 years [25]. The overlap between age groups has led to the loose and interchangeable use of these terms in the obesity and chronic disease prevention literature. To ensure adequate coverage of adolescent participation in policy and guideline development landscape the study team classified an adolescent as one within age range of 10–24 years old.

Concept

The concept under investigation is adolescent participation. Participation was defined based on the Lansdown-UNICEF conceptual framework for measuring outcomes of adolescent participation. A preliminary search determined that the concept of '**participation**', is often used synonymously with 'engagement' and 'decision-making' to represent adolescents individually or collectively taking part or involved in influencing activities or matters that impact their life [26].

Context

Grey literature was examined in the context of obesity and non-communicable disease prevention. Policies

and guidelines related to all aspects of nutrition, diet, healthy eating, and physical activity were extracted and assessed. Policies and guidelines were limited to countries of similar demographic and health ethos and included Australia, Canada, the United Kingdom, and the United States. Policy and guideline documents from the UN and WHO were also examined to better understand the international obesity and chronic disease prevention policy and guideline context. Policy and guideline documents of all languages with a summary published in English were considered for inclusion. Furthermore, our review encompassed policy and guideline documents published from the year 1995–2021. Documents published within this year range, and which were current were included for review as these were determined to be the most relevant in understanding and guiding current practice.

Source of evidence

A preliminary search determined the most relevant grey literature sources for the purpose of this review. It was decided that policy, guideline, strategy, and framework documents would be included in the review as they play a significant role in the context of national public health agendas. Definitions are outlined in Table 1. In this review we will refer to policy, guideline, strategy, and framework documents collectively as ‘policy and guideline documents’.

The phrase ‘policy and guideline documents’ encompasses the breadth of significance of policy, guideline, strategy, and framework documents with the common goal to influence and form the foundation for national public health agendas and best practice in health delivery [31].

Policies and guidelines that specifically target adolescents and those intended for the general population were considered for inclusion. Policies and guidelines in which all participants were aged at either extreme of the adolescent age bracket ‘10–12’ years or ‘20–24’ years were excluded. The rationale for this decision was based on the awareness that pre-teens (10–12 years) and young adults (20–24 years) differ significantly in their lived experience, as well as biological and psychosocial development and

Table 2 Information sources

Country/international organization	Grey literature sources
Australia	National Health and Medical Research Council [33] Department of Health and Aged Care [34]
Canada	Health Canada [35]
The United Kingdom (UK)	National Institute for Health and Care Excellence [36]
The United States (US)	Agency for Healthcare Research and Quality [37]
International organizations	United Nations (UN) [38] United Nations Children's Fund (UNICEF) [39] World Health Organization (WHO) [40]
All (Aust, Canada, UK, US, UN, WHO)	Google Advanced search [41] Tripdatabase.com [42]

therefore participation for each of these groups would have a different meaning [32]. A representative sample of adolescents would ideally comprise adolescents of varied ages.

Information sources

National and international grey literature information sources were investigated between January 2021 and February 2022, inclusive. National websites of policy and guideline databases, as well as official organization websites of the UN and WHO were examined (Table 2). Next, a grey literature register (TRIP database) and a custom search engine (Google advanced search) were examined for additional policy and guideline documents associated with the countries and international organizations of interest.

Search

Search terms reflecting the PCC concepts and source of evidence were developed by the research team in consultation with an academic liaison librarian. Terms included ‘policy’, ‘framework’, ‘adolescent’, ‘youth’, ‘teenager’, ‘young people’, ‘nutrition’, ‘health’, ‘physical activity’, ‘obesity’, ‘prevention’, ‘decision-making’, ‘participation’ and ‘engagement’. Phrases identified encompassed ‘chronic disease prevention’, ‘obesity prevention’, ‘obesity prevention in youth’, ‘obesity prevention framework’, ‘overweight and adolescence’, ‘physical activity guidelines’, ‘diet and young people’, ‘youth health’, ‘adolescent nutrition’, ‘nutrition guidelines’, ‘nutrition policy’ and ‘youth health policy’. Terms and phrases were searched across country and organization specific sites. It was agreed that searches would be limited to the first five pages, or first 50 records of results as they would comprise the most relevant

Table 1 Definitions

Term	Definition
Policy	A high-level course or method of action to guide and determine present and future decisions [27]
Guideline	An indication or outline of policy or conduct [28]
Strategy	A careful plan or method [29]
Framework	A basic conceptional structure of ideas [30]

records. The search strategy varied slightly between websites depending on the search function capabilities. Advanced search options were used when available. Where only the basic search function was present, key words and phrases were searched followed by a thorough hand search of the site.

Selection of sources of evidence

Initial screening of title and summary or table of contents by reviewer one (MM) was undertaken to determine relevance of the document. Duplicates were removed and review of the full text of the remaining documents followed. Full-text screening was undertaken by reviewer one (MM) and checked by reviewer two (SRP) for agreement (Fig. 1).

Data charting, data items and synthesis

As per scoping review guidelines a data extraction form was developed in Excel and piloted by the research team to ensure the necessary data were obtained [23]. Data extraction was conducted by one reviewer (MM) and checked by another reviewer (SRP) for confirmation and agreement. Data charting categories were developed to reflect characteristics of sources of evidence, demographic data, purpose of adolescent engagement, main chronic disease or risk factors of interest and the mode and nature of adolescent participation in the policy development process.

Mode of adolescent participation

The Lansdown-UNICEF conceptual framework for measuring outcomes of adolescent participation [26] informed data charting categories representing the mode of adolescent participation. The mode of participation was defined based on the degree of influence adolescents imparted on the policy and guideline development process. ‘Consultative’ participation, involves adults leading and managing, while adolescents are given the opportunity to express their views. ‘Collaborative’ participation typifies a partnership between the adults and the adolescents, with adolescents having more influence over the process and the outcomes. ‘Adolescent-led’ participation represents the highest degree of influence, where adults act as facilitators, while adolescents have full control over the process and the outcomes.

Nature of adolescent engagement

The Australian NHMRC consumer involvement guidelines [7] informed data categories representing the nature of adolescent engagement in the policy and guideline development process. The phases of adolescent engagement were defined as ‘Stage 1. ‘Scoping the topic and Identifying needs’ to ensure policies are relevant to the

consumer. ‘Stage 2. Planning’, to ensure outcomes of most importance are addressed. ‘Stage 3. Conducting an evidence review’, to incorporate existing evidence into the process. ‘Stage 4. Reviewing draft recommendations’, to ensure policies are practical and suitable for the target consumer group. ‘Stage 5. Resource development’, to ensure that associated resources are suitable for the target group and, ‘Stage 6. Implementation/ dissemination’, to enable adolescent consumers to use their experience and knowledge to guide the policy implementation and dissemination process.

Participatory outcomes were assessed based on the Lansdown-UNICEF conceptual framework [26]. Data charting categories reflected participatory markers of empowerment and influence including, ‘sense of self-worth/ self-esteem/ efficacy’, ‘being taken seriously’, ‘making decisions’ and ‘public/civic engagement’. Obesity and chronic disease outcomes were not charted as these data were not available in the policy and guideline literature. Qualitative data were collected in the data extraction form by reviewer one (MM) and checked by reviewer two (SRP) for consistency.

Results

A total of five national government department websites [33–37], three international sites [38–40] and two universal databases [41, 42] were searched. Overall, 1402 records were screened by title and summary (Fig. 1). Next, 59 full-text policy and guideline documents were screened for eligibility. Of the full-text documents reviewed, 50 documents were excluded with reasons (Fig. 1) and nine policy and guideline documents met all inclusion criteria and were examined within this review.

Characteristics of sources of evidence

Table 3 summarises the characteristics of each policy and guideline document. The nine grey literature documents included comprised of three guidelines [11, 43, 44], two strategies [16, 45], three frameworks [46–48], and one policy [49]. All policy and guideline documents were published from 2015 onwards, with two published in 2021. Overall, four documents were under international jurisdiction, published by the WHO alone or in partnership with UN agencies with the aim to influence policy and intervention development of national policymakers. Two WHO policy documents were linked, one was a global health strategy [10] and the other its implementation guidance specifically targeting an adolescent audience [11]. Five policy documents were published under national jurisdiction, two Australian [43, 46], two Canadian [16, 49] and one British [47].

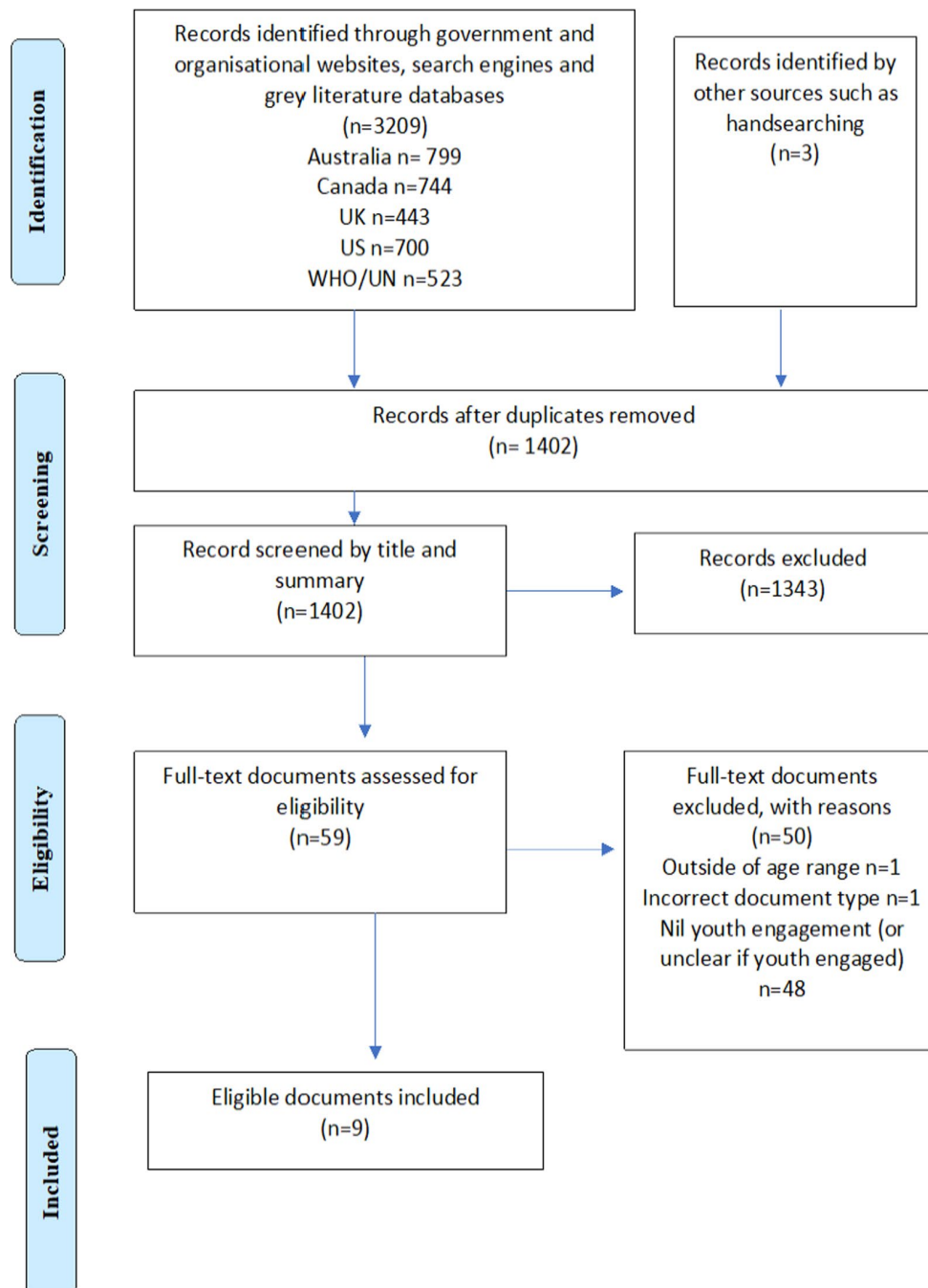


Fig. 1 Prisma flow diagram: adolescent engagement in policy and guideline development for obesity and chronic disease prevention

Demographics

Demographic characteristics of adolescent participants were ambiguously reported in all nine policy and guideline documents examined. Gender of participating adolescents was the most overlooked characteristic and was not reported in any of the documents reviewed. Age range was reported in six of the nine policy and guideline

documents, with wide variations in age stratification of adolescent participants across the documents [16, 43, 46–49]. Age groups included '<16 years', '<17 years', '9–16 years', '10–24 years', '15–24 years', '17–20 years', '17–24 years', '13–29 years' and '21–24 years' (the older age group was only included if the policy or guideline

Table 3 Adolescent participation in policy and guideline development data extraction

References	Document name	Document type/policy format	Country/organisation	Jurisdiction	Demographics (adolescent)	Purpose of engaging adolescents	Duration of participatory activities conducted	Adolescent engagement description	Main chronic disease or risk factors of interest
Public Health England [47]	Improving young people's health and wellbeing: A framework for public health	Framework	Public health England	National	N = 51 (10–24 years)—survey NR for discussions Mixed group, included vulnerable adolescents	To include adolescent voices/opinions into policy and program development	NR	Surveys and twitter discussion hours'	Health and wellbeing
WHO [10]	Global Strategy for women's children's and adolescent's health (2016–2030)	Strategy	WHO	International	NR	Variety of views/stakeholder representation	12 months	Face-to-face consultations, via conferences, surveys	Health and wellbeing
Health Canada [16]	Health Canada's Healthy Eating strategy	Strategy	Canada, Health Canada	National	N = 97 (17–24 years) N = 2 (< 17 years) General members of the public	Variety of views/stakeholder representation	2 years	Online consultation workbook	Health and wellbeing- healthy eating
WHO [11]	Global Accelerated Action for the Health of Adolescents (AA-HAI): guidance to support country implementation	Guideline	WHO	International	NR Young and vulnerable adolescents included	"Nothing for them without them", "To put young people in the driver's seat"	NR	Consultation workshops Helped develop adolescent friendly version of guidance	Health and wellbeing
Government of Canada [49]	Canada's Youth Policy	Policy	Canadian government	National	Online have your day booklet participants Total N = 4804 N = 1690 (< 16 years old) N = 1512 (17–20 years old) N = 1601 (21–24 years old)	To give adolescents a voice in the decision making	NR	Online 'have your say' booklet Online discussion forum Video comment submissions Youth roundtables face-to-face (discussions)	Physical and mental health

Table 3 (continued)

References	Document name	Document type/policy format	Country/organisation	Jurisdiction	Demographics (adolescent)	Purpose of engaging adolescents	Duration of participatory activities conducted	Adolescent engagement description	Main chronic disease or risk factors of interest
Commonwealth Department of Health [43]	Australian 24-h movement guidelines for children (5–12 years) and young people (13–17 years): an integration of physical activity, sedentary behaviour, and sleep	Guideline	Australia, Department of Health	National	N = 10 (9–16 years) Include indigenous adolescents & mixed backgrounds	To ensure adolescents will be able to use the resource	NR	Reviewed draft resource, interviews, focus groups, dissemination strategies discussion	Health and wellbeing
Ross et al. [48]	Adolescents Well-being framework	Framework	UN H6+	International	Online consultations N = > 340 (13–29 years) Other activities NR Mixed group, included indigenous and vulnerable adolescents	To include adolescent voices/ opinions into policy and program development	NR	Consultations Involvement in planning of the global summit for adolescent wellbeing 2023	Health and wellbeing
UNESCO [44]	Making every school a health-promoting school: Implementation guidance	Guideline	WHO/ UNESCO	International	NR	To ensure adolescents will be able to use the resource	NR	Consultations	Health and wellbeing
Department of education, skills and employment [46]	Australia's Youth Policy framework	Framework	Australian government	National	15–24 years Focus on marginalised adolescents	To include adolescent voices/ opinions into policy and program development	> 2 months	Consultation exercises Surveys	Health and wellbeing

NR not reported; Y yes

development process also included younger adolescent age groups).

The number of participants reported varied significantly between policy and guideline documents. The lowest number of participants was ten [43] and the highest number was 4804 [49]. Overall, international documents reported on demographic characteristics of participating adolescents the least [10, 11, 44, 48]. All four international documents failed to report any details on age or number of participating adolescents. Five of the nine documents reported an intentional focus on including first nations, vulnerable, or marginalised adolescents [11, 43, 46–48].

The purpose of engaging adolescents

The reasons for engaging adolescents in the policy and guideline development process varied broadly between policy and guideline documents (Table 3). Two guidelines engaged adolescents to ensure that these resources could practically be utilised by adolescents themselves [43, 44]. Four documents sought to ensure that adolescent voices and concerns were addressed and incorporated into future program and intervention development [46–49]. Engagement motives also included incorporating a variety of stakeholder views and representation [16, 45] or to give adolescents more control over the decision-making process and “to put young people in the driver’s seat” [11].

Main chronic disease or risk factors of interest

Improving health and wellbeing was the main focus of all nine of the policy and guideline documents examined (Table 3), though ‘Canada’s Health Policy’ also included mental health within its scope [49]. The documents under examination varied in their approach to improving health and wellbeing. Two policy and guideline documents targeted specific chronic disease risk factors, either through promoting physical activity [43] or improving eating habits [16], while others had a more broad focus and endeavoured to take into consideration all facets of adolescent health and determinants of health for young people [10, 11, 44, 46–49].

Participation

Mode and nature of adolescent participation

The mode in which adolescents participated in the policy and guideline development process was relatively consistent across nine policy and guideline documents reviewed (Table 4). Six of the nine policy and guideline documents involved adolescents in a consultative capacity, while one implementation guidance [11], one policy [49] and

one framework [48], engaged adolescents in a collaborative mode. Collaborative participation was intended by policymakers to give adolescents more power over the decision-making process, still this only correlated to involvement in 30% [11, 49] or 50% [48] of stages of the policy and guideline development process.

Overall, all nine policy and guideline documents involved adolescent consumers in at least one of the six stages of the policy and guideline development process. Five documents involved adolescents in more than one stage, with three policy and guideline documents engaging youth in two stages and two engaging youth in three stages [46, 48]. The majority (8/9) of policy and guideline developers engaged adolescents in stage 1 of the policy and guideline development process ‘scoping the topic and identifying needs’. Two policy and guideline developers engaged young people in the ‘planning’ stage although this was within a consultative capacity [46] [48]. Another engaged youth in ‘reviewing draft recommendations’ [43] to ensure useability by adolescents themselves. In the development of an additional guideline adolescent consumers were engaged in ‘resource development’ assisting in the development of an adolescent friendly version of the guidance. Four policy and guideline documents reported young people informed ‘implementation or dissemination’ strategies such as providing recommendations for action [43, 46, 49] and involvement in the planning of a global conference to advocate for framework implementation [48].

Participatory methods

All nine policy documents included within this review utilised consultation, discussion or focus group exercises to engage adolescents in the decision-making process (Table 3). Still, consultation exercises varied in approach, four policy and guideline developers employed online/digital platforms [16, 47–49], one specifically reported consulting with young people face-to-face [10, 49] and four did not specify consultation approach [11, 43, 44, 46]. Additionally, surveys were used in the development of three policy and guideline documents [10, 46, 47], conference meetings in one global strategy [10], video comment submissions in another [49] and interviews in one national guideline [43]. With a maximum of four participatory methods used in the development of a policy or guideline.

Participatory outcomes

All nine policy and guideline documents reviewed indicated engaging adolescents as a priority. However, participatory guiding principles such as participatory action research strategies were only recommended in one

Table 4 Mode and nature of adolescent participation in policy and guideline development

References	Document name	Mode of adolescent participation (Lansdown-UNICEF conceptual framework)	Nature of adolescent engagement in the policy/guideline development process (Australian NHMRC consumer involvement guidelines)						Participatory outcomes (Lansdown-UNICEF conceptual framework)		
			1. Scoping the topic/ identifying needs	2. Planning	3. Conducting evidence review	4. Reviewing recommendations	5. Resource development	6. Implementation/ dissemination	Sense of esteem/efficacy	Being taken seriously	Public/ civic engagement
Public Health Improvement England [47]	Improving young people's health and wellbeing: A framework for public health	Y	Y						NR	NR	NR
WHO [10]	Global Strategy for women's children's and adolescent's health (2016–2030)	Y	Y						NR	NR	NR
Health Canada [16]	Canada's Healthy Eating strategy	Y	Y						NR	NR	NR
WHO [11]	Global Accelerated Action for the Health of Adolescents (AA-HAI): guidance to support country implementation	Y	Y				Y		NR	NR	NR
Government of Canada [49]	Canada's Youth Policy	Y	Y					Y	NR*	NR*	NR*

Table 4 (continued)

References	Document name	Mode of adolescent participation (Lansdown-UNICEF conceptual framework)	Nature of adolescent engagement in the policy/guideline development process (Australian NHMRC consumer involvement guidelines)						Participatory outcomes (Lansdown-UNICEF conceptual framework)		
			1. Scoping the topic/identifying needs	2. Planning	3. Conducting evidence review	4. Reviewing recommendations	5. Resource development	6. Implementation dissemination	Sense of esteem/efficacy	Being taken seriously	Public/ civic engagement
Commonwealth Department of Health [43]	Australian 24-h movement guidelines for children (5–12 years) and young people (13 to 17 years): an integration of physical activity, sedentary behaviour, and sleep	Y				Y		Y	NR	NR	NR
Ross et al. [48]	Adolescent Well-being framework	Y	Y	Y				Y	NR*	NR*	NR*
UNESCO [44]	Making every school a health-promoting school: Implementation guidance	Y	Y						NR	NR	NR
Department of Education, Youth Policy Skills and Employment [46]	Australia's Youth Policy framework	Y	Y					Y	NR	NR	NR

NR not reported; Y yes

*Participatory outcomes were not measured or reported; however, participants were asked about the importance of these outcomes, and these were discussed during the participatory exercises

document [44]. Furthermore, participatory outcomes were not measured or reported in any of the policy and guideline documents reviewed (Table 4); therefore, participatory outcomes could not be examined in this review. Nevertheless, one policy document acknowledged the importance of participatory outcomes by asking adolescent participants about their opinions on participatory outcomes such as civic engagement [49].

Discussion

In this review we examined the emerging concept of adolescent participation in the development of national and international obesity and chronic disease prevention agendas. All the policies and guidelines included within this review were published in the last seven years, with health and well-being the core focus. International and national public health agendas emphasise the significance of adolescent consumer engagement on matters relevant to adolescents [8, 16, 50, 51]. This message is reiterated by policymakers and funding bodies as a recommendation for best practice and critical to the attainment of sustainable development goal targets [7, 11, 52]. Our review revealed that current recommendations for adolescent consumer engagement are rarely reflected in the obesity and chronic disease prevention policy and guideline development process. Yet, our review also indicates that international organisations are more committed to engaging adolescents compared to national governments, though outcomes of such efforts are yet to be seen [53].

It is apparent that policies and guidelines that currently involve some forms of adolescent engagement have focussed mainly on general health and wellbeing rather than specific health risk factors like obesity. For example, Australia and Canada's national youth policies were developed in consultation with adolescents and exemplify a whole of systems approach to adolescent engagement [46, 49]. While a general health and wellbeing focus is important in recognising the multitude of biopsychosocial determinants of chronic disease [54] ensuring adequate adolescent engagement for obesity policies is equally important in order to generate effective solutions for this pressing public health issue [8]. Nevertheless, only nine policy and guideline documents met inclusion criteria for this review, indicating that the application of youth engagement in policy and guideline development for chronic disease prevention is infrequent and is still an objective and unregulated practice.

Overall, this review revealed systematic inconsistencies in the reporting of demographic characteristics as well as reporting on the nature of adolescent involvement in obesity and chronic disease prevention policy and guideline development. This meant that several policies, and guidelines could not be included in this review.

Inconsistent reporting creates challenges for establishing the incidence and manifestation of adolescent engagement in obesity and chronic disease prevention policy and guideline development [9, 17]. Incomplete reporting of adolescent engagement data in different data domains was reflected in the UN Youth 2030 strategy [9]. The UN Youth 2030 strategy was developed to enhance efforts to achieve the SDGs by meaningfully engaging youth in the implementation of the strategy. Youth are engaged to varying degrees in the national and international implementation of components of the strategy, albeit incomplete data on 'youth' participants, it is unclear which SDGs were targeted and whether youth engagement played any part in SDGs related to improving health and reducing the burden of chronic disease [55, 56]. Furthermore, the UK's NICE guidelines for obesity and chronic disease prevention [17, 57] and Australia's Preventative Health Strategy [15] recognise the importance of engaging consumers in the policy and guideline development process. However, these documents make reference to consultation with 'people using the health and care services', 'people from communities affected by the guideline' [58] or 'consumer or community engagement' [15] without providing context or detail of their ages. Conversely, Australia's National Obesity Strategy 2022–2032 explicitly engaged 'young people' in 'targeted engagement'. Although their consultation with 21–26-year olds was not representative and does not truly address the needs of the general adolescent population [59]. Poor data reporting, low participant numbers [43, 59, 60] and inclusion of only 'young adult' youth [59] deny adolescents equitable representation on matters that are important to them.

Unclear reporting of participant data is not unique to the adolescent engagement literature and is apparent across the obesity and chronic disease prevention policy and guideline literature [52, 61]. On one hand, these current practices may be viewed as tokenistic and may be attributed to the increasing requirement to engage consumers as part of 'best practice' guidelines for policymakers [6, 62] and a lack of a universal adolescent engagement framework. On the other hand, such practices may also be the first step toward greater participation of adolescents in policy development as nations recognize the importance of end user engagement in policy making. Despite the emphasis on consumer engagement in policies and guidelines developed for adolescents [63, 64], adolescents are yet to be recognised as fundamental stakeholders despite their unique insight which many policy and guideline development processes require [65]. Furthermore, our review determined that when engaged within obesity and chronic disease prevention policy and guideline development processes, participation is

superficial in nature. A consultative capacity was the primary mode of participation, while no policy or guideline documents assessed within this review engaged adolescents in an adolescent-led approach. This is consistent with findings from adolescent engagement in health research literature [66].

Adolescents are more likely to be involved in the formative stages of the policy and guideline development process, where perspectives and needs are established. Not involving adolescents throughout the entirety of the policy and guideline development process has implications for policy and guideline design, translation, and implementation. In grassroots initiatives at state and local levels this has resulted in inconsistencies in outcomes of adolescent engagement [67]. Increasing popularity of youth councils, youth parliaments and youth advisory groups at local and community levels has resulted in pockets of action with no national consensus [6, 11, 67]. A consolidated effort is necessary to ensure adolescent engagement is meaningful and impactful [51].

Furthermore, participatory outcome data in the policy and guideline literature is lacking therefore it is unclear how participation is impacting adolescent consumers. Participatory outcomes such as empowerment and influence enable adolescents to help themselves and their peers to improve their own lives and reduce chronic disease risk factors [51]. Yet this review has found that policies and guidelines aimed at improving health and wellbeing of adolescents are not underpinned by participatory principles or frameworks.

This scoping review has several limitations which were challenging to mitigate, however important to note. The review was limited to established chronic disease risk factors, namely diet, physical activity and overweight and obesity. Other risk factors, such as sleep, and screen time were outside the scope of this review and were not included as individual search terms. An absence of standardised measures to quantify participatory outcomes, meant that measurement and documentation of participation was subjective in nature. Within the literature the term ‘participation’ is often used to refer to participants taking part in a process, however not necessarily engaged in a meaningful manner as per participatory frameworks [26]. Furthermore, within the grey literature the use of ‘consumer’ or ‘stakeholder’ consultation was often used. However, a paucity of specific details on the participants of the consultations, made it difficult to determine the extent and nature of adolescent engagement. Additionally, this review was limited to documents that reported adolescent engagement in policy and guideline development. Recognising that there may potentially be policies or guidelines which engaged adolescents however did not report it within the published policy or guideline

documents. Moreover, documents that were published after the end of the systematic search may have been missed. Finally, this review was limited to policy and guideline documents of the specified high-income countries and organisations. Therefore, this review does not reflect the state of adolescent participation in policy and guideline development in Low- and Middle-Income Countries (LMICs) or globally.

A limitation specific to reviewing the grey literature included the fact that different sites and databases have different search options and navigation tools making a standardised search strategy challenging to execute. Scoping reviews have innate limitations of importance to consider. By design scoping reviews are broad in scope and aim to map the literature therefore the included policy and guideline documents were varied in their scope and purpose. This can make direct comparisons between the policy and guideline documents challenging. Furthermore, although search terms used were broad and the strategy was systematic, as with any review it is possible for some policy and guideline documents to have been missed. Moreover, policy and guideline documents were limited to those published in English, this self-selection limitation may have by default excluded documents not published in English. Further, the policy and guideline search were limited to countries with similar demographics and health ethos and would therefore not be representative of the entire global condition. Finally, scoping review guidelines, deem it unnecessary to rate the quality of the data or conduct a critical appraisal of the evidence used in scoping reviews, this may have implications for practice [23].

Conclusions

Adolescent consumer engagement is recognised as a component of best practice for chronic disease prevention policy and guideline development yet appears to be scarcely implemented. Furthermore, participatory frameworks need to address small participant numbers and inconsistencies in reporting to enhance representation, translation, and transparency of adolescent participation in chronic disease prevention policy and guideline development.

Abbreviations

UN	United Nations
SDGs	Sustainable Development Goals
WHO	World Health Organization
UK	United Kingdom
NICE	National Institute for Health Care Excellence
NHMRC	National Health and Medical Research Council
PRISMA-ScR	Preferred Reporting Items for Systematic reviews and Meta-analysis extension for Scoping Reviews
PCC	Population, Concept, Context

UNICEF	United Nations International Children's Emergency Fund
UNESCO	The United Nations Educational, Scientific and Cultural Organization
UN H6+	A collaboration between UNFPA, UNICEF, UN Women, WHO, UNAIDS and World Bank Group
AA-HAI	Accelerated Action for the Health of Adolescents
PMNCH	Partnership for Maternal, Newborn and Child Health
UNAIDS	The joint United Nations Programme on HIV/AIDS
UNFPA	United Nations Population Fund
LMICs	Low- and Middle-Income Countries

Supplementary Information

The online version contains supplementary material available at <https://doi.org/10.1186/s41256-023-00294-2>.

Additional file 1. Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) checklist.

Acknowledgements

Not applicable.

Author contributions

Conceptualization, methodology, investigation, and writing—review and editing (MM, SM, HC, JR, SRP). Writing—original draft preparation (MM), supervision (JR and SRP). All authors have read and agreed to the published version of the manuscript.

Funding

This research was supported by a National Health and Medical Research (NHMRC)/National Heart Foundation Early Career Fellowship (Grant Number APP1157438) awarded to SP. While JR was funded by a National health and Medical Research Council Career Development Fellowship (Grant Number APP1143538).

Availability of data and materials

All data generated or analysed during this study are included in this published article [and its Additional file 1].

Declarations

Ethics approval and consent to participate

Not applicable.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 24 August 2022 Accepted: 5 March 2023

Published online: 27 March 2023

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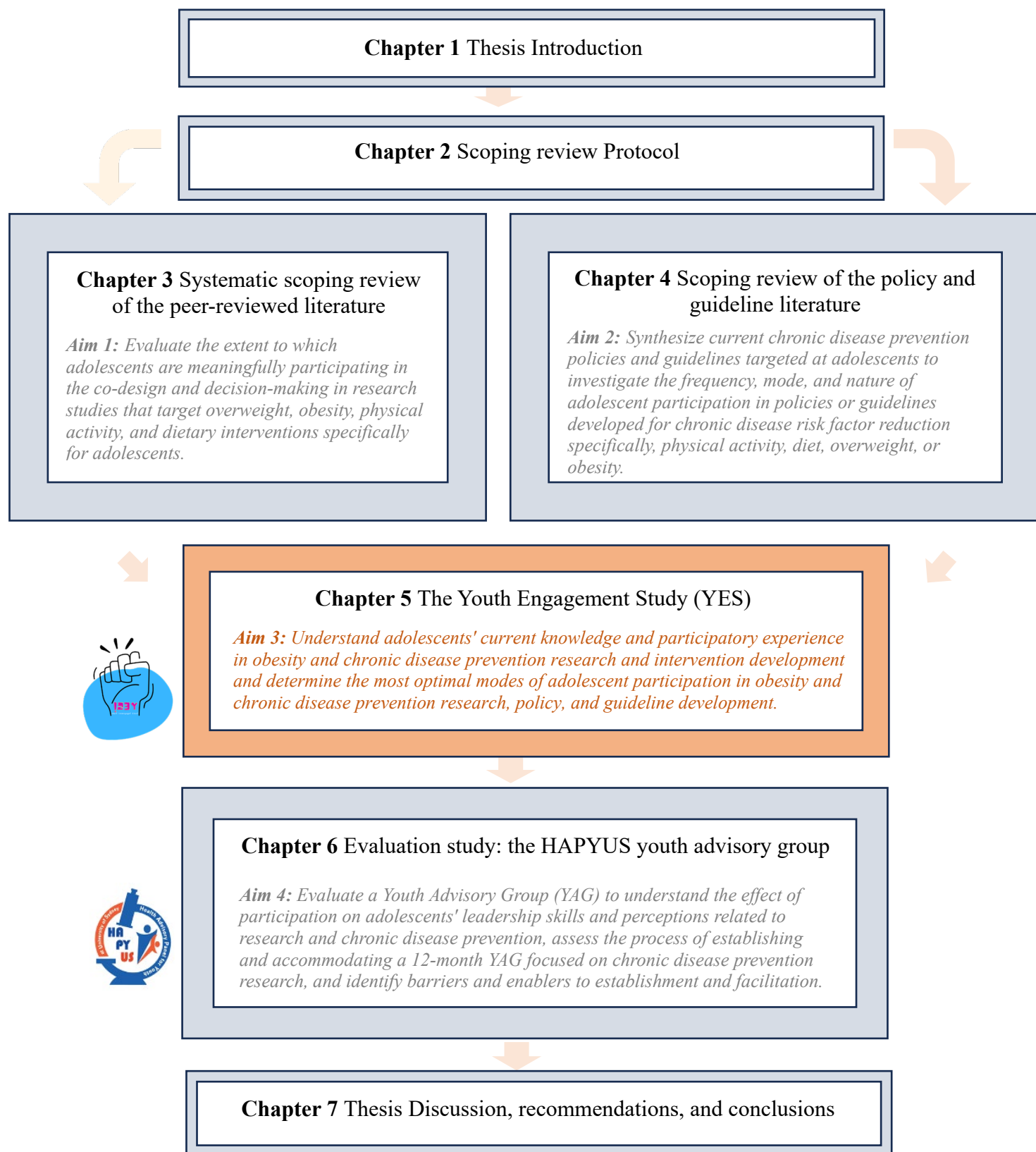
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CHAPTER FIVE: THE YOUTH ENGAGEMENT STUDY



Schematic Representation of Thesis Outline

Preface to Chapter Five

Chapter four presented findings from a scoping review that examined adolescent engagement in obesity and chronic disease prevention policy and guideline development. The review addressed aim two of this thesis and found that adolescents are rarely involved in obesity and chronic disease prevention policy and guideline development. When engaged, the adolescent's role was generally consultative and limited to the formative stages of the policy and guideline development process. Chapter five presents the results of the Youth Engagement Study (YES) and addresses the third aim of this thesis. This study examined Australian adolescents' perceptions, experiences, and preferences for engagement in chronic disease prevention decision-making. The study established that Australian adolescents are not commonly engaged in chronic disease prevention decision-making; however, when engaged, adolescent involvement is usually in an adult-led capacity within the secondary school setting. Adolescents reported a willingness to participate if given the opportunity and perceived youth engagement as essential for enhancing chronic disease prevention decision-making. Optimal youth engagement approaches will involve overcoming the multiple barriers to youth engagement, such as accessibility, lack of opportunities and time and strengthening enablers, such as hybrid delivery, skill development opportunities and payment. Chapter five has not been published and is presented within this thesis as a standard thesis chapter.

TITLE: Optimal strategies to engage adolescents in chronic disease prevention research and intervention development: outcomes of the Youth Engagement Study (YES)

BACKGROUND

Chronic diseases, such as cardiovascular disease (CVD) and Type 2 Diabetes Mellitus (T2DM), are the principal causes of premature morbidity and mortality worldwide.^{1, 2} CVD continues to be the single most consequential contributor to the overall global disease burden, associated with 17.9 million deaths annually, and T2DM responsible for a further two million deaths globally.^{2, 3} The most recent Global Burden of Disease Study 2019 established the most significant increase in risk exposure worldwide due to chronic disease risk factors, including elevated blood glucose, high body mass index (BMI), and high blood pressure.³ The rise in prevalence of metabolic chronic disease risk factors is recognised to be a direct consequence of unhealthy diets, physical inactivity, and increasing rates of obesity.^{3, 4} The impact of chronic diseases extends beyond clinical effects, with implications on quality of life,⁵ health systems⁶ and economies.⁷⁻⁹

Adolescence (10-19 years)¹⁰ is a significant yet often overlooked stage in the development and progression of chronic diseases and their risk factors.¹¹⁻¹³ The World Health Organisation (WHO) attributes more than two-thirds of preventable adult mortality to risk factors established in adolescence.¹¹ Today, eight out of ten adolescents worldwide do not meet WHO physical activity recommendations.¹⁴ Moreover, stigma, poor mental health, poor body image, and development of eating disorders are linked to overweight and obesity in adolescence.¹⁵⁻¹⁷

Evidence suggests that early prevention of chronic disease risk factors improves population health¹⁸ by reducing the onset and progress of chronic disease into adulthood.¹⁹⁻²¹ Chronic disease prevention interventions targeted at adolescents are limited, but indications of positive effects on physical health (strength, fitness), mental health indicators, BMI, and metabolic and immune function are apparent.²¹⁻²⁴ Furthermore, early chronic disease prevention interventions reduce morbidity rates and healthcare costs, yielding positive long-term economic outcomes.²⁵ Additionally, early intervention reduces premature mortality rates associated with adolescent overweight and obesity.²⁶

The WHO Sustainable Development Goal (SDG) 3.4 aims to “reduce by one-third premature mortality from non-communicable diseases (NCDs) through prevention and treatment” by the year 2030.²⁷ Global action plans and recommendations to support the control of chronic diseases and their risk factors have been developed and widely endorsed.²⁸⁻³¹ The complexity of chronic disease risk factors and heterogeneity of populations has contributed to suboptimal implementation of chronic disease prevention action plans.^{3, 32, 33} Largely, nations worldwide have fallen short in managing chronic diseases and their risk factors.^{28, 32}

Adolescents are increasingly acknowledged as health consumers whose engagement in decision-making is critical to adding value to research development,^{34, 35} research translation,^{36, 37} and public health agendas globally.^{11, 38} Youth engagement has been shown to inform policy and practice that is responsive and relevant to youth needs, enhancing adolescent health equity.³⁹ Various consumer engagement frameworks have sought to guide researchers on how best to involve consumers in health research and intervention decision-making.⁴⁰⁻⁴³ A recent national report from Australia stated that there needs to be more information representing the voice of adolescents in national health and wellbeing data

sources.⁴⁴ Scoping reviews of the peer-reviewed⁴⁵ and grey literature⁴⁶ found that globally, adolescent participation in chronic disease prevention research, intervention decision-making,⁴⁵ and policy and guideline development⁴⁶ is limited. Nevertheless, increasing adolescent participation contributed to more meaningful chronic disease prevention outcomes.⁴⁵

Adolescent engagement in decision-making processes is necessary to transform and tailor chronic disease prevention research and intervention development.^{11, 40, 47, 48} However, it is still unclear how adolescents currently engage in chronic disease prevention research and intervention development and the best strategies for adolescent engagement.

This study aimed to understand adolescents i) perceptions of health, chronic disease risk factors, and chronic disease prevention strategies, ii) engagement in chronic disease prevention research, policy, and guideline development, iii) barriers and facilitators to adolescent participation in chronic disease prevention research, policy, and guideline development, and iv) preferences for engagement in research, policy, and guideline decision-making for chronic disease prevention.

METHODS

Study design

The study consisted of two concurrent qualitative phases. Phase 1 comprised a cross-sectional survey open for six months, from the 24th of January to the 10th of August 2022, and was administered online using the Research Electronic Data Capture (REDCap) web application. Phase 2 was a series of five focus group discussions held online using Zoom (Zoom Video Communications, Inc.) between the 19th of June and the 12th of August 2022. Focus group discussions sought to enrich and build a greater understanding of data obtained from the

survey (Appendix C). Ethics approval was granted from the University of Sydney Human Research Ethics Committee (project number 2021/864) (Appendix C).

Participants

Participants were included in the study if they were aged 13-18 years (inclusive), currently living in Australia, and provided informed consent. The age group 13-18 years was selected for the purpose of this study as it aligns with high school age in most states of Australia. Furthermore, 13–18-year-olds are more likely to have had exposure to similar experiences and opportunities compared to adolescents younger than 13 years who are still transitioning from childhood. Moreover, adolescents older than 18 years have often completed formal schooling, transitioned into adulthood, and therefore differ from younger adolescents in their experience and world view. Parental consent was not required for participation in the study. Young people often communicate via social media and online without parental consent. Previous research suggests that from age 12 years onwards, adolescents are competent in decision-making processes; 14 years and older have equal capacity as adults to consider multiple viewpoints and weigh conflicting information in the context of research participation.⁴⁹ There is agreement that for health research that is low-risk or minimally harmful, it is acceptable to assume that adolescents are likely to be competent to understand the nature and implications of the study.⁵⁰ In addition, there is little to no risk involved in completing the survey or participating in the focus group. Participants were recruited via targeted advertising on social media platforms as well as through schools and established youth networks. For phase 2 of the study, potential participants were also recruited from a database of phase 1 participants who expressed interest in further research.

Non-probability quota sampling methodology determined a sample size of 500 to be meaningful for our study.^{51, 52} National proportions of different demographic groups were identified as a 50:50 male-to-female ratio, 30% rural or remote, 40% low socioeconomic status, and 20% from culturally and linguistically diverse (CALD) groups.^{53, 54} Focus groups were conducted until thematic saturation was reached.⁵⁵

Outcome measures

Phase 1

To ensure that participant responses were focused on the primary outcome measures of interest in this study, the survey instrument began with a brief description of the survey context and aims, which stated: ‘We are interested in finding out if and how you are currently participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease, and diabetes. In this survey, youth participation is defined as young people (individually or together) forming and expressing their views and influencing matters of importance to them.’

Demographic questions collected information on age, gender identity, postcode, a language other than English spoken at home, current school year, the highest level of education of participants and the highest level of education of parents or guardians. The YES survey comprised 41 questions in total, including a 5-point Likert scale, multiple-response, and open-ended type questions. Where relevant, multiple-response items with ‘other’ as an answer option were designed to prompt participants to provide a free-text response for further specification.

The Australian Burden of Disease Study⁵⁶ and National Obesity Strategy Consultation Report³⁶ informed the development of questions assessing perceptions of health and chronic disease risk factors. Despite its relevance to current public health agendas, ‘COVID-19’ was not included as a category option for the ‘health’ or ‘chronic disease risk factor’ questions. This decision was made based on evidence suggesting that lifestyle factors that impact ‘mental health’ account for the biggest effect of COVID-19 on young people.⁵⁷ Furthermore, given that COVID-19 was influencing everyone’s life in one way or another, it seemed appropriate to omit ‘COVID-19’ as a category to avoid bias and provide the option of the ‘other’ category for participants to provide responses that were not specified. Study-specific questions were formulated to construct the main sections of the survey (‘perceptions of health’ and ‘participation’).

No pre-existing questions were identified for the survey’s final section (‘participation’) as similar studies were yet to be conducted. General guidelines on survey development were used to structure and organise the overall questionnaire.⁵⁸⁻⁶⁰ The survey’s final section (‘participation’) began with a branching question to establish prior engagement in chronic disease prevention strategies and interventions. This section also included open-ended questions to maximise understanding of participants’ participation experience or lack thereof. The questions relating to adolescent participation were developed based on the features, modes, and social ecology of meaningful participation as well as participatory outcomes outlined in the Lansdown- UNICEF Conceptual Framework for Measuring Outcomes of Adolescent Participation.⁶¹

Phase 2

A purpose-built discussion guide guided the focus group discussions (see Appendix C). The outcomes were qualitative data to understand the results of quantitative data gained from phase 1 of the study, specifically related to adolescents' perceptions, experiences, and preferences in participating in chronic disease prevention intervention development.

Questions were open-ended, and prompts were used to encourage discussion. Focus groups were conducted by one member of the research team (MM), were between 45- and 60-minute duration, delivered online, recorded, and transcribed verbatim. Focus groups included, on average, four participants (ranging from 2 to 6). Thematic saturation was assessed following the third and fourth focus groups and determined to be achieved in the fifth focus group when no new concepts or meanings were identified.⁵⁵

Data analysis

Methodological triangulation⁶² was used to comprehensively assess data collected through the different data collection methods employed in phases 1 and 2 of the study. Survey data was collected in REDCap and exported into SPSS version 28.0, where quantitative data were cleaned, recategorized when necessary, and summarised. Further analyses were conducted on specific outcomes and explanatory variables.

Qualitative focus group data were recorded and transcribed using Otter.ai online software.

Transcriptions were then imported into NVivo version 1.7. Braun & Clark's six-stage reflexive thematic analysis was determined as an appropriate data assessment methodology.^{63,}

⁶⁴ The stages of Braun & Clark's thematic analysis framework include 1) familiarisation with the data, 2) generation of initial codes, 3) search for themes, 4) review themes, 5) define and name themes and 6) report findings.⁶³ One researcher (MM) assessed the entire data set,

while a second researcher (AT) double-coded the data. The two researchers then met to cross-check codes, discuss, and agree upon themes.

The statistical analysis involved exploring survey responses to the chosen outcome variable: “In the last two years, have you ever been involved in any activities that promote young people to eat better, be more physically active, or prevent chronic diseases (such as obesity, type 2 diabetes and heart disease)?” where answers were categorised as ‘yes,’ ‘no,’ and ‘unsure/ can’t remember.’ The category of ‘no/ unsure’ was created by combining the survey responses of ‘no’ and ‘unsure/ can’t remember’ as they are related categories in this context, indicating a lack of consequential participation. For variables considered for statistical analysis, categories containing low case counts of less than five were combined, when possible, with other naturally meaningful categories. A new variable was created where categories were combined to reflect the change.

Explanatory variables and descriptive analyses

Nine independent explanatory variables: one continuous (age) and eight categorical (gender, language other than English spoken at home, socioeconomic status, geographical location, current school year, highest education level, parental educational attainment, and previous volunteer work) were considered for analyses against the outcome variable. Exploratory Data Analysis (EDA) was conducted to visualise the data and identify trends. Graphical representations of the independent variables in the form of bar charts for categorical variables and histograms for numerical variables were created to understand the structure of the data. Cross-tabulation were developed to explore the crude relationships between the outcome variable and categorical explanatory variables, with counts and proportions within categories summarised in Appendix C- Supplementary Table 1.

Inferential analyses

A series of univariable binary logistic regression models were constructed to evaluate the association between the nine individual explanatory variables (Appendix C- Supplementary Table 1) and the outcome variable. Assumptions of binary logistic regression were checked prior to interpretation. The linearity of the continuous variable (age) in relation to the logit of the dependent variables was evaluated via the Box-Tidwell (1962) method.⁶⁵ If $P > 0.05$ using this method, the continuous variable was established to be linearly related to the dependent variable.^{65, 66} Multicollinearity between pairs of independent variables was determined using the Variance Inflation Factor (VIF) derived via the 'linear' function in SPSS.

A multivariable binary logistic regression was then applied to explore the relationship between multiple explanatory variables and the dichotomous outcome variable. Variables with P -value < 0.20 from the univariable associations were eligible. A manual forward-stepwise selection process was executed with variables added consecutively based on their P -values, with lowest P -value added first. A P -value < 0.05 was considered statistically significant for the univariable associations and the final multivariable model. To confirm non-significance, all non-significant variables were re-tested in the final model.

RESULTS

Phase 1

A total of 501 participants (mean age 16 years, SD: 1.2) completed phase 1 of the study (Table 5.1). Participants predominantly identified as female ($n=308$, 62%) and were most likely to be in year 11 ($n=141$, 31%) or year 12 ($n=157$, 34%) of school. Overall, 24% ($n=118$) of participants reported living in a rural or regional geographical area. Additionally,

65% of participants lived in an area with an IRSAD score in the fourth (n=87, 17%) or fifth (n=238, 48%) quintile. Classification into the top two IRSAD quintiles (fourth and fifth) indicated that participants live in areas with higher relative advantage and lower relative disadvantage. A language other than English was reported to be spoken by 37% (n=183) of participants, the most common languages reported being Mandarin (n=29, 16%), Cantonese (n=24, 13%), and Arabic (n=20, 11%). A high degree of parent/ guardian educational attainment was evident, with 78% (n=390) of participants reporting that at least one parent/guardian was currently studying or had completed tertiary education.

Table 5.1. YES Phase 1: Survey participants' demographic characteristics.

Demographic characteristics (n=501)		N (%)
Age (Mean = 16.0 years, SD: 1.2)	13	19 (4)
	14	44 (9)
	15	95 (19)
	16	143 (29)
	17	177 (35)
	18	23 (5)
Gender	Male	151 (30)
	Female	308 (62)
	Other ¹	39 (8)
	I prefer not to say	3 (1)
Education	Year 7	4 (1)
	Year 8	21 (5)
	Year 9	41 (9)
	Year 10	95 (21)
	Year 11	141 (31)
	Year 12	157 (34)
	Not attending school	42 (8)
	Enrolled in Diploma/ technical course	7 (1)
	Enrolled in University undergraduate degree	31 (6)
<i>Socio-economic indicators</i>		
Geographical distribution	Metropolitan	383 (76)
	Rural/ regional	118 (24)

Demographic characteristics (n=501)		N (%)
IRSAD Quintile²	1 st	40 (8)
	2 nd	41 (8)
	3 rd	86 (17)
	4 th	87 (17)
	5 th	238 (48)
Language	Language other than English spoken at home	183 (37)
	Main language (other than English) spoken.	
	Mandarin	29 (16)
	Cantonese	24 (13)
	Arabic	20 (11)
	Other ³	110 (60*)
Parent/guardian educational attainment	Parent/ guardian one education level	
	Some High school	56 (11)
	Completed high school	49 (10)
	Currently studying for a degree or diploma	9 (2)
	Completed a trade or technical qualification	37 (7)
	Completed a degree or diploma	207 (41)
	Completed a postgraduate degree	113 (23)
	Other	5 (1)
	Don't know	17 (3)
	I prefer not to say	8 (2)

Demographic characteristics (n=501)	N (%)
Parent/ guardian two education level	
Some High school	29 (6)
Completed high school	70 (14)
Currently studying for a degree or diploma	10 (2)
Completed a trade or technical qualification	43 (9)
Completed a degree or diploma	204 (41)
Completed a postgraduate degree	90 (18)
Other	2 (0)
Don't know	35 (7)
I prefer not to say	10 (2)
At least one parent with tertiary education	390 (78)

Notes

¹ Encompasses categories for 'other gender' such as 'non-binary/ gender diverse' or 'other, my gender identity is not listed.'

² Missing values (n=9, 1.8%)

³ Encompasses all other categories listed but with low counts, including: 'Greek,' 'Hindi,' 'Italian,' 'Korean,' 'Spanish,' 'Tagalog,' 'Tamil,' 'Vietnamese,' and 'other.'⁴

Includes the categories: 'currently studying for a degree or diploma,' 'completed a trade or technical qualification,' 'completed a degree or diploma,' and 'completed a postgraduate degree.'

*Percentage of 'Speak a language other than English at home.'

Perceptions of health and chronic disease

Phase 1 participants' perceptions of health and chronic disease are presented in Figures 5.1 and 5.2. Overall, 79% (n=394) of participants perceived mental health disorders such as depression and anxiety to be the biggest health issue confronting youth today (Figure 5.1). An unhealthy diet (n=385, 77%), low physical activity (n=361, 72%), mental health (n=266, 53%), and cost/access to healthy food (n=178, 36%) were perceived to be the biggest chronic disease risk factors impacting the health of youth (Figure 5.2). Additionally, 92% (n=463) of participants perceived health interventions as important for adolescent health.

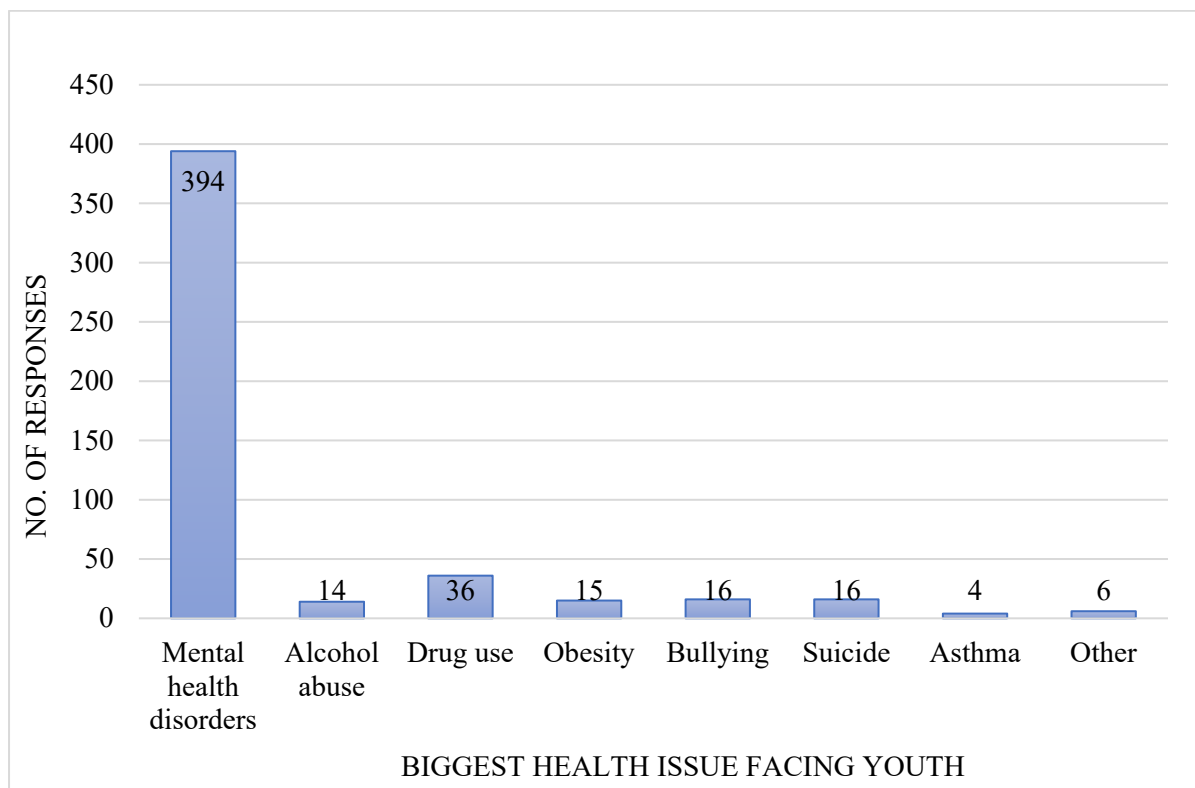
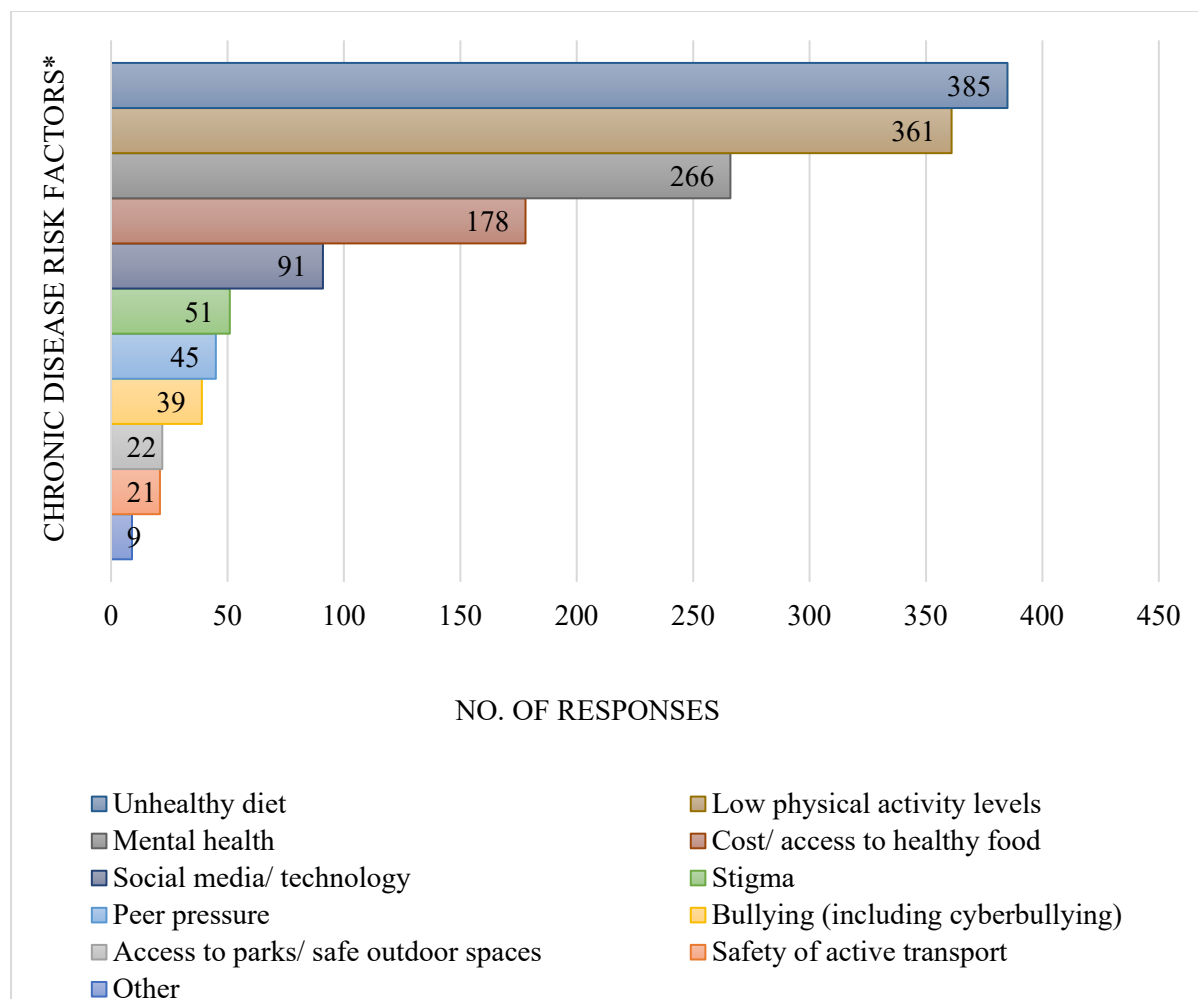


Figure 5.1. YES participants' perceptions of health and chronic disease: Biggest health issue facing youth.



*Multiple response questions ‘choice of up to three’

Figure 5.2. YES participants’ perceptions of health and chronic disease: Biggest chronic disease risk factors impacting youth health.

Experience of participation

Table 5.2 presents phase 1 participants’ experience of participation in health-promoting activities. One in five (20%) reported participating in health-promoting activities. Of those who reported participation, ‘peer leader/ mentor/ educator’ (n=40, 40%) and participation in a ‘community event’ (n=39, 39%) were the most frequent experiences. ‘Secondary school’ was reported to be the most common participation setting (n=64, 64%). Of the participants who reported ‘participation,’ 87% (n=87) felt their contribution was ‘meaningful,’ and 40% (n=40) described their participatory experience as ‘adult led.’

Preferences for participation

Greater than 60% (n=308, 62%) of phase 1 participants reported a willingness to participate in health-promoting activities if given the opportunity. Preferred participatory activities reported were ‘participate in research’ (n=340, 68%) and ‘be consulted in guideline development’ (n=263, 53%). Participants said a ‘hybrid’ of online and in-person settings was the preferred participatory setting (n=225, 45%) (Table 5.2).

Table 5.2. YES Phase 1: Experience and preferences for youth engagement.

Variable	Categories	N (%)
<i>Experience of participation</i>		
Participation in health-promoting activities	Yes	100 (20)
	No	278 (56)
	Unsure/ Can’t remember	123 (25)
Participation Method ¹	Peer leader/ mentor/ educator	40 (40)
<i>(For those who reported participation)</i>	Community event	39 (39)
	Youth/ peer advocacy	26 (26)
	Focus/ discussion group	24 (24)
	Questionnaire	22 (22)
	Social media	18 (18)
	Youth advisory group/ board/ committee	14 (14)
	Other	9 (9)
	Co-design workshop	8 (8)
	I can’t remember/ I don’t know	7 (7)
	Interview	3 (3)

Variable	Categories	N (%)
	Photovoice/ photography	1 (1)
Participation Setting ¹	Primary school	17 (17)
<i>(For those who reported participation)</i>	Secondary school	64 (64)
	Tertiary education (college, TAFE, university)	4 (4)
	Community	23 (23)
	Social clubs	24 (24)
	Other	5 (5)
Contribution	Meaningful	87 (87)
<i>(For those who reported participation)</i>	Not meaningful	11 (11)
	Unsure	2 (2)
Participation description	I felt my views or opinions were not considered, and I had no ability to influence the process	6 (6)
<i>(For those who reported participation)</i>	Adult-led	40 (40)
	Equal partnership	27 (27)
	Youth-led	27 (27)
<i>Preferences for participation in activities that promote young people to eat better, be more physically active, or prevent chronic disease</i>		
Willingness to participate	Yes	308 (62)
	No	50 (10)
	Unsure	143 (29)
Preferred participatory activity ¹	Participate in research	340 (68)
	Be consulted in guideline development	263 (53)

Variable	Categories	N (%)
	Be consulted in policy development	189 (38)
	A learning role	174 (35)
	Other	17 (3)
Preferred participatory setting	Hybrid	225 (45)
	In-person	143 (29)
	Online	128 (26)
	Other	5 (1)
Participatory methods with the most influence	Social media/ marketing	131 (26)
	Focus/ discussion group	84 (17)
	Youth/ peer advocacy	61 (12)
	Co-design activities	56 (11)
	Peer leader/ mentor	49 (10)
	Questionnaire	48 (10)
	Youth advisory group	46 (9)
	Interview	18 (4)
	Other	8 (2)
Preferred gains from the participatory experience	Skill development	156 (31)
	Research experience	112 (22)
	Payment	107 (21)
	Networking	59 (12)
	A gift voucher	54 (11)
	Other	13 (3)

¹ Multiple responses/ 'select all that are relevant' question.

Perceived benefits of participation

Overall, participants perceived participation in activities that promote health as beneficial (Figure 5.3). Most participants reported participation to be ‘likely’ to improve their sense of self-worth, self-esteem, and self-efficacy (n=378, 75%), sense of being taken seriously (n=299, 60%), confidence in decision-making (n=349, 70%) and confidence in public and community engagement (n=366, 73%). Furthermore, >80% of participants perceived participation to add value to and improve multiple health domains, including research, intervention development, policy development, healthy diet and lifestyle awareness, health-promoting environments, behaviours, and health outcomes (Figure 5.3).

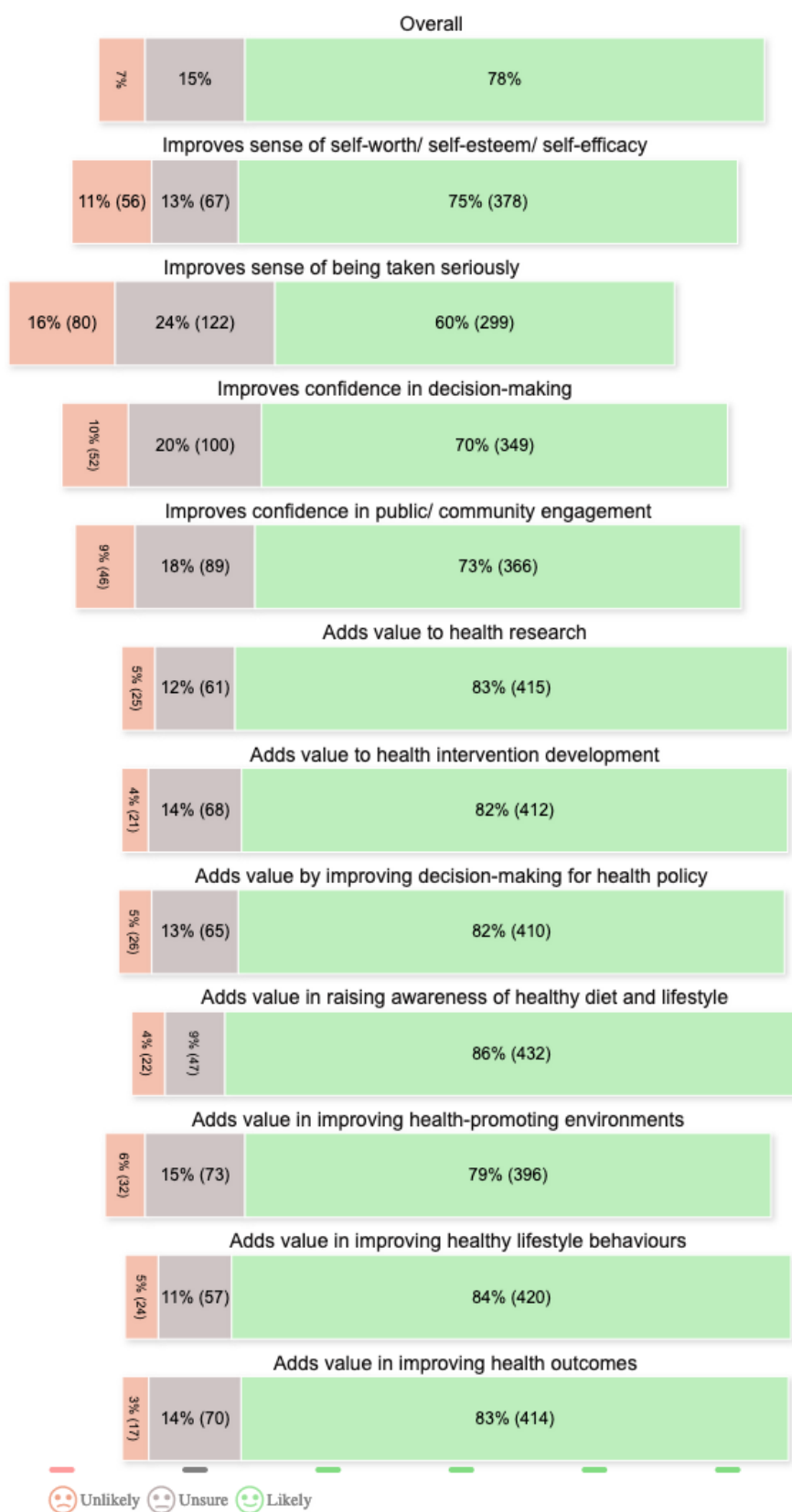


Figure 5.3. YES participants' perceptions of the benefits of participation in health-promoting activities.

Univariable and multivariable model results

All pairs of independent variables had a VIF < 10, indicating no multicollinearity between independent variables.⁶⁶ Logistic regression case diagnostics found all standard residuals to have a value of less than 2.5 standard deviations, showing the lack of significant outliers in the data set.⁶⁶

Univariable logistic regression revealed that only the independent variable ‘previous volunteer work’ showed strong evidence ($X^2(1) = 17.20$, $P < .001$) of a relationship with participation in health-promoting activities (Table 5.3). 73% of participants who reported having previous volunteer work experience also reported participation in health-promoting activities (Appendix C, Supplementary Table 2). While the explanatory variable ‘socioeconomic status’ showed some sign ($X^2(4) = 7.27$, $P < .122$) of a relationship at the liberal cut off $P < 0.20$. Almost 43% of youth who reported participation in health-promoting activities lived in an area with an IRSAD score in the 5th quintile, indicating a higher level of relative advantage and lower relative disadvantage (Appendix C, Supplementary Table 2).

Only one independent (explanatory) variable was statistically significant at $P < 0.05$ in the multivariable model: ‘previous volunteer work.’ Accordingly, the univariable model will be interpreted as the final model (Appendix C, Supplementary File 1.). Further, upon re-adding non-significant variables to this final model, none achieved statistical significance. This model was statistically significant using the Omnibus test $X^2(1) = 17.78$, $P < .005$. The model explained 5.60% (Nagelkerke R^2) of the variance in ‘participation in health-promoting activities’ and accurately classified 80.10% of cases. Participants who had ‘previous volunteer work’ experience had 2.74 times the odds of participating in health promoting activities (Appendix C, Supplementary File 1.).

Table 5.3. Univariable associations between youth participation and socio-demographic characteristics

Socio-demographic characteristics		Wald	<i>p</i>	Odds Ratio (95% CI)
Gender	Male*	.276	.871	
	Female	.155	.694	1.103 (.676, 1.800)
	Other gender	.032	.858	.920 (.369, 2.292)
Geographical classification		.014	.906	.970 (.580, 1.621)
Socioeconomic status (SES)	Quintile 1*	7.467	.113	
	Quintile 2	1.007	.316	1.729 (.594, 5.034)
	Quintile 3	.116	.733	.840 (.307, 2.297)
	Quintile 4	1.799	.180	1.901 (.744, 4.859)
	Quintile 5	.001	.982	1.010 (.419, 2.438)
Language other than English spoken at home		.012	.913	1.026 (.651, 1.615)
Current school year	Year 7 or 8*	.500	.973	
	Year 9	.128	.720	1.273 (.340, 4.760)
	Year 10	.203	.652	1.312 (.403, 4.278)
	Year 11	.202	.653	1.301 (.413, 4.094)
	Year 12	.414	.520	1.451 (.467, 4.514)
Highest level of education	In year 10 or below*	3.293	.510	
	Completed year 10	.236	.627	1.133 (.685, 1.873)

Socio-demographic characteristics	Wald	<i>p</i>	Odds Ratio (95% CI)
Completed year 12	2.958	.085	2.286 (.891, 5.863)
Enrolled in Diploma/ Technical course	.490	.484	1.829 (.337, 9.910)
Enrolled in University	.034	.853	1.097 (.412, 2.924)
At least one parent with Tertiary education	.719	.396	1.269 (.731, 2.203)
Previous volunteer work experience	15.808	<.001	2.664 (1.643, 4.317)
Age	.170	.680	1.040 (.864, 1.252)
*Reference category			

Phase 2

Five online focus group discussions were conducted for phase 2 of the YES with 19 participants (mean age 17 years, SD: 0.9) (Table 5.4). Over half of phase 2 participants (n=11, 58%) identified as female. Three participants (16%) lived in a rural or regional area. 58% (n=11) of participants spoke a language other than English, with the most common language spoken being Mandarin (n=4).

Table 5.4. YES Phase 2: Focus group participants' demographic characteristics.

Demographic characteristic		N	%
Total No. of Participants		19	100
Age (mean: 17 years, SD: 0.9)			
Gender	Male	8	40
	Female	11	60
Geography	Metropolitan	16	84
	Rural/ regional	3	16
Speak a language other than English at home		11	60
Main language other than	Mandarin	4	36*
English spoken at home	Other ¹	7	64
¹ Includes: Tamil (2, 18%), German (1, 9%), Tagalog (1, 9%), Hindi (1, 9%), Urdu (1, 9%), Cantonese (1, 9%)			
*Percentage out of those who speak a language other than English at home			

Thematic analysis

Table 5.5 presents the two main themes: 'role' and 'influence', identified in phase 2 of the study. 'Role' was associated with the sub-themes: 'advocacy,' 'choice,' 'implementation' and 'prevention.' 'Influence' was related to the sub-themes of 'acceptability,' 'relevance,' and 'empowerment.' Quotes supporting the main themes and sub-themes are presented in Table 5.5.

Role

Participants recognised adolescents' important role in shaping health promotion and chronic disease prevention processes and outcomes. The necessity for adolescents to take on an

influential role in health ‘advocacy’, to raise awareness among peers and within society more broadly of the impact of chronic disease risk factors on health and the importance of prevention was clearly articulated. Participants described the significance of improving adolescent visibility by ensuring youth have opportunities for a more active role in the ‘implementation’ of health-promoting activities. Nonetheless, participants acknowledged the diversity of adolescents in multiple personal, social, and academic domains. Participants established that adolescents should autonomously have a ‘choice’ of role, level of commitment to the role and choice in the delivery and participatory method they wish to engage in.

Influence

‘Influence’ was perceived by participants as a key enabler prompting change in adolescent health trajectories. Participants recognised youth engagement in chronic disease prevention decision-making to have the potential to yield health-promoting activities that are ‘acceptable’ and ‘relevant’ to young people, hence positively influencing lifestyle choices. Moreover, it was agreed that the influence exerted by youth engagement extends further by ‘empowering’ youth on a personal level via engagement in the decision-making process. Youth engagement was affirmed to empower adolescents by fostering the development of leadership skills and self-confidence, both fundamental elements for future influence (Table 5.5).

Interconnections between themes

The themes and sub-themes identified from the focus group discussions were distinct; however, innate interconnections between themes and sub-themes related to youth engagement were evident (Figure 5.4). ‘Influence’ and ‘role’ were inherently connected by

the capacity of a meaningful ‘role’ to be ‘empowering’ and create ‘influence’ *“To have such an active role made me feel really involved, and I felt like I had really an active grasp on how I was affecting the community.”* Furthermore, the ability to influence health promotion decision-making and a youth ‘role’ in the ‘implementation’ of health-promoting activities were vital to designing ‘acceptable’ and ‘relevant’ chronic disease prevention strategies. *“If young people are playing a bigger role in, like, nutrition and healthy diets, then that is going to have an impact on people around them.” “I think if you have, like, young people say involved in making these health promotion strategies, like in whatever level... this is how we can make it more effective; this is how we can help it reach more people.”*

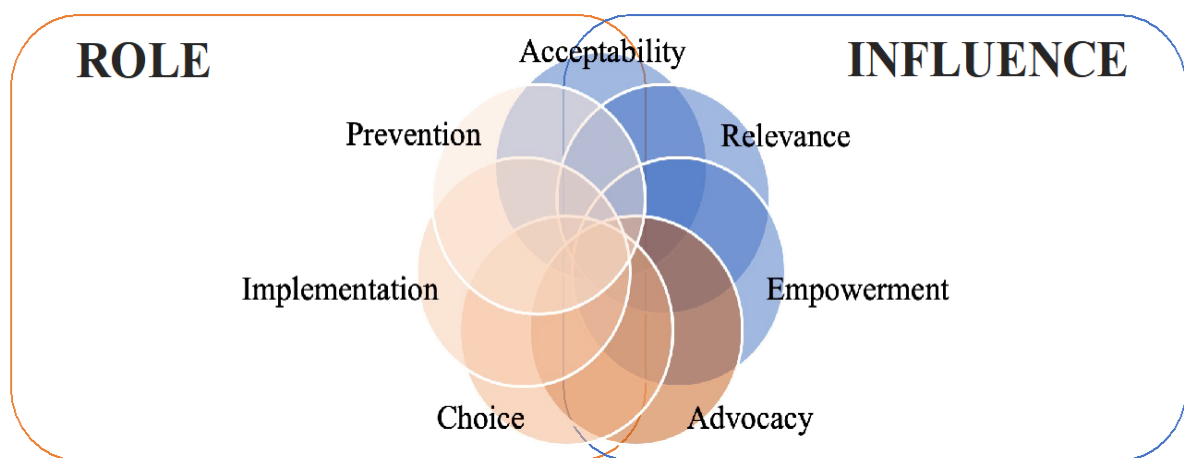


Figure 5.4. Interconnection between themes and sub-themes identified within YES focus group discussions.

Barriers and facilitators to youth engagement in chronic disease prevention

Table 5.6. presents barriers and facilitators to youth engagement identified from the YES focus group discussions. Primary barriers to youth engagement in chronic disease prevention activities included accessibility limitations due to distance or technology, limited opportunities for youth engagement in health-promoting activities, lack of awareness of opportunities, and time restraints due to school, work, or extracurricular commitments.

Participants described facilitating elements that enable greater youth engagement in chronic disease prevention activities (Table 5.6). Facilitators to youth engagement included a hybrid participatory mode consisting of online and in-person components. Skill development opportunities were considered valuable for gaining experience and research skills for future endeavours. Participants reported the importance of monetary reimbursement as a fair incentive and compensation for their time and work.

Table 5.5. Themes and sub-themes identified within YES focus group discussions.

Themes	Sub-themes	Supporting Quotes
ROLE	Advocacy	“Opportunities should be broadcasted more, and there should be more active roles for the youth to participate in these kinds of major decisions.” (M, age 17)
		“Raising awareness is quite important and something that young people and only young people can really do. So that other youth listen and understand.” (F, age 17)
		“If the young people themselves are doing the advocacy work, then youth in those health-promoting activities will be more likely to take part and trust those activities.” (F, age 18)
	Choice	“I think it can depend on the type of health-promoting activity, and it could also depend on the youth, like a willingness to be involved in various levels.” (M, age 15)
		“It should also depend on opening it up to everyone so that youth can decide what kind of role they would like to take, and the level of participation will not always necessarily be the same.” (M, age 16)
		“The most effective are programs that treat you like an adult and sort of go; not everyone might be ready or willing to take on this level, but it is there, and if you want to come and do it, we are prepared to give you the absolute full experience, we are prepared to enable you to have all the control and to learn and take from it as much as you want.” (M, age 17)

Themes	Sub-themes	Supporting Quotes
	Implementation	“It would be helpful to have young people as the face of the campaign because if young people identify more with a campaign, they're more likely to feel like it applies to them, instead of some corporate campaign they do not care about.” (F, age 18) “In final implementation, it is important to bounce ideas off a bunch of young people and see how they feel about the campaign. Because if those young people do not connect with the campaign, it is unlikely that other young people would care about it.” (F, age 17) “It would be useful to have more programmes that we are working with young people to sort of establish working on the knowledge of what they need to do to improve their health, and then work with them to establish how they are going to do that.” (M, age 17)
	Prevention	“Young people encouraging other young people to live healthily is important, rather than other generations encouraging it is not the same. I think it can be done better when it is like from your peers.” (M, age 15) “Young people should be aware of and take steps to prevent it (chronic disease).” (M, age 18)

Themes	Sub-themes	Supporting Quotes
		“It is so much more useful for youth to talk to other people of the same age because it does not come off as overbearing or like a lecture. It is more like a friendship communal kind of thing. It is more beneficial.” (M, age 17)
INFLUENCE	Acceptability	“If the young people themselves are doing the advocacy work, then in those health-promoting activities, it will be more likely that other young people will take part and sort of trust those activities.” (F, age 18)
		“The influence is big, and when you see your peers in those kinds of things, the mutual like encouraging each other to go into like physical activities, it is beneficial for health promotion.” (F, age 17)
		“If my peers were participating in healthy decision-making activities, then I would be more likely to follow in their footsteps. I would not want to be excluded. I take them as role models.” (M, age 17)
	Relevance	“Young people can do something about it if they get the opportunity to advise on how to make it a little bit more relevant to young people.” (M, age 16)

Themes	Sub-themes	Supporting Quotes
		“If someone can connect to us in any similar way, I think it is more efficient than someone completely different to us, not involved in anything we do, and cannot relate to us, informing us that we should live our lives in a certain way.” (M, age 15) “If you have young people involved in making health promotion strategies, like in whatever level, school, government or whatever, if you have young people, then that helps make the programme more relevant. Input from people from the group that you are targeting, then this is how we can make it more effective, or this is how we can help it reach more people.” (M, age 17)
	Empowerment	“It was empowering to have an entire group of people work towards events that actually happened. It was nice to see something come out of our efforts.” (F, age 18) “It was a good feeling that you could help out more disadvantaged people and helped me build my leadership portfolio.” (F, age 17) “Whenever you get an opportunity to make a change, it does feel a bit empowering, and it gives you a bit of confidence.” (M, age 17)

Table 5.6. Barriers and facilitators to youth engagement in chronic disease prevention.

Barriers and facilitators to youth engagement	Exemplar quotes		
Accessibility (<i>barrier</i>)	“It's just a matter of, like, the accessibility for those people, whether it's convenient for them to get involved with it.” (M, age 15)	“A lot of young people do work to support themselves and do need the money. So doing things like that to make it more accessible.” (M, age 17)	“I think a hybrid sort of mix. Because if it's just like in person, then someone who can't travel or they live far away, they won't be able to contribute.” (M, age 17)
Limited opportunities/ lack of awareness of opportunities (<i>barrier</i>)	“I haven't personally seen any instances where youth are being invited to work on the development of these sorts of projects. I didn't know that was an option until very recently.” (M, age 15)	“I don't recall there being any opportunity to do anything like that at school. But I do feel like when you're in a very big population, your chances are also more limited, especially when there are people that have more experience.” (F, age 18)	“Recently, I did see a Youth Advisory Group for my suburb, but it wasn't focused on health. I don't think I have seen that much stuff advertised.” (F, age 17)

Barriers and facilitators to youth engagement	Exemplar quotes		
Time (<i>barrier</i>)	“I feel like people that already have a busy schedule and a lot of pressure to do well in school may feel limited. Because they don't have time to do anything.” (F, age 16)	“I don't really have the time, but most young people would probably be the same unless it's a job or you're being paid.” (M, age 17)	“Breaking it down so that it's more accessible in close quarters or even paying people like, you know, if you've got work commitments.” (M, age 17)
Hybrid delivery (<i>facilitator</i>)	“If it's online, some people might not have reliable internet, and so they can't, like, contribute. So, if you have a hybrid sort of thing, more people can contribute.” (M, age 17)	“Using a mix of like, in person and online resources is the best option.” (M, age 16)	“I think the best setting would be first school because every student has to go to school. So that will be a good place to expose them to this and online.” (F, age 18)

Barriers and facilitators to youth engagement	Exemplar quotes		
Skill development opportunities <i>(facilitator)</i>	“I think skills, research, and networking. All this combined is so important for future learning, tertiary education, or any kind of a job opportunity.” (M, age 17)	“Definitely the research experience or the skill development.” (M, age 16)	“Depending on what the programme is, I'd really love the opportunity to be able to participate. So, I'd be happy with the skills gained.” (M, age 15)
Payment/ compensation for time <i>(facilitator)</i>	“I think payments can incentivise people to get involved.” (F, age 18)	“There's also a kind of implication that they're young people who don't need to be paid. Like we can just be happy to just take them and kind of use them.” (F, age 16)	“There has been a history of youth being exploited. They did get used for programs without being appropriately paid, even though they've been doing just as much work as any other adult.” (M, age 17)

DISCUSSION

The youth engagement study investigated adolescents' perceptions, experiences and preferences related to youth engagement in chronic disease prevention decision-making. Data from a sample of Australian adolescents established that youth aged 13-18 years rarely participate in chronic disease prevention research and intervention development decision-making. Adolescents indicated enthusiasm for engagement; however, time, accessibility, and lack of opportunities presented major barriers to participation. Overall, adolescents considered youth engagement in chronic disease prevention decision-making a key element for developing health-promoting environments important to them and enriching chronic disease prevention interventions and policies targeted at adolescents.

Effectively supporting adolescent health needs requires researchers and policymakers to understand and consider adolescents' perceptions of health, chronic disease risk factors, and chronic disease prevention strategies. The present study revealed that adolescents in a high-income country such as Australia are cognisant of the health challenges faced by their generation. In contrast, research in a low-and-middle-income context established a low awareness of chronic disease risk factors and NCDs among rural youth.⁶⁷ This finding could be explained by a comparatively lower prevalence of chronic disease risk factors such as obesity in the rural communities studied and competing health priorities related to a higher level of socioeconomic disadvantage.⁶⁷ The present study established that adolescents perceived mental health disorders to be the leading health issue affecting their cohort. This finding is supported by global and national data, which indicate that one in seven adolescents globally and two in five Australian adolescents live with mental illness.^{68, 69} Further, unhealthy diet and low physical activity were perceived to be the most prevalent risk factors for chronic disease. A systematic review of 20 studies identified a statistically significant

relationship between poor dietary habits and mental health in young people.⁷⁰ Additionally, a synthesis of 32 studies found strong evidence of a correlation between depressive symptoms, ill mental health, and duration of recreational screen time.⁷¹ Moreover, a review of reviews examining physical activity and mental health in youth established evidence of an association between physical activity and improved anxiety, depressive symptoms, self-esteem and cognitive functioning.⁷² Adolescents identify mental health as a top health priority related to chronic disease risk. Australian government health wellbeing frameworks cover mental health, obesity, and chronic disease risk factor reduction as priority areas; nonetheless, approaches and strategies to manage these health challenges are disconnected.⁷³⁻⁷⁵ Diet, nutrition, and physical activity interventions are primary components of obesity prevention strategies⁴³ but not mental health frameworks.⁷⁶ Findings of the present study indicate a need for a holistic approach to adolescent health and well-being, which integrates management of chronic disease risk factors, obesity, and mental health.

Enhancing the uptake of chronic disease prevention programs for adolescents requires analyses of adolescent's insights and experiences. Overall, the present study found that adolescents perceive obesity and chronic disease prevention interventions to be important for adolescent health. However, current obesity and chronic disease prevention programs specifically targeting adolescents are usually school-based and overlook adolescents who do not go to school.⁷² Furthermore, when obesity and chronic disease interventions are implemented online or in-person, they result in only short-term improvements in health-promoting factors such as fruit and vegetable consumption and screen time.^{77, 78} Systematic reviews examining the effectiveness of adolescent-focused obesity and chronic disease prevention interventions recognise that overall, there is a scarcity of programs that consider the distinct needs of youth and engage adolescents in their design.^{77, 78}

The obesity and chronic disease prevention literature acknowledges the capacity of youth engagement to enable the development of successful programs and policies, modify health-related behaviours, support long-term results and foster capacity-building qualities in adolescents.⁷⁷⁻⁸¹ Nonetheless, the present study revealed that meaningful youth engagement in chronic disease prevention decision-making is uncommon, similar to findings from systematic scoping reviews of the peer-reviewed policy and guideline literature.^{45, 46, 79} Still, adolescents perceived the benefits of youth engagement to extend beyond chronic disease risk factor reduction alone. Similar to previous studies, this study established that adolescents recognise a relationship between participatory outcomes such as influence over decision-making processes, empowerment, having a platform for health advocacy, and the development and implementation of acceptable and relevant health-promoting activities.^{34, 82}

The present study determined that the likelihood of youth engagement in chronic disease prevention activities was not significantly linked to any specific demographic characteristics. However, the lack of statistical significance between youth engagement and socioeconomic status may have been influenced by the lower number of participants living in areas with IRSAD scores in the first and second quintiles. Consequently, the relationship between youth engagement and socioeconomic status may manifest differently in a larger more representative dataset. A significant association was seen between having prior volunteer experience and the likelihood of engagement in chronic disease prevention decision-making. The relationship between volunteering and engagement is logical, given that volunteering is linked with higher self-confidence, academic aspirations and intrinsic motivation to value community contribution.⁸³

Understanding and valuing adolescents' preferences for engagement in chronic disease prevention research, policy and guideline development ensures adolescents are not only included as a symbolic gesture in the pursuit of developing more effective interventions. Results of the present study suggest adolescents frequently lack certainty in their skill or abilities to undertake new participatory tasks or feel overburdened by engagement expectations. The present study established that adolescents require the flexibility of choice in deciding the role, participatory method, delivery, and level of engagement they are comfortable with. 'Choice' is foundational to ensuring equity and autonomy are maintained throughout the youth engagement process.⁸⁴ Skill-building opportunities and financial reimbursement provide an incentive for engagement while simultaneously providing capacity-building opportunities and experience necessary for personal growth.⁸⁵ Overall, participants in the present study were predominantly from more advantaged backgrounds. Less advantaged adolescents commonly face more complex barriers to engagement than their more advantaged counterparts; at the same time, less advantaged adolescents are at an increased risk of health disparities.⁸² Empirical research involving the engagement of high-risk and marginalised youth promoted positive youth development, systems change outcomes and obesity reduction.^{86, 87} Targeted recruitment of marginalised and less advantaged adolescents is warranted to ensure chronic disease prevention research, policies, and guidelines are acceptable and relevant to adolescents from all backgrounds.

Limitations

The present study was designed and implemented as planned. Nonetheless, logistical limitations need to be acknowledged. This study collected data from a sample of adolescents living in Australia; however, this sample may not represent the entire Australian youth population. Further, the present study was digital, and therefore, both survey and focus group

components required a digital device and internet access. Consequently, the findings of this study may not represent the views of more disadvantaged youth or adolescents living in very remote areas in Australia. Additionally, innate limitations to the study design were present. The cross-sectional study design meant that surveys and focus groups collected participant perception, experience, and preference data at a single time. The data collected can indicate the prevalence of youth engagement and associations with adolescent characteristics.⁸⁸ Nonetheless, the results of the present study are limited in that they cannot deduce an accurate cause-and-effect relationship between youth engagement, participatory outcomes and chronic disease outcomes.^{88, 89} Further, cross-sectional study methods such as surveys and focus groups rely on participants' understanding of the questions and willingness to share information and, therefore, are at risk of being affected by recall and nonresponse biases.⁸⁹ Additionally, research methods such as focus groups have inherent limitations. Focus groups are time-consuming, and participants are usually self-selected and do not represent the entire population of interest.⁹⁰

CONCLUSION

The present study established that adolescents are infrequently engaged in chronic disease prevention decision-making despite global and national adolescent health agenda recommendations. Adolescents perceive multiple benefits to youth engagement in chronic disease prevention activities, including personal benefits such as empowerment and influence and improvements in individual and societal chronic disease prevention outcomes. Largely, adolescents exhibited a willingness to engage in chronic disease prevention activities. However, ensuring youth engagement is equitable and meaningful requires researchers and policymakers to consider and address key barriers experienced by adolescents, including access, limited opportunities, and time limitations. While supporting factors that facilitate

youth engagement in chronic disease prevention decision-making, such as hybrid delivery, skill development opportunities, and compensation for time, ensure adolescents' needs are met, capabilities are enhanced, and youth engagement is ethical.

Acknowledgements

The authors acknowledge the technical assistance of Dr Alexandra Green and Dr Stanislaus Stadlmann of the Sydney Informatics Hub, a Core Research Facility of the University of Sydney.

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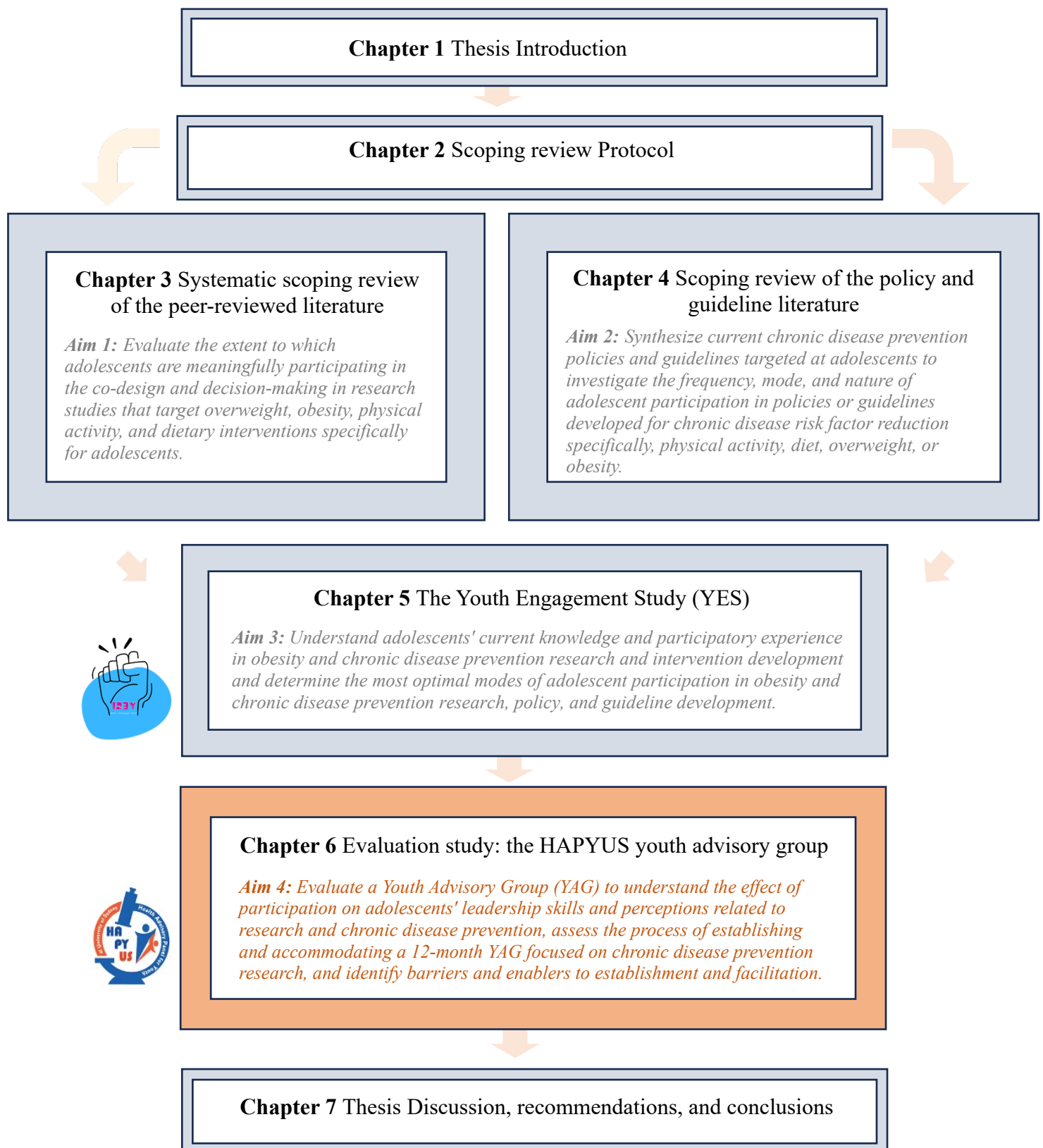
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CHAPTER SIX: EVALUATION OF THE HAPYUS YOUTH ADVISORY GROUP



Schematic Representation of Thesis Outline

Preface to Chapter Six

Chapter five presented findings from the Youth Engagement Study and addressed aim three of this thesis. Chapter five determined that in Australia, adolescent engagement in chronic disease prevention is limited and predominantly adult-led. More optimal youth engagement would require addressing common barriers such as accessibility, lack of opportunities and time. Chapter six addresses aim four of this thesis and determined that participation in a health research focused youth advisory group (YAG) led to improvements in adolescents' leadership and life skills and enhanced participants feelings of empowerment and influence over chronic disease prevention decision-making. Further, a YAG was a practical and effective method of meaningfully engaging adolescents in chronic disease prevention research.

Mariam Mandoh co-authored a comment highlighting researcher perspectives and insights gained through the establishment and facilitation of a YAG focused on chronic disease prevention research with implications for future youth engagement research practice. Furthermore, Mariam supported the YAG members to write an independent comment discussing their experience as young people participating in a YAG focused on chronic disease prevention research. The YAG members comment highlights important insights for future research engaging young people (see Appendix D). Both comments are under review with the journal *Research Involvement and Engagement*. The manuscript that forms chapter six has been peer-reviewed (submitted 1st July 2023, resubmitted with corrections according to reviewer comments on 24th October 2023) and published in *BioMed Central Public Health Journal* on 27th November 2023. Author's contributions to this manuscript are outlined in the authorship attribution statement. Chapter six has been disseminated as follows:

Published peer reviewed manuscript

Mariam Mandoh, Rebecca Raeside, Allyson Todd, Julie Redfern, Seema Mahrshahi, Hoi Lun Cheng, Philayrath Phongsavan, Stephanie R Partridge. Evaluating the effect of a 12-month youth advisory group on adolescent's leadership skills and perceptions related to chronic disease prevention research: a mixed-methods study, *BioMed Central Public Health*. 2023; 23:2344. This work is licensed under a Creative Commons Attribution 4.0 International License (CC BY 4.0).

Conference presentations

1. [NATIONAL] **Mariam Mandoh**, Stephanie R. Partridge. Enhancing nutrition research: Evaluation of the Health Advisory Panel for Youth at University of Sydney. Dietitians Australia conference, Adelaide, Australia (August 2022). Oral presentation (selected from abstract).
2. [NATIONAL] **Mariam Mandoh**, Stephanie R. Partridge. Assessing the impact of a 12-month youth advisory group on empowering adolescents in chronic disease prevention research involvement: a mixed-methods evaluation. Australian Association of Adolescent Health (AAAH) (November 2023). Oral presentation (selected from abstract).

Authorship attribution statement: This statement is to stipulate that contribution made by Mariam Mandoh in the preparation and submission of the following manuscript “Evaluating the effect of a 12-month youth advisory group on adolescent’s leadership skills and perceptions related to chronic disease prevention research: a mixed-methods study.” The convention is that the author with the principal contribution to the manuscript is the first author.

Mariam Mandoh during her PhD candidature developed the original concept of the evaluation study, Mariam Mandoh and Stephanie R. Partridge designed and refined the study protocol, designed the data collection instruments, drafted, and managed the ethics submission. Mariam Mandoh interviewed participants, collected the data, analysed the data, interpreted the results, drafted the manuscript, and coordinated submission of the manuscript. The individual roles of co-authors are listed below:

Task	Role of co-author
Designing the evaluation study	MM, RR, AT, SM, HC, PP, JR, SRP
Refining the analysis plan	MM, RR, AT, SM, HC, PP, JR, SRP
Conducting participant recruitment and follow-up	MM, SRP
Data analyses	MM, AT
Writing- review and editing	MM, RR, AT, SM, HC, PP, JR, SRP
Supervision	JR, SRP
Management of manuscript submission	MM, SRP

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Date: 05.12.2023

As supervisor for the candidature upon which this thesis is based, I can confirm that the authorship attribution statement is correct.

Dr Stephanie R Partridge

Date: 05.12.2023

RESEARCH

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Evaluating the effect of a 12-month youth advisory group on adolescent's leadership skills and perceptions related to chronic disease prevention research: a mixed-methods study

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Abstract

Background Youth Advisory Groups (YAGs) represent a promising method to engage adolescents in research of relevance to them and their peers. However, YAGs are rarely implemented or evaluated in chronic disease prevention research. The aims of this study were firstly, to evaluate the effect of participation in a 12-month YAG on adolescents' leadership skills and perceptions related to chronic disease prevention research and secondly, to evaluate the process of establishing and facilitating a 12-month YAG and identify barriers and enablers to establishment and facilitation.

Methods This study was a 12-month pre-post study. Eligible participants were adolescents (13–18-years) and current members of an established YAG. Data collection involved online surveys and semi-structured interviews at baseline, six-months and 12-months follow-up. Participatory outcomes such as self-efficacy, leadership skills, and collective participation were derived from Youth Participatory Action Research Principles (YPAR), and the Lansdown-UNICEF conceptual framework for measuring outcomes of adolescent participation. Process evaluation data were captured via meeting minutes, Slack metrics and researcher logs. Quantitative data was analysed using descriptive statistics and qualitative data was thematically analysed using a reflexive thematic analysis approach.

Results Thirteen (13/16) YAG youth advisors consented to participate in the evaluation study (mean age 16.0 years, SD 1.3; 62% (8/13) identified as female). Survey data assessing participatory outcomes found an increase in leadership and life skills scores over 12-months (+ 8.90 points). Semi-structured interview data collected over the 12-month term revealed three key themes namely: influence, empowerment, and contribution. Comparison of pre-post themes determined a positive trend at follow-ups, demonstrating improved participatory outcomes. Process indicators revealed that at 12-month follow-up the YAG was implemented as planned. Semi-structured interview data

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determined barriers to YAG facilitation included time and limited face-to-face components, while enablers to YAG facilitation included flexibility, accessible delivery methods, and a supportive adult facilitator.

Conclusion This study found that a YAG fostered positive participatory outcomes and unique opportunities for youth participants. A successful YAG based on YPAR principles requires researchers to ensure YAG establishment and facilitation is an iterative process. Taking into consideration important barriers and enablers to YAG facilitation ensures adolescent engagement in a YAG is both meaningful and impactful.

Keywords Youth advisory, Adolescents, Participation, Engagement, Action research, Chronic Disease, Prevention, Youth, Young people

Background

In society today, adolescents (10–19-years) [1] face unique and evolving challenges [2]. The combination of challenges includes, but are not limited to, the rapidly changing digital landscape, the climate crisis, inequitable food systems, economic uncertainty, and the ongoing implications of the Coronavirus Disease 2019 (COVID-19) pandemic [3–8]. These societal issues present proximal challenges for adolescents that hamper their ability to eat well and be physically active, [2] including easy access to digital environments with limited regulations and protections, low availability or affordability of healthful foods and limited options for active travel in many countries [4, 9, 10]. Unseen in previous generations, this amalgamation of challenges is not conducive to optimising health and wellbeing and subsequently adolescents, globally, are at an increased risk of developing chronic diseases earlier in adulthood [11, 12]. As researchers, we need to see these challenges through the eyes of adolescents and work with them to develop solutions [3, 10, 13].

Youth engagement in chronic disease prevention research has the potential to yield solutions to overcome such adolescent health challenges [3, 8, 14–17]. Over the past three decades the concept of youth engagement has become widely accepted [16]. Youth engagement is grounded in the 1989 United Nations Convention on the Rights of a Child (UNCRC) [18], which clearly articulates the rights of young people (<18 years) to be involved in matters of importance to them. Notably, the significance of youth engagement extends beyond basic rights, with the World Health Organisation (WHO)-UNICEF-Lancet commission [19, 20], the 2018 World Youth Report [21], and the international, multiorganization ‘make adolescent well-being a priority: call to action’ [22] identifying adolescent engagement in decision-making in health related matters as a necessity to empower adolescents to be the change makers of the future [23], improve adolescent well-being and as a criteria to achieve health related Sustainable Development Goal (SDG) targets [23, 24].

At the end of the last decade, adolescents believed their voices in the chronic disease dialogue had been tokenised and were generally dismissed [23, 25, 26]. More recently, the 2020 UNICEF-Lancet-Financial Times commission

U-report poll revealed more than 23,000 youth globally are interested in engaging in new health solutions research and call for involvement in “all stages of digital health research design, implementation and governance” [27, 28]. Such engagement in research may be realized by employing Youth Participatory Action Research (YPAR) principles, which involves adolescents constructing knowledge by identifying, researching, and addressing health problems through adolescent–adult partnerships [29]. A recent systematic review of 63 adolescent-related studies employing YPAR principles, described evidence for improvements in adolescents’ skill development [30]. However, only 19 studies were related to health, and adolescents were predominantly research participants with a passive role as opposed to research collaborators [30]. Further, a systematic scoping review investigating the mode and nature of adolescent participation in chronic disease prevention research [31, 32] identified only six studies which engaged adolescents in an adolescent-led capacity where they had influence over the entire process and outcomes of the research, while adults operated as facilitators. Of the adolescent-led studies, youth advisory groups, youth advocacy and peer leadership were shared components. Despite these studies recognising the importance of adolescent participation, participatory outcomes were rarely measured, and these studies rarely evaluated [32].

Initiatives that involve active youth participation throughout the research cycle reported improved participatory outcomes [31, 32]. Participation in a formal youth advisory capacity (e.g., Council, Board, Group) involves adolescents working in partnership with researchers at various phases of the research cycle. Evaluation of a twelve-month international youth council involving sixteen young people aged 13–23 years old found that members reported that participation had a positive impact on the transition from paediatric to adult care for youth with a chronic condition [33]. In a global context a health focused Youth Advisory Group (YAG) during the COVID-19 pandemic empowered adolescents to find solutions to adolescent health needs during the pandemic [34, 35]. Nonetheless, in 2019, researchers found that less than 1% of all empirical child and adolescent studies

published that year used a YAG to inform their child or adolescent focused health research [36, 37].

The use of YAGs epitomises an innovative [33] and practical strategy to meaningfully engage adolescents in an adolescent-led approach throughout all phases of the research cycle [38, 39] to enhance research development and translation [34, 36, 40]. However, the lack of YAG evaluation studies and measurement of participatory outcomes leaves a gap in the adolescent participation in chronic disease prevention research literature. The aims of this study were to, firstly, evaluate the effect of participation in a YAG on adolescents' leadership skills and perceptions related to research and chronic disease prevention and secondly, to evaluate the process of establishing and accommodating a 12-month YAG focused on chronic disease prevention research and to identify barriers and enablers to establishment and facilitation.

Health Advisory Panel for Youth at the University of Sydney (HAPYUS) YAG structure

The HAPYUS YAG was designed as a leadership initiative to allow adolescents to collaborate with a team of four full-time public health researchers to identify and advocate for research issues that matter to them. Adolescents were given the opportunity to contribute towards and help shape chronic disease prevention research projects [3, 41, 42]. This opportunity aimed to help create leadership and capacity building opportunities for adolescents within the research sector. Participation in the YAG aimed to help increase adolescents' self-efficacy, leadership skills and research aptitude through skill development sessions with researchers and health professionals in chronic disease prevention field. The YAG consisted of three co-chairs and 13 general members aged 13 to 18 years. Co-chairs were responsible for taking the lead on activities led by the YAG and ensured that communication and engagement on the online platform was safe, inclusive and respectful. Current evidence on research- and health-related YAGs suggests YAG of 16 members is manageable and ensures members are engaged throughout their 12-month term [36]. Sixteen members was also an appropriate size for our research team's capacity and composition [43]. Members were recruited via an application process from across NSW, Australia via paid advertising on social media and were asked demographic questions and asked to respond two questions (maximum 150 words for each) 'Why do you want to join our Youth Advisory Group? Please don't feel pressured to write a lot. We just want to know a bit more about you and why you are interested in being involved' and 'What life experiences have you had which would assist you in con-

the two questions and demographic data to ensure the group was gender balanced, with representation of adolescents from different ethnic backgrounds and regional and rural areas. All members were reimbursed with AUD\$30 gift voucher for their time each month. The YAG was responsible for collaborating with the research team on research relating to adolescents, chronic disease prevention and other associated research; identifying opportunities for development of key skills for adolescents related to research; advocating for adolescents to be engaged in research for the prevention of chronic diseases; developing and monitoring strategies and initiatives to engage adolescents in research; and ensuring broad and inclusive representation of adolescents views especially those without direct group representation. YAG members were given the opportunity to decide on a name for the group, upon consensus the YAG was named the Health Advisory Panel for Youth at the University of Sydney (HAPYUS).

Framework for collaboration

The HAPYUS YAG was informed by Youth Participatory Action Research (YPAR) principles [44, 45] and by the guidelines on adolescent participation and civic engagement, specifically the essential features of meaningful adolescent participation [46, 47] and theory of change for adolescent participation [48]. The 12-month term required youth advisors to participate in monthly 90-minute video teleconferencing youth-led meetings that consist of a 30-minute research skill development session led by the research team, guest researcher or health professional. The research skill development sessions were iterative, and topics were selected by members of the research team over the course of the YAG. Research skill topics included, but were not limited to YPAR principles, cooperative learning, and teamwork; conducting effective, beneficial, and useful research projects; advocacy; and consent and assent. Following the research skill development sessions was a 60-minute youth advisory meeting guided by the YPAR principles: (i) inquiry based, topics of discussion were grounded in youth advisors lived experience and concerns related to chronic disease prevention; (ii) participatory, youth advisors are collaborators in the research process; and (iii) transformative, youth advisors actively intervene to change research to improve the lives of youth and their communities from the negative impacts of chronic diseases. The essential features of meaningful participation state that 'adolescents need safe and inclusive opportunities that provide them with space and time to form and freely express their views and opinions'; adolescents

decisions'; 'adolescents' views must be respectfully and seriously heard by those with the power and authority to act on them'; and 'adolescents' views should receive proper consideration, and adolescents should receive timely feedback about the outcome(s) and the extent of their influence'. In-between meetings youth advisors engaged and contributed to topics of discussion and collaborated on research projects using Slack, an online communication platform. The Slack team was accessible only to the 16 youth advisors and members of the research team.

Methods

Study design

The Youth Advisory Group (YAG) evaluation was a 12-month convergent parallel mixed-methods pre-post study design, approved by the University of Sydney Human Research Ethics Committee (Approval No. 2021/749). Research techniques, using a variety of qualitative and quantitative methods are common components and strengths of youth participatory action research studies [29] and an appropriate methodology to assess the effects of participatory research on adolescents and their environment [49]. A logic model describing the YAG structure and evaluation is presented in Fig. 1. This study presents short term outcomes related to adolescents' leadership skills and perceptions related to research and chronic disease prevention.

Participants

Adolescents aged 13–18 years (inclusive), who were members of a YAG at The University of Sydney and provided informed e-consent. All youth advisors participating in the established HAPYUS YAG were invited to participate in the YAG evaluation study after the first meeting at the start of their 12-month term. The WHO recognises adolescents as young people aged between 10 and 19 years [1], however the YAG only included young people aged 13–18 years as this age range coincides with a higher level of independence and with secondary education in New South Wales, Australia where the study was conducted. Participation in the evaluation component was voluntary and a decision not to participate did not impact their youth advisory group role.

Data collection and study outcomes

Demographic data was collected at baseline and derived from standardised Australian national surveys. Participants provided self-reported data on age (years), gender identity (male, female, non-binary/gender diverse, other or prefer not to say), postcode (for categorizing socioeconomic Indexes for Areas (SEIFA) and major city, regional or remote residential areas), school attendance and language spoken at home. Participants' residential postcodes were used to determine the SEIFA Index of Relative Socioeconomic Disadvantage (IRSD) [50] quintile (quintile 1 representing the 20% most disadvantaged areas) and the Australian Statistical Geographical Standard

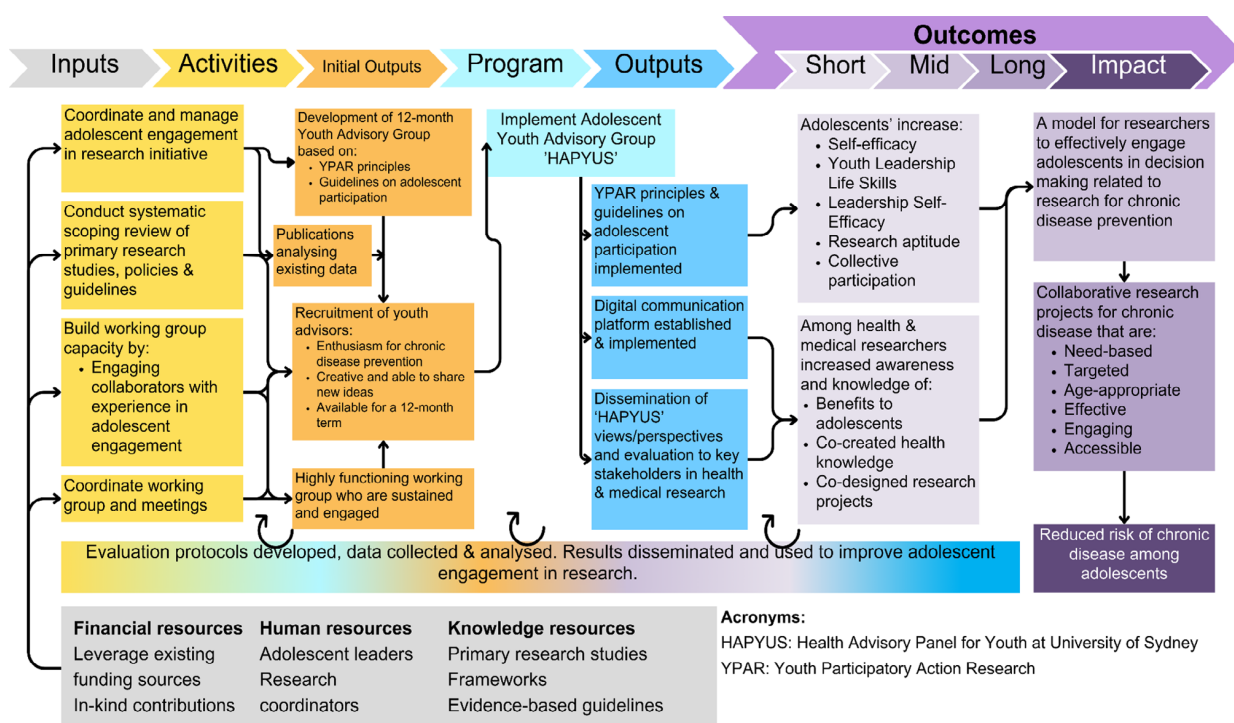


Fig. 1 YAG Evaluation Logic Model

Remoteness Areas (ASGS-RA) [51] as a measure of geographical location and relative access to services.

Outcome evaluation

Short-term outcome indicators of interest are presented in Fig. 1. and include participatory outcomes derived from the Lansdown-UNICEF conceptual framework for measuring outcomes of adolescent participation [46]. The Lansdown-UNICEF framework [46] does not provide comprehensive evaluation measures, therefore the evaluation framework was adapted using established surveys which have demonstrated good reliability and validity in adolescent populations [52–56]. Table 1. describes the YAG participatory outcome indicators of interest and the chosen assessment tool. The General Self-Efficacy scale (GSE) [52] measured self-efficacy, self-confidence and ability to make changes, the Leadership/ Teamwork Self-Efficacy Scale (LTSES) [53, 54] assessed changes in leadership, teamwork, and collaboration indicators and the Youth Leadership Life Skills Development Survey (YLLSDS) [55, 56] measured youth leadership and engagement skills such as communication, decision-making, learning, confidence, problem-solving and group work in the participatory research setting (Table 1.).

A purpose built semi-structured interview guide was developed by the research team to encompass and build upon the scope of participatory outcomes outlined in the Lansdown-UNICEF framework [46] and the theory of change for adolescent participation [48]. The semi-structured interview questions were open-ended and broad to contextualise the nature and extent of participatory experience, research skills, confidence, experience of being listened to and taken seriously, making decisions, sense of engagement and any unexpected outcomes of involvement in participatory research activities that may emerge. Baseline semi-structured interviews were conducted by two members of the research team (MM, SRP). At baseline all youth advisors were new to the study and did not know the research staff. At six-months follow-up semi-structured interviews were conducted by one researcher (MM), who had limited involvement in the youth advisory meetings and activities. To avoid courtesy bias, 12-month semi-structured interviews were conducted by one researcher (AT), who was external to the YAG study team and unknown to the study participants.

Quantitative survey data and qualitative semi-structured interview data were captured from participants at baseline, six-months, and 12-months except the

Table 1 Description of YAG outcome evaluation indicators and assessment

Participatory Outcome indicator (Based on the Lansdown-UNICEF framework)	Assessment Outcome measured	Survey	Description	Reliability and Validity
Participatory outcomes associated with empowerment and influence, including: i) Sense of self-worth, self-esteem, or efficacy , - characterised by self-confidence and the ability to make changes. ii) Being taken seriously , - connected with sense of influence, motivation, potential to make a difference and opportunities. iii) Making decisions , - characterised by self-confidence, improved knowledge, sense of responsibility and adults' confidence in adolescents' abilities; and iv) Public or civic engagement , - related to learning and knowledge, potential to influence issues of importance, sense of responsibility, opportunities and collaboration [45].	Self-efficacy, self-confidence, ability to make changes	General Self-Efficacy scale (GSE) [51]	The GSE is 10-item scale, with responses made on a 4-point scale ranging from 'not at all true'=1 to 'exactly true'=4. The total score for the ten GSE items ranges from 10 (lowest) to 40 (highest total score), where higher scores indicate higher GSE.	In data from 23 countries, GSE was found to be valid and reliable with a Cronbach's alpha between 0.76 and 0.90 [51].
	Leadership, teamwork, and collaboration indicators	Leadership/ Teamwork Self-Efficacy Scale (LTSES) [52, 52]	The LTSES is a 10-item scale designed to measure perceived ability to collaborate, communicate with and lead others within a research team context. Items are measured on a 5-point Likert-type scale ranging from 'strongly disagree'=1 to 'strongly agree'=5. The total score for the ten LTSES ranges from 10 (lowest) to 50 (highest total score). There are two subscales for teamwork factors and leadership factors ranging from 5 (lowest) to 25 (highest sub score) for both subscales.	The LTSES has a good internal reliability and validity, with Cronbach's alpha > 0.50 [52, 53].
	Youth leadership and engagement skills, such as: communication, decision-making, learning, confidence, problem-solving and group work in the participatory research setting	Youth Leadership Life Skills Development Survey (YLLSDS) [54, 55]	The YLLSDS is a 30-item survey that ask participants to select a response of 'no gain'=0 to 'a lot of gain'=3 when reflecting on their experience being a part of the YAG. The total score for the 30 YLLSDS items ranges from 0 (lowest) to 90 (highest total score) indicating the most gain in leadership life skills.	The YLLSDS has a high internal reliability and validity with Cronbach's alpha > 0.90 [54].

YLLSDS, which was only administered at 6-months and 12-months. Surveys were administered online via the Research Electronic Data Capture (REDCap) platform and semi-structured interviews were conducted via Zoom teleconferencing software.

Process evaluation

To evaluate the process of establishing and accommodating a 12-month YAG and address aim two, we measured activities and outputs to indicate whether the program was implemented as planned. We documented meeting minutes to capture participant's attendance at monthly Zoom meetings from all 16 members. Slack workspace metrics over the 12-months were downloaded and analysed, including number of active weekly members, total number of messages sent, where conversations happened, and the number of files uploaded. Further, barriers and enablers to establishing and accommodating the 12-month YAG were identified from ongoing correspondence with participants via Slack and as feedback in monthly Zoom meetings.

Data analyses

Descriptive statistics were reported for continuous and categorical survey data. Semi-structured interviews were audio recorded on Zoom, transcribed verbatim and thematically analysed in NVIVO version 12.0 (QSR international). Braun and Clarke's reflexive thematic analysis approach was determined to be the most suitable method of analysis of the qualitative semi-structured interview data [57, 58]. Reflexive thematic analysis is an approach involving reflexive, repetitive engagement with the dataset to generate a strong analysis [59, 60]. Braun and Clarke emphasise thematic analysis to be a recursive process, outlining six phases to guide analysis: (1) Familiarisation with the dataset; (2) Coding; (3) Generating initial themes; (4) Developing and reviewing themes; (5) Refining, defining, and naming themes; (6) Writing up. Thematic analysis was led by one researcher (MM), who coded the interviews, a second researcher (AT) crosschecked 20% of interviews for consistency. MM and AT then met to compare, discuss, and resolve any inconsistencies. Direct quotations from the semi-structured interviews were used to demonstrate consensus among participants and individual opinions regarding key themes. The shift in themes over the 12-month study period (negative, positive, neutral) were discussed between two researchers (MM and AT) until consensus was reached.

Results

Thirteen of the 16 members of the youth advisory group provided informed consent to participate and completed baseline assessments. Eleven and ten participants

completed assessments at 6-months and 12-months, respectively. The mean age of participants was 16.0 years, Standard Deviation (SD) 1.3. Eight (8/13; 62%) participants were enrolled in the final two grades of high school. Eight (8/13; 62%) participants identified as female. Five (5/13; 38%) participants reported a language other than English as the main language spoken at home. Four (4/13; 31%) participants reported living in a rural or remote suburb. Eight (8/13; 62%) participants lived in a suburb with an IRSD score in the top two quintiles, reflecting a relative lack of disadvantage and higher socio-economic status.

Outcome evaluation data

Table 2 presents results on the key participatory outcomes. Participants reported high mean scores on general self-efficacy, leadership, and teamwork skills scales at all timepoints with no meaningful change over the 12-month period. However, when reflecting on their experience participating in the YAG in the YLLSDS at six- and 12-months intervals, an increase in mean scores was apparent.

Thematic analysis

Table 3 presents the three main themes and sub-themes, with illustrative quotes, which were identified from the semi-structured interview data, namely: (1) influence, (2) empowerment, and (3) contribution.

Influence

Influence was reflected through the desire of participants to have the power to affect change in chronic disease prevention and health research. Within the central theme of influence, three overlapping but separate sub-themes were identified: representation, voice, and platform.

Participants perceived influence as a product of adolescent 'representation'. Representation was integral to young people perceiving their opinions as valued. Participants also considered adolescent representation necessary for the development of research and interventions that are relevant to young people, to guarantee inclusive research and ensure relatable role models. Participants felt underrepresented in research at baseline, which transformed to feeling represented at follow-up. The evolution of influence through giving young people a voice developed from feeling unheard to being given an active voice in decision-making. Participants associated influence with the need for a 'platform' or 'safe space' to have their voices heard and influence matters of importance to them. Participants recognised YAGs as an example of an effective 'platform' for them to effectively participate in chronic disease prevention research at baseline and this appreciation remained constant over the 12-month study period.

Table 2 Effect of participation in a youth advisory group on adolescents' self-efficacy, leadership, and teamwork skills

Outcome measures	Baseline (n = 13)	6-months (n = 11)	12-months (n = 10)	Mean difference ² (baseline-6 months)	Mean difference ² (6-12 months)	Mean difference ² (baseline-12 months)
GSE total (10–40)						
Mean score (SD)	34.08 (3.77)	31.55 (3.83)	33.90 (3.54)	-2.53	+ 2.35	-0.18
Median score (mode)	34 (39)	31 (28)	35 (36)			
LTSES total (10–50)						
Mean score (SD)	46.23 (3.83)	44.36 (5.14)	45.50 (4.45)	-1.87	+ 1.14	-0.73
Median score (mode)	47 (50)	46 (43)	46.5 (50)			
LTSES Leadership factors (5–25)						
Mean score (SD)	23.08 (2.22)	22.91 (2.47)	22.90 (2.89)	-0.17	-0.01	-0.18
Median score (mode)	24 (25)	23 (25)	23 (25)			
LTSES Teamwork factors (5–25)						
mean score (SD)	23.15 (2.07)	21.45 (3.88)	22.60 (2.17)	-1.70	+ 1.15	-0.55
Median score (mode)	23 (23)	23 (23)	23 (24)			
YLLSDS¹ (0–90)						
Mean score (SD)	-	62.45 (17.05)	71.40 (13.61)	-	+ 8.90	-
Median score (range)		63 (34–90)	72.5 (45–89)			

Abbreviations

MD: Mean Difference

GSE: General Self-Efficacy Scale- 10-item scale: scores range from 10–40

SD: Standard Deviation

LTSES: Leadership/ Teamwork Self-Efficacy Scale- 10-item scale: scores range from 10–50

YLLSDS: Youth Leadership Life Skills Development Survey- 30-item scale: scores range from 0–90.

¹ No baseline data collected as this survey reflects on gains from the experience being studied.² The change in mean score between the two time points.**Empowerment**

The theme of empowerment is embodied in the process of the participants gaining confidence especially in controlling their own life and claiming their rights. Three separate but intertwined sub-themes of empowerment were identified: skill development, gaining knowledge and, opportunities. Participants recognised skill development as central to youth empowerment. At baseline skill development was recognised as important for “*study or your career advancement*” with research skills necessary for developing critical thinking skills, at follow-up skill development was also correlated with improved self-efficacy. At baseline participants reported a desire to acquire knowledge about chronic diseases and prevention for the purposes of personal development, to benefit peers, to help with future study and career aspirations, and to learn about research. At follow-up gaining knowledge was associated with increased confidence and self-efficacy. Initially participants felt their ability to make a difference in the chronic disease prevention space was connected to whether they could “*access opportunities*”. At follow-up, participants felt “*more competent*” because of the “*opportunities*” and “*doors that have opened and connections*”.

Contribution

The desire for participants to be active contributors in health research was evident throughout the study. Contribution as a main theme had three distinct but inter-connecting sub-themes: meaningful, tangible outputs, and impact. At baseline participants expressed a lack of ‘meaningful’ contribution on matters concerning them, at follow-up participants reflected positively on their experience of involvement in the YAG and contrasted it to previous experiences in which youth engagement felt like a tokenistic or ‘tick box’ task. Contribution towards ‘tangible outputs’ was another important factor participants valued. At baseline ‘tangible outputs’ were perceived to help improve chronic disease burden and improve access to health promoting resources. At follow-up, tangible outputs such as an essay published in a peer-reviewed journal [3] enabled participants to comprehend the potential of their contribution.

Contribution was significantly underpinned by the desire for participants to make an ‘impact’ on health research related to adolescents. At baseline ‘impact’ was more personal and related to a sense of purpose and being helpful. At follow-up participants perceptions of impact transformed into enabling young people to be impactful in prevention efforts on a personal and

Table 3 Themes and sub-themes identified from semi-structured interview data

Theme	Sub-theme	Baseline	Follow-up	Shift* (positive, negative, neutral)
Influence	Representation	<i>"Young people are very under-represented in society, and everyone should be listened to what they think and be able to express that." (M, age 14)</i>	<i>"there's a lot of voices in this space of people who are middle aged or older and I really like that this group brings representation to younger voices" (F, age 17)</i> <i>"I think the most exciting part of it was to be able to represent them (youth) in like, public articles like the Sydney Morning Herald" (F, age 16)</i>	Positive
	Voice	<i>"I think the voices of young people are still not heard enough" (M, age 16)</i>	<i>"I wanted, like, to really be able to have my voice heard, and help other people who are struggling with chronic illnesses and diseases. And I feel like that this research project actually did a lot to support that" (F, age 15)</i>	Positive
	Platform	<i>"Being part of those groups including these advisory groups gives me safe space to express my opinions and use my voice for what I truly believe in yeah." (F, age 16)</i>	<i>"The group was a really good platform for the issues that I'm interested in, which is youth advocacy and youth health research and obesity research" (M, age 16)</i>	Neutral
Empowerment	Skill development	<i>"We need to learn to be discerning and critical in our research for whatever we choose to do in life" (F, age 17)</i>	<i>"My skill set has been so broadened by this experience I feel that I probably now would have far more credibility" (F, age 17)</i>	Positive
	Gaining knowledge	<i>"I want to learn a lot and just learn more and if in any way give back whether that's through research or being able to just support research." (M, age 17)</i>	<i>"The confidence and the knowledge I have gained, I feel like it does boost your knowledge and makes you feel like you could lead, and you could do something and take on leadership roles." (F, age 15)</i> <i>"I always feel a little bit more empowered after having these meetings and like I can take action with the knowledge I have gained after the meeting." (F, age 17)</i>	Positive
	Opportunities	<i>"I think I have the potential to make a difference but it's about whether or not I can access opportunities and avenues where I can actually make change." (F, age 17)</i>	<i>"...having opportunities to speak up about matters that affect me and those of my age." "Right now, I'm more competent about being able to do things and being able to change stuff" (M, age 14)</i>	Positive
Contribution	Meaningful	<i>"[There's] not an awareness young people are keen to be involved in these decisions and it's often just forgotten." (F, age 17)</i>	<i>"You can really strike the comparison between when you are being actively engaged with and active participation is encouraged. And then there's also research groups that they want to have youth consultants so that they can say they have a youth voice, but they don't actually want to consult with you. So, I think that's something that this group does really well, like it is youth focused and youth based and all opinions that are shared are our own, which is really wonderful." (F, age 17)</i>	Positive
	Tangible outputs	<i>"I want to create technology to help people who suffer from chronic illnesses and like diseases as well and all that sort of stuff and make it more accessible within other areas like rural and regional areas as well." (F, age 15)</i>	<i>"With the lancet article that has reached up to thousands of people, I think we've definitely been able to make some sort of change in the world as a group." (M, age 16)</i>	Positive
	Impact	<i>"I can have a voice for youth it enables me to have an impact on I guess the broader the wider sort of landscape for youth in the future and allows me to help." (M, age 16)</i>	<i>"With different conferences and being able to talk there and attending the in real life events. Talking to researchers and then yeah, voicing our opinions on Sunrise and in Sydney Morning Herald. Definitely has created an impact." (M, age 16)</i>	Positive

Abbreviations

F: Female

M: Male

*The shift represents the change of perception status from baseline.

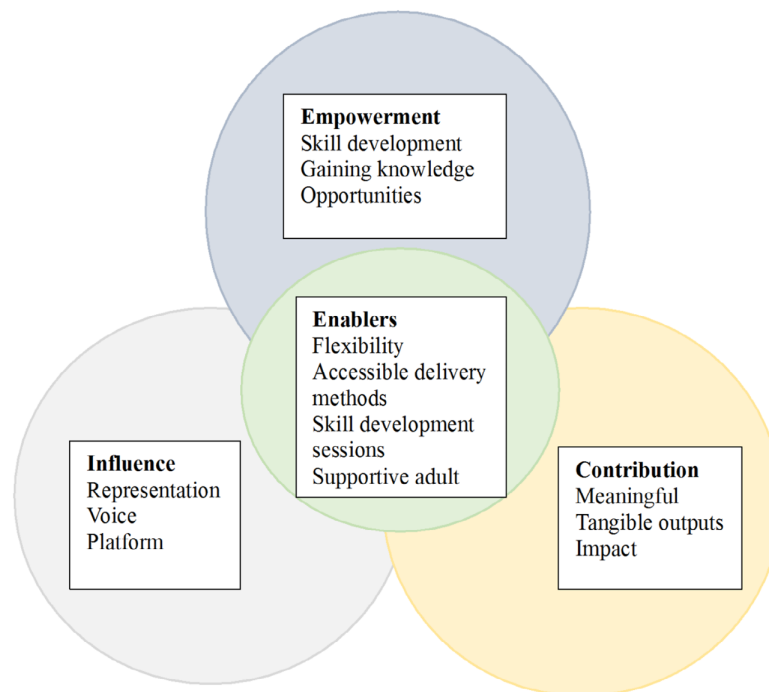


Fig. 2 The Intersection between participatory outcomes and process outcomes of a YAG evaluation

Box 1 Supporting quotes for intersecting themes identified from semi-structured interview data

Example 1. Female, age 15:

"When I applied, it was more or less just, I wanted to learn a little bit more about health research, I wanted to contribute to health research, I hadn't seen any opportunities similar to like, the youth advisory group", "throughout the programme, our opinion as like younger people was so valued, and we were able to contribute so heavily to it. And it was just really great to know that everyone wanted to know what we thought", "we have made a bigger difference, and it can be even bigger than that."

Example 2. Male, age 14:

"I feel that there's a good platform there for any issues that I feel that I [want to] act upon and yes and you feel that as a member of this youth advisory group you can make changes that we can I mean in this article already it's been it's been shown that we can if we come together and collaborating with that we can definitely make change and that just translates into the individual people in the YAG going off and also being like inspired that they can make change so yes we can definitely make change."

community level. Further, recognising that contribution to tangible outputs and opportunities also created impact on research and the broader society *"with different conferences and being able to talk there and attending the in real life events. Talking to researchers and then yeah, voicing our opinions on Sunrise and in Sydney Morning Herald. Definitely has created an impact."*

Intersecting themes

Overall, although themes were unique and evolved over the duration of the 12-month YAG term, the YAG framework for collaboration was informed by participatory action research principles which meant that themes and sub-themes were also naturally intertwined (Fig. 2). Participants demonstrated an awareness that learning, knowledge, access to opportunities and capacity to contribute were interlinked to youth empowerment and the ability to have influence over and impact matters of

importance to adolescents (Box 1, example 1). Furthermore, participants perceived a platform, meaningful engagement, and tangible outputs to be interrelated with empowerment, the ability to have influence, and impact (Box 1, example 2).

Process evaluation data

Eight online zoom meetings (mean meeting time 58 min, range 35 to 88; mean attendees 8, range 3–16) and one in-person workshop (7 h total, 9 attendees) were held over the 12-month term. Meetings were held outside of school hours (between 4pm to 7pm) on weekdays (Monday to Friday) or purposely scheduled for school holidays to accommodate the youth advisors' varying schedules (including, but not limited to, study, family, and casual work commitments). Online polls were conducted on Slack with three options to select a day and time most youth advisors were available. Polls were youth friendly,

and members voted using an emoji icon. There were no meetings for three months of the 12-month term due to high school exam periods (November 2021, June 2022) and unplanned youth advisory group events (media engagements regarding youth advisory group's published essay [3], which required the youth advisors' time for interviews and photos).

At the first online meeting, all 16 members agreed Slack was the best platform for group activities for the 12-month term and all 16 members joined the Slack workspace when it was established on 18th October 2021. As well, four members of the research team joined as administrators. Of the total 20 members, there were a median of 15 actively weekly members (range 0–19). There was a total of 1,681 messages sent (53% in public channels, 15% in private channels and 32% in direct messages). Administrators sent 789/1681 messages in total (46.9%) and youth advisors sent 892/1681 messages in total (53%; range 1–186 per advisor). Over the 12-months, there was a total of 183 files uploaded for collaborative

research or for knowledge sharing. At first, multiple channels were created in the Slack workspace for different research projects and types of conversations. However, members agreed there should be minimal channels for better communication and provided this feedback to the research team. As such, a total of four channels were established, one for general communication and three others for the key research projects the members contributed to over their 12-month term.

Barriers and enablers to YAG establishment and facilitation

Table 4 presents barriers and enablers to YAG establishment and facilitation. Barriers included time and limited face-to-face components. These barriers were largely due to the nature and complexity of engaging adolescents and COVID-19 restrictions during their 12-month YAG term. Enablers to YAG establishment and facilitation were determined to be flexibility, accessible delivery methods, skill development sessions and a supportive and organised adult facilitator. The barriers and enablers described

Table 4 Barriers and enablers to YAG establishment and facilitation and lessons learnt

Barriers and enablers	Supporting participant quote	Lessons learnt
Time (barrier)	<i>"I think another barrier to sort of expressing my opinions with young people's health and activity have certainly been time I mean like a lot of us are very busy these days and part of that is because we are doing our own health and activities but also there isn't enough priority given to our wellbeing often it's forgone in favour of school marks or that sort of thing" (F, 17)</i>	The research team needs to be flexible with working hours: - Schedule meetings after school hours or in school holidays - Ensure suitability of meeting times by giving youth advisors the opportunity to vote for meeting date and time via a Slack poll.
Limited face-to-face components (barrier)	<i>"...the lack of face to face, because I struggle with like online stuff, because I get really nervous." (F, 15)</i>	Use alternate forms of communication and collaboration to suit a variety of needs e.g., use a platform such as Slack: - Provides channels for discussion on various research projects. - Enables youth advisors to get to know each other better and develop friendships.
Flexibility (enabler)	<i>"I found the most helpful it's very flexible like if you just can't make it that one day or you get to choose like the meeting times on voting if you can't make it that one day it's ok going to be recorded you can still participate and it's also like it gives you opportunities." (F, 15)</i>	The research team needs to be flexible and adaptable to cater to the needs and time of school aged youth. - Meeting times scheduled outside of regular working hours. - Meeting attendance optional, and meeting recordings uploaded to Slack for viewing at youth advisors' convenience.
Accessible delivery methods (enabler)	<i>"The use of sort of virtual collaboration so the use of online platform slack and the zoom meetings that we have has really facilitated a lot of discussion both within the meetings but also outside of it, so the groups become quite dynamic and able to accomplish a lot even though we only meet periodically" (F, 17)</i>	Cater to the needs of geographically distant participants: - Virtual collaboration via multiple methods e.g., Zoom and Slack.
Skill development (enabler)	<i>"The skill development sessions because they were targeted, they I think they accomplished a lot more than trying to sort of talk about the whole broad world of academic research" (F, 17)</i>	Ensure meetings enhance participants skills and capacity by incorporating opportunities for: - Gaining knowledge about academic research, and - Skill development
Supportive & organised adult facilitator (enabler)	<i>"[Researcher name] supporting us through all of it. She really guided us through what it means to be a leader." (F, 16)</i> <i>"Very friendly group. It was led very well. So, it was all well organised." (M, 16)</i> <i>"It's just really like a really nice environment because everybody is so understanding so kind so nice." (F, 15)</i>	A YAG requires a dedicated and organised adult facilitator to: - Build rapport with participants and create a trusting environment. - Support participants to navigate the complexities of academic research. - Connect participants with opportunities and ensure participants are not being tokenised.

Abbreviations

M: Male

F: Female

here are the perception and experience of participants. However, ensuring YAG establishment and facilitation was an iterative process allowed researchers to progressively overcome barriers and strengthen enablers to ensure meaningful adolescent engagement (Fig. 2.).

Discussion

The current evaluation study found that adolescents participating in a YAG perceive adolescent engagement in chronic disease prevention and health research decision-making as essential to both youth capacity building as well as improving youth involvement in chronic disease prevention research. Participation in a YAG led to improvements in indicators of adolescents' leadership and life skills development. Adolescents reported high general and leadership and teamwork self-efficacy at baseline with no meaningful changes over the YAG term. Further, key outcomes of YAG participation included influence, empowerment, and contribution. Adolescents' perceived influence to be linked to representation, a youth voice in health advocacy and being provided a platform or safe space to participate. Furthermore, empowerment was perceived to be linked to skill development, gaining knowledge and access to opportunities. Contribution was recognised through adolescents engaging in a meaningful capacity, contributing towards tangible outputs, and making an impact. Overall, our findings indicate that participation in a YAG had a positive effect on adolescents' skill development as well as perceptions related to research and chronic disease prevention. Process data revealed synergies between process indicators which enable YAG facilitation and enhanced participatory outcomes, indicating that a YAG is a feasible method to meaningfully engage adolescents in all stages of research processes.

Overall, there is limited evidence of the impact of participation in a YAG on adolescent's or chronic disease prevention research [32]. Nonetheless, our study results are consistent with findings from the broader YPAR literature. A systematic review of 63 YPAR studies in the United States found the most common outcomes developed by youth to be those related to agency and leadership followed by academic or career outcomes [30]. Furthermore, another systematic scoping review found meaningful collaboration between researchers and youth enabled adolescents involved in participatory research the ability to influence research and development processes [32]. In partnership with the research team, an outcome of our YAG was a published an essay in a peer-reviewed journal [3]. This example of a tangible output of adolescent participation from a YAG that enabled adolescents to highlight their perspective on youth health prioritise and served as a foundational element in the research teams youth health research agenda [3]. A recent

systematic review and meta-analysis of methods and effects of engaging relevant consumers in research determined the enhanced relevance and positive outcomes for health research resulting from youth engagement [17]. Similarly, global consultations with young people have confirmed this message, youth calling for transgenerational equal partnerships with young people and influence over agenda setting as a crucial step to securing adolescent wellbeing for the future [27, 28, 61].

Our results fill a gap in the chronic disease prevention literature, demonstrating the potential adolescent engagement provides for enhancing research practice but also upskilling and empowering adolescents [30]. Improvements in YAG members perceived skill development and capacity building was an expected outcome of YAG participation. Meaningful and effective adolescent engagement is often inhibited by difficulties including the need to prepare and upskill youth for engagement activities [40, 62]. To overcome this issue and enhance participatory research quality, the research team integrated skill development sessions into the regular YAG monthly meetings. Skill development sessions were reported by adolescents to be a key enabler to ongoing participation in the YAG. A scoping review of youth engagement in chronic disease prevention literature [31, 32] determined that participatory activities have the potential to improve capacity building, empowerment, influence, and confidence. It was also evident that increasing adolescent involvement in the form of youth advisory groups, co-design and decision-making processes contributed to more meaningful obesity and chronic disease prevention associated outcomes. Meaningful participation led to improvements in empowerment and influence [63, 64] of the participating youth [65] and their peers [66–68].

The YAG provoked unanticipated interest across multiple sectors including academia, public, media and government sectors. Interest in the YAG's youth-led health research provided further engagement and advocacy opportunities for adolescents and enhanced their reach and influence. The YAG gave adolescents a platform to raise awareness and appreciation of the need for youth representation and a voice in the chronic disease prevention research agenda. A systematic review assessing YPAR in youth substance use prevention research found that adolescent participation increased community awareness of the problem and potential solutions [69]. Furthermore, adolescent engagement supported change by generating youth specific research, data and prevention materials [69].

The process of establishing and facilitating a YAG focused on health research required a supportive, iterative, and flexible approach to ensure adolescents remained engaged in a fulfilling and meaningful capacity. Similarly, although in a mental health context, a

critical and reflective attitude to overcoming barriers was found to be pivotal to increasing youth engagement and enhancing youth related research outcomes in the Matilda Centre Youth Advisory Board [40] and the Oxford Neuroscience, Ethics and Society Young People's Advisory Group (NeurOx YPAG) [70]. The CO-CREATE project for obesity prevention research and policy action also identified the need for ethical considerations when engaging youth [71]. Still, the large number of participants and logistics of a multi-country study amplified barriers to engaging adolescents [71]. Similarly to our YAG, the CO-CREATE project highlights the requirement of a flexible and youth specific framework to ensure the process of adolescent participation is safe and empowering [72].

Our study demonstrated that a YAG exemplifies a novel youth engagement method which provides adolescents the opportunity to influence all stages of the research and development process. Advisory groups with adult participants have demonstrated improvement in health research and knowledge translation for healthy public policy [73]. Similarly, the literature indicates that meaningful adolescent engagement based on YPAR principles has the potential to generate individual capacity building and health benefits for participating youth [23, 30, 61, 74]. On a broader scale, participatory research has been associated with improvements in health outcomes by ensuring research is relevant and acceptable to those it is intended for [75]. Adolescent engagement enhances research agendas and methodology by ensuring research conduct is targeted and specific to youth [30, 43]. Evidence from a Canadian YAG focused on child participatory research found that youth involvement adds a critical ethical element to research methods [76]. Moreover, youth advisory structures with a specific research focus such as health services research in pharmacy [75] and overweight and obesity prevention [77] have been shown to add value to enhancing research and implementing youth centred solutions. Furthermore, meaningful youth engagement and co-design of research via participation in a YAG, has the potential to improve distribution of medical research funding [78]. Directing chronic disease prevention research funding towards research priorities and interventions which are targeted, and identified by the target population as relevant and acceptable is key to improving population based health solutions [79].

Limitations

We endeavoured to conduct the study as rigorously as possible however there are some limitations to the study which are important to note. Our research study was predominantly based on qualitative research methods. Innate limitations of qualitative research [80] include that the quality of the research is reliant on the specific skills

of the researcher and therefore more easily influenced by the researcher's individual subjective biases and interests. Participant responses may have been influenced by the presence of the researcher during data collection methods such as the semi-structured interviews.

Additional limitations specific to the development and facilitation of the YAG should be noted. Most of the adolescents who applied to participate in the YAG either had previous leadership experience and were keen to have a career in the research or health sectors. Further, participants recruited to participate in the YAG were chosen through a selection process in which participants who had more research or leadership experience or demonstrated potential were more likely to be selected. Survey and interview data conducted at baseline evidenced this via high baseline self-efficacy, leadership, and teamwork skills. It is apparent that adolescents with high baseline self-efficacy and leadership skills are more likely to apply for such opportunities, however it is important to identify how to engage a diverse sample of adolescents in chronic disease prevention research. Future YAGs may consider baseline assessments of self-efficacy to ensure adolescents with less belief in their general capacities and leadership and teamwork capacities can participate and develop their skills. Furthermore, only 16 adolescents were recruited to participate in the YAG. This small sample size was important as it enabled participants to build rapport with the research team, while a larger group may have increased feelings of tokenism and made meaningful adolescent engagement difficult [70]. Finally, the projects the YAG participants contributed to are ongoing, therefore it is difficult to evaluate the effect of their participation on research outcomes.

Conclusion

Meaningful youth engagement in a YAG based on YPAR principles generated numerous benefits for adolescents personally and for chronic disease prevention research more broadly. Improvements in participating adolescents' leadership skills, together with enhanced participatory markers of empowerment and influence enabled adolescents to advocate for and contribute towards chronic disease prevention research for young people. Enhanced participatory outcomes were linked to successful facilitation of a YAG, which required the research team to be iterative, flexible, and adaptable in their approach, thus strengthening enablers and overcoming barriers to establishment and facilitation of the YAG.

List of abbreviations

YAG	Youth Advisory Group
YPAR	Youth Participatory Action Research
UNICEF	United Nations Children's Fund
COVID-19	Corona Virus Disease 2019
UNCRC	United Nations Convention on the Rights of a Child
WHO	World Health Organization

SDG	Sustainable Development Goal
AUD	Australian Dollar
SEIFA	Socioeconomic Indexes for Areas
IRSD	Index of Relative Socioeconomic Disadvantage
ASGS-RA	Australian Statistical Geographical Standard Remoteness Areas
GSE	General Self-Efficacy scale
LTSES	Leadership/Teamwork Self-Efficacy Scale
YLLSDS	Youth Leadership Life Skills Development Survey
REDCap	Research Electronic Data Capture
SD	Standard Deviation
NeuroX YPAG	Oxford Neuroscience, Ethics and Society Young People's Advisory Group

Acknowledgements

The authors wish to thank all the participants who took part in this study for their time and contribution.

Author Contributions

Conceptualisation, methodology, investigation, and writing- review and editing (MM, RR, AT, PP, SM, HLC, JR, SRP). Writing- original draft preparation (MM), supervision (JR and SRP). All authors have read and agreed to the published version of the manuscript.

Funding

The Youth Advisory Group is funded by the Australian Government Department of Health Medical Research Future Fund Primary Care Grant (2006315). The in-person Youth Advisory Group workshop held on 14th July 2022 was funded by the Charles Perkins Centre at The University of Sydney. SRP is supported by a National Heart Foundation Future Leader Fellowship [Grant number: 106646]. JR is funded by a NHMRC Investigator Grant (GNT1143538). The funders had no role in the study design, collection, analysis, and interpretation of data or writing of the manuscript.

Data Availability

All data generated or analysed during this study are included in this published article.

Declarations

Ethics approval

The study was performed in line with the principles of the Declaration of Helsinki. This project received ethics approval by the Human Research Ethics Committee (HREC) of the University of Sydney, date: 27.10.2021, approval No. 2021/749.

Consent to participate

The HREC of the University of Sydney approved (No. 2021/749) the lack of receiving parent/ legal guardian informed consent for those participants under the age of 18 years. Other participants provided informed e-consent on Research Data Capture (REDCap) to participate in the youth advisory group evaluation study.

Consent for publication

Not applicable.

Competing interests

The authors declare no competing interests.

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Received: 1 July 2023 / Accepted: 21 November 2023

Published online: 27 November 2023

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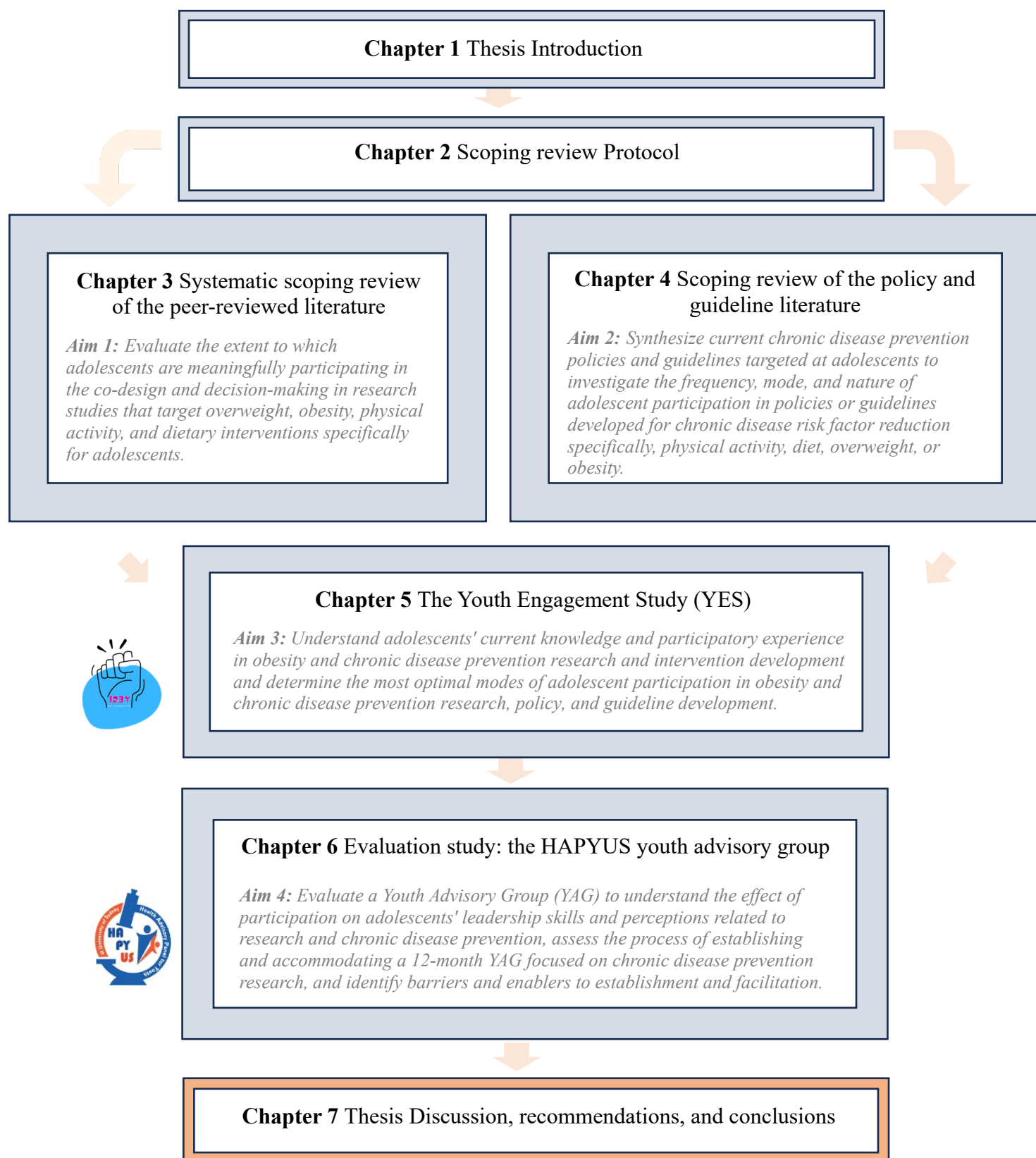
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CHAPTER SEVEN: THESIS DISCUSSION, RECOMMENDATIONS AND CONCLUSIONS



Schematic Representation of Thesis Outline

DISCUSSION

This thesis evaluated youth engagement in obesity and chronic disease prevention research, policy, and guideline development. This chapter summarises the key findings, important implications for practice, recommendations for future research, and limitations of this research.

Summary of key findings

Overall, systematic review evidence found that most studies do not engage adolescents in obesity and chronic disease prevention research, policy, and guideline development (Chapters 3 and 4). However, a small body of evidence from this review indicated that engaging adolescents in research positively impacts research outcomes (Chapter 3). Chapters 5 and 6 found that adolescents want to be engaged in obesity and chronic disease prevention decision-making, and when they are engaged, there are positive impacts on their skills and capabilities. This thesis set out to evaluate the current evidence-based literature on youth engagement in obesity and chronic disease prevention research, policy, and guideline development and to establish recommendations on best engaging adolescents in chronic disease prevention decision-making.

A systematic scoping review (Chapter 3) examined the state of adolescent engagement in chronic disease prevention primary research studies. Seventy-one studies engaged adolescents in a meaningful capacity and were included in the review. Adolescent engagement was assessed based on the Lansdown- UNICEF conceptual framework for measuring outcomes of adolescent participation.¹ Overall, thirty-five studies engaged adolescents in the research process in a consultative capacity, where they could give opinions or provide feedback. Twenty-nine studies employed a collaborative approach, where

adolescents were partners in the research process. Six studies utilised an adolescent-led approach in which adolescents influenced research decision-making and outcomes. Further, this review found that when engaged, adolescents were usually involved in the formative stages of the research process. At the same time, only eight studies reported engaging adolescents throughout all research cycle stages. A scoping review (Chapter 4) explored adolescent engagement in published policies and guidelines targeted at obesity and chronic disease prevention in adolescents. A total of nine policy and guideline documents met the inclusion criteria. Five national and four international documents engaged adolescents in a meaningful capacity during the policy and guideline development process. Like chapter 3, chapter 4 reported that adolescent participation is primarily limited to consultative methodologies in the formative stages of policy and guideline development. No policy or guideline was found to engage adolescents in all policy and guideline development stages. Both reviews (Chapters 3 and 4) found that research, policies, and guidelines engaging adolescents often include representation from underprivileged groups. However, most studies, policies, and guidelines do not report the characteristics of engaged adolescents, indicating that youth participation may be considered a formality rather than an approach that is important in and of itself; this is further implied by the lack of evaluation of participatory outcomes reported (Chapter 3 and 4).

The Youth Engagement Study (YES) (Chapter 5) used a mixed-methods cross-sectional study design to understand adolescents' perceptions, experiences, and preferences for engagement in chronic disease prevention decision-making. The YES survey gathered data from a diverse sample of Australian adolescents and revealed that similarly to international findings from Chapters 3 and 4, adolescents living in Australia seldom engage in health-promoting activities or chronic disease prevention decision-making. Assessment of the relationship

between adolescent engagement, demographic and socio-economic characteristics found no statistically significant association. However, a significant relationship was established between ‘previous volunteer experience’ and the likelihood of youth engagement.

Adolescents with previous volunteer experience were three times more likely to have been engaged in chronic disease prevention activities than their non-volunteering peers (Chapter 5). Qualitative focus group data revealed significant barriers to adolescent engagement including: 1. accessibility, 2. limited opportunities or lack of awareness of opportunities, and 3. time.

Nevertheless, adolescents overwhelmingly reported an interest in participating in chronic disease prevention decision-making. Adolescents perceived the benefits of participation to add value to chronic disease prevention strategies by improving health research, health intervention development, and health policy, raising awareness of healthy diet and lifestyle, improving health-promoting environments, and improving healthy lifestyle behaviours and health outcomes more broadly. Further, adolescents recognised the personal benefits of their engagement in improving their sense of self-worth, self-esteem, self-efficacy, sense of being taken seriously, confidence in decision-making, and confidence in public or community engagement (Chapter 5).

Chapter 6 presented a 12-month mixed-methods pre-post evaluation study of the Health Advisory Panel for Youth at the University of Sydney (HAPYUS) Youth Advisory Group (YAG), a leadership initiative underpinned by Youth Participatory Action Research (YPAR) principles.² Quantitative survey data established an increase in mean scores for leadership and life skills indicators at 12-month follow-up. Qualitative data analysis revealed the emergence of three overarching themes across the study period: 1. influence, 2. empowerment, and 3. contribution. Furthermore, nine additional unique but intersecting sub-

themes developed over the 12-month study term and included representation, voice, platform, skill development, gaining knowledge, opportunities, meaningful engagement, tangible outputs, and impact. Enablers to adolescent engagement in chronic disease prevention research methods included: flexibility, accessible delivery methods, skill development sessions, and supportive adult facilitators. At the same time, barriers to engagement included time and limited face-to-face components because of COVID-19 restrictions.

Implications and strengths of youth engagement in chronic disease prevention research, policies, and guidelines

Over the past few decades, the significance of chronic disease prevention among adolescence has gained increasing attention.^{3, 4} Still, the 2019 Global Burden of Disease study data indicates that current chronic disease prevention strategies have not been sufficient to moderate the effects of increasingly unhealthy dietary patterns, declining physical activity levels and the ongoing obesity epidemic.⁵ Understanding the complexity of underlying determinants of adolescent health and risk factor development requires thoroughly considering adolescent's perceptions of health and well-being, unique challenges, and lived experiences.

The 2016 Lancet Commission on adolescent health and Well-being,⁴ and the 2020 WHO-UNICEF-Lancet Commission⁶ have highlighted the case for investing and redirecting resources to progress adolescent health goals.^{4, 6} Adolescent health outcomes are significant in determining global health trajectories.^{4, 6} Consequently, adolescents have been positioned at the centre of the 2030 Sustainable Development Agenda,^{7, 8} the Global Strategy for Women's Children and Adolescent's Health (2016-2030)⁹ and the 2023 Global Accelerated Action for the Health of Adolescents (AA_HA!) country implementation guidance.¹⁰

Acknowledging the unique role and distinctive benefit adolescents can impart on chronic disease prevention decision-making processes.

This thesis provides systematic scoping review evidence that overall adolescent engagement in chronic disease prevention empirical research studies is limited (Chapter 3).¹¹ This finding is reiterated in Chapter 4, in which scoping review evidence of obesity and chronic disease prevention policies and guidelines found that significantly few chronic disease prevention policies and guidelines have engaged adolescents in the development stages.¹² Further, chronic disease risk factors were not often assessed in participatory studies (Chapter 3).¹¹ Nonetheless, when investigated, there was evidence that adolescent engagement in intervention development significantly reduced chronic disease risk factors such as unhealthy diets and low physical activity levels among intervention participants (Chapter 3).¹¹ The Longitudinal Study of Australian Children (LSAC) established a positive association between engagement in prosocial behaviours such as volunteering in early adolescence and improved mental health in later adolescence.¹³ To test causal theories between adolescent engagement in research and intervention development and impact on chronic disease risk factor development it is necessary to embed relevant exploratory variables into existing longitudinal studies such as LSAC.¹³ Additionally, the design of longitudinal studies explicitly examining the association between youth engagement and the effectiveness of chronic disease prevention interventions is necessary to bridge this knowledge gap.

Youth engagement in chronic disease prevention decision-making has the potential to change chronic disease prevention strategies designed for adolescents.⁴ Chapter 5 presented findings from our mixed-methods YES. The YES findings established that adolescents are aware of the most pertinent health issues and chronic disease risk factors affecting the health and well-

being of their cohort (Chapter 5). Similarly, to findings from chapters 3 and 4 of this thesis, chapter 5 established that adolescents are infrequently engaged in chronic disease prevention activities in the Australian context. In contrast, adolescent engagement is more apparent in the adolescent mental health and sexual health literature.¹⁴⁻¹⁷ Systematic reviews examining the mental health and sexual health evidence base determined evidence of the effectiveness of youth engagement in improving intervention development, intervention acceptance, and health outcomes in adolescents.¹⁴⁻¹⁷

Adolescents can identify unique health priorities and determinants, such as cost or access to healthy food, that may not be the typical risk factors addressed by common chronic disease prevention interventions (Chapter 5).¹⁸ Chapter 6 of this thesis evaluated a 12-month YAG that engaged adolescents in chronic disease prevention research. The mixed-methods evaluation study found that adolescents are capable of identifying distinctive needs, generating solutions, advocating, and disseminating knowledge and ideas.¹⁸ Further, adolescents are keen to take on opportunities to lead and contribute, raise awareness, represent their peers, and advocate for adolescent-specific health objectives (Chapter 6).¹⁸ The evidence base examining the use of YAGs in empirical research found that less than 1% of studies that reported using a YAG applied advice from adolescents in their research decision-making.¹⁹ Still, YAGs are recognised to impart epistemological benefit to youth and enhance the interpretation of research findings.²⁰

Adolescent engagement can facilitate the development of tailored chronic disease prevention research, interventions, policies, and guidelines.²¹ Furthermore, today's adolescents have unique strengths such as 'digital fluency,' which enables innovative solution generation.²² Assessment of the literature on strategies and interventions for adolescent health established a

gap in adolescent nutrition interventions.³ Recommendations to address this gap in the literature included developing the agency of adolescents and engaging youth in nutrition advocacy within a wider ecological setting.³ Correspondingly, adolescents participating in the YES stated that their involvement and contribution to chronic disease prevention decision-making would add value to all facets of chronic disease prevention research, intervention, policy, and guideline development (Chapter 5). Qualitative data from YES focus groups (Chapter 5) and YAG evaluation study interviews (Chapter 6) revealed that adolescents feel they can impart elements of lived experience and understanding of adolescent-specific needs on the research and development process. Further, adolescents report that they have the capacity to inform intervention development that is appropriate and acceptable to today's youth and therefore more likely to be influential and effective.

Implications and strengths of youth engagement in adolescent empowerment and capacity building

Youth engagement as a methodological approach supports researcher and policymaker objectives, providing adolescents with opportunities to develop skills and capabilities and contribute more broadly to their community and society.¹ Youth engagement promotes the rights of adolescents to be heard and involved in decision-making, which impacts their lives.²³ Furthermore, while adolescent engagement is widely recognised to positively affect research and intervention development, involvement in participatory decision-making also positively impacts adolescents personally. Participatory outcomes are the positive individual-level effects adolescents experience because of engagement in decision-making processes. Participatory outcomes outlined by the UNICEF-Lansdown conceptual framework for measuring outcomes of adolescent participation include developments in the sense of self-worth, self-efficacy, self-esteem, decision-making, being taken seriously, and public and civic

engagement.¹ The degree and nature of youth engagement varies significantly between studies and decision-making processes; nevertheless, improvement in participatory outcomes indicates increasing levels of adolescent empowerment and influence.¹

In Chapters 3 and 4 of this thesis, scoping review evidence determined that participatory outcomes have not been evaluated in the chronic disease prevention research, policy, and guideline literature.^{11, 12, 24} This was an unexpected finding since all the assessed studies involved a degree of meaningful youth engagement and 48% of studies were explicitly based on participatory frameworks (Chapter 3).¹¹ Nevertheless, a lack of evaluation and reporting of participatory outcomes is not unique to the chronic disease prevention literature. A systematic review examined 14 studies that engaged youth in mental health research. Overall, some participatory implications were discussed; however, no studies evaluated participatory outcomes.¹⁴ Moreover, an integrative review of studies involving participatory action research and children or adolescents examined participatory outcomes in 45 papers.²⁵ This review was not specific to health but included seven health-based papers. This evidence synthesis described multiple positive participatory outcomes resulting from the youth engagement process.²⁵ However, outcomes were determined via different approaches with no standard assessment method; therefore, the validity of the reporting of these outcomes was unclear.

The absence of reporting of participatory outcomes in the adolescent health and chronic disease prevention field highlights that researchers and policymakers perceive adolescent engagement as solely a methodological approach to adhere to best practice guidelines and enhance intervention outcomes (Chapters 3 and 4). An under recognition of the benefit of

adolescent engagement on participating youth leads to potentially lost opportunities for cultivating capacity building and empowerment during this critical developmental life stage.

The YES (Chapter 5) revealed that adolescents are cognisant of the positive implications of youth engagement beyond enhancing chronic disease prevention agendas. Most participants of the YES perceived engagement in health-promoting activities to improve their sense of self-worth, self-esteem, self-efficacy, sense of being taken seriously, confidence in decision-making, and confidence in public and community engagement (Chapter 5). Further, adolescents perceived having a meaningful role in the decision-making process to be empowering and influential (Chapter 5). Additionally, youth engaged in mental health research observed their engagement to increase the relevancy of the research topics, acceptability of the findings, and enhanced dissemination of findings.¹⁴

Chapter 6 findings affirmed the results from chapter 5. The evaluation of the HAPYUS YAG (Chapter 6) established that engagement across the research development cycle significantly enhanced adolescents' leadership and life skills scores. Further, qualitative interview data revealed improved skills, knowledge, capacity for contribution, and impact. Overall, participants felt influential and empowered by their engagement experience. Similar to findings from Chapters 5 and 6, the literature more broadly describes youth engagement benefits such as increased confidence, sense of empowerment, knowledge and awareness, social-emotional and cognitive development, relationship building, and social connectedness.^{14, 25}

Building adolescents' capabilities improves confidence and self-efficacy, empowering them to act on matters of importance to them and their peers and become agents of change.^{14, 25, 26}

Participatory implications of youth engagement extend into other aspects of an adolescent's life and have the potential to benefit their community and society more broadly.^{1, 22, 25}

Participatory outcomes that have a broader impact on organisations and communities include adolescent-tailored intervention design, improved funding distribution, a platform for intergenerational discussion, advocacy, fostering community awareness, and promoting infrastructural change within society.^{3, 4, 25} Elevation of adolescent voices in research and development processes enables knowledge translation, solution generation, and practical implementation.²⁶

Youth engagement methods foster transferrable skills and capabilities in adolescents.

Adolescent engagement can potentially enhance chronic disease prevention decision-making and promote positive participatory outcomes in adolescents. Furthermore, the evolving capacities of adolescents mean that these participatory outcomes also support youth to be more empowered contributors to society.

Future direction and recommendations

Engaging adolescents in chronic disease prevention research, policy, and guideline decision-making has significant implications for chronic disease prevention outcomes and empowerment and capacity building of adolescents.^{6, 27} However, often, in the attempt to make progress on chronic disease outcomes, researchers and policymakers may engage adolescents, unintentionally taking advantage of their skills and insight while overlooking their needs and aspirations.^{11, 28}

It is essential to consider adolescents' unique needs and circumstances before the participatory process commences, this ensures that adolescent engagement in chronic disease

prevention research is ethical and meaningful for adolescents now and into the future. Existing tools such as the well-being health and youth engagement framework²⁹ and the young and resilient co-research tool kit^{30, 31} provide comprehensive guidance on youth engagement in health research. However, the said frameworks²⁹⁻³¹ focus on improving healthcare services for young people and, therefore, may not apply to research focused on prevention. Accelerating progress on adolescent health priorities and addressing chronic disease risk factors in adolescents requires clear youth engagement recommendations for researchers and policymakers specific to chronic disease prevention. A Preliminary recommendations framework for youth engagement in chronic disease prevention decision-making is proposed below. The P-BASIC framework was developed based on qualitative data detailing barriers and facilitators to adolescent engagement gathered from Chapters 3, 4, 5, and 6 of this thesis.

P-BASIC

FRAMEWORK

ENGAGING YOUTH IN MEANINGFUL AND ETHICAL
CHRONIC DISEASE PREVENTION DECISION-MAKING

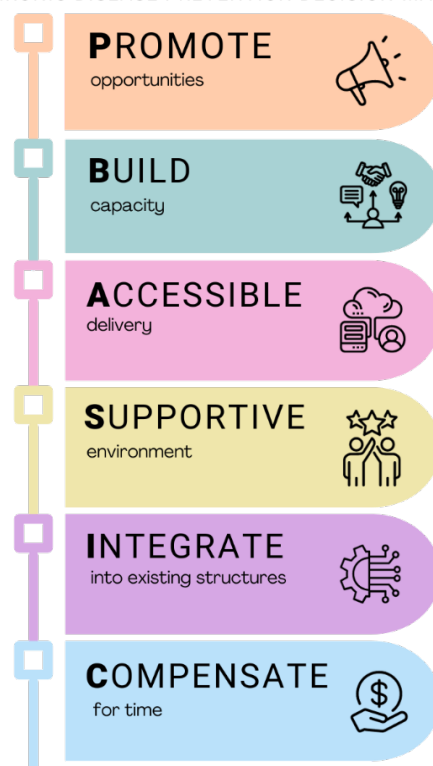


Figure 7.1. P-BASIC framework: Recommendations for youth engagement in chronic disease prevention decision-making

Promote opportunities

Adolescents consistently reported a lack of opportunities or lack of awareness of opportunities for them to engage in chronic disease prevention decision-making.

Recommendations:

1. Provide more opportunities for adolescents to be engaged in decision-making processes in all stages of the research cycle.
2. Enhance advertising of youth engagement in chronic disease prevention opportunities. Ensure a variety of advertising strategies and mediums are used.
3. Be more intentional in recruiting and engaging minority and underprivileged adolescents.

Build capacity

Adolescent empowerment and capacity building are intertwined with processes and methodologies that provide youth a platform, encourage youth voice, and enable influence over chronic disease prevention decision-making processes. The research presented in this thesis has shown that adolescents value and endeavour to develop their research skills, individual aptitude, and leadership competence.

Recommendations:

1. Employ collaborative and adolescent-led strategies such as youth advisory groups digital platforms for collaboration and co-design in chronic disease prevention decision-making.
2. Incorporate skill development activities, leadership, networking opportunities, and mentoring into youth engagement approaches.
3. Enable adolescents to contribute to the tangible output of youth engagement, such as publications, program development, presentations, policy change, and media coverage.

Accessible delivery

Overcoming accessibility barriers to youth engagement in chronic disease prevention decision-making ensures equity and diversity. Adolescents report the benefits of in-person engagement activities as they foster interpersonal connections, team building, and a sense of belonging. Additionally, in-person activities are not dependent on internet or technology access. Nevertheless, adolescents report requiring the convenience of online participatory activities due to distance, time constraints, and other commitments. Adolescents

recommended a combination of in-person and online components as an ideal arrangement to facilitate accessible engagement in chronic disease prevention activities.

Recommendations:

1. Provide a flexible hybrid of in-person and online participatory components to cater to adolescents' needs and circumstances.
2. Recognise individual adolescents' accessibility needs and adjust youth engagement activities accordingly.
3. Employ adaptable moderation and communication styles to ensure adolescents remain engaged and supported throughout the youth engagement process.

Supportive environment

Establishing a supportive participatory environment is a crucial facilitator of meaningful and ethical youth engagement in chronic disease prevention decision-making. Supportive environments nurture and promote belonging.

Recommendations:

1. Establish an online platform for communication and set boundaries and expectations for conduct.
2. Assign a dedicated, organised, and supportive adult facilitator (preferably someone who has prior experience working with young people)
3. Strengthen individual competencies by identifying youth needs and objectives and appropriately offering opportunities.
4. Provide peer support and mentoring opportunities where possible.

Integrate into existing structures.

Adolescents experience time constraints driven by an increased academic load, navigating growing independence, family, and work obligations.

Recommendations:

1. Partner with established youth-based social structures such as schools, community centres, and organisations to integrate youth engagement activities into existing programs, agendas, and curricula.
2. Provide adolescents who wish to engage in a choice of role, activity, and level of commitment.
3. Youth engagement activities should be scheduled on mutually agreed-upon days and times.
4. Youth engagement activities should have reasonable, age-appropriate expectations and should not overburden adolescents or put pressure on adolescents to achieve a specified goal or objective.

Compensate for time

Adolescence is a period of increasing independence, and therefore, many adolescents work to support themselves in their spare time. Adolescents report feeling undervalued when they are 'expected' to apply their knowledge, lived experience, and skills and use their time participating in activities in which they do not feel they are personally benefitting.

Recommendations:

1. Compensate adolescent participants through payment or another pre-approved recompense for their time and expertise.
2. Consider hiring adolescents for youth engagement roles that require prolonged and sustained commitment.

3. Reimburse adolescents for additional costs incurred or arising from youth engagement roles, attendance at youth engagement activities, or activities arising from the youth engagement role, e.g., conferences, media appearances, and events. Costs may include but are not limited to travel expenses and accommodation (including for a parent or guardian).

Limitations

This body of work was conducted as planned. This thesis forms the foundational work for a youth engagement toolkit mentioned in Chapter 2; however, the toolkit itself is outside the scope of this doctoral work. Nonetheless, there are some limitations of note. Adolescent engagement in chronic disease prevention is a developing field of study, and while the peer-reviewed publications within this dissertation referenced current literature at the time of publication some references are now outdated. All effort has been made to ensure that all unpublished chapters reference the most up-to-date literature. Furthermore, this thesis may have some limitations related to generalisability, methodology, and application.

First, the evidence from Chapter 3 found that 94% of empirical research studies employing adolescent engagement in chronic disease prevention research were conducted in a high-income country (HIC). Additionally, this thesis sought to consolidate the grey literature of relevance to the Australian context; therefore, Chapter 4 inclusion criteria were explicitly limited to countries with a sociodemographic profile like Australia's. Furthermore, Chapters 5 and 6 were limited to participants living in Australia. Overall, the results within this thesis are predominantly limited to the Australian context but may have some applicability to other HICs. Although many studies included in Chapter 3 were conducted in minority or

underserved communities within HICs, the results may not be generalizable to low and middle-income countries, where the biggest populations of adolescents reside.³²

Second, Chapter 5 sample size was determined through non-probability quota sampling methodology,^{33 34} and although our goal sample size was attained, it does not represent a nationally representative sample. Additionally, the youth advisory group evaluation study presented in Chapter 6 had a sample size of 13; although this appears small, in the context of YAG research, this is considered standard practice as it is essential for rapport building and supports meaningful adolescent engagement.^{19, 35} Nevertheless, this research was intended to be investigative and develop a greater understanding of adolescent engagement in the field of chronic disease prevention, in which adolescent engagement is still underdeveloped.¹⁹ Additionally, the research methods used in this thesis were predominantly qualitative in nature. Qualitative data was crucial to understanding the depth and complexity of adolescent's perceptions, lived experiences, barriers, enablers, and preferences related to adolescent engagement and chronic disease prevention. Nonetheless, as with all qualitative methods, the interpretation of results often depends on the researcher's analysis and, therefore may be subjective.³⁶ Established qualitative data analysis methodologies were used to ensure data was assessed correctly.³⁷⁻⁴⁰

Third, the scarcity of measurement and reporting of participatory outcomes in chronic disease prevention research, policy, and guidelines development processes was established in Chapter 3 and 4. It is apparent that adolescent engagement in the chronic disease prevention field is currently considered a methodological approach to comply with best practice guidelines.¹⁰ However, by overlooking the independent significance and impact of youth engagement on adolescents in chronic disease prevention, decision-making researchers and policymakers risk

compromising ethical and meaningful adolescent engagement practice. Further, measuring and determining the effectiveness of adolescent engagement in chronic disease prevention outcomes was challenging to assess due to a lack of evaluation frameworks specifically designed for the chronic disease prevention field. Also, although we can assess short-term outcomes such as uptake, acceptability, and relevance of chronic disease prevention programs on adolescents, it is more challenging to examine long-term effects. Assessing chronic disease prevention outcomes is a long-term process. Consequently, since adolescent engagement in chronic disease prevention is an emerging field of research, youth engagement may be applied in methodological decision-making processes and lack long-term evaluation data. More studies are needed to examine the effectiveness and relationship between adolescent engagement and long-term chronic disease prevention outcomes.

Fourth, COVID-19 restrictions in Australia coincided with qualitative data collection methods, namely the focus groups (Chapter 5) and interviews (Chapter 6). Therefore, all focus groups and interviews were conducted online via Zoom teleconferencing software. Online delivery had shortcomings in that conversations require much more rigidity to enable all participants to speak and be heard. Also, if individuals do not turn on their cameras, facial expressions and body language cannot be considered when interpreting the dialogue. Nevertheless, online delivery was well-received by adolescents and was positive in that many rural or regional living adolescents could participate despite the distance barrier.

CONCLUSIONS

Obesity and chronic disease risk factors continue to contribute significantly to the morbidity and mortality rates of adolescents worldwide.⁵ This thesis sought to evaluate current evidence and practice of adolescent engagement in chronic disease prevention research, policy, and

guideline development and to identify optimal strategies to engage adolescents in chronic disease prevention decision-making. Overall, it was apparent that adolescent engagement in chronic disease prevention research, policy, and guideline decision-making is limited. Nonetheless, adolescents are keen to be engaged and recognize the significant impact youth engagement can have on empowering them, building their individual capacity, and enhancing chronic disease prevention outcomes for their generation. The final chapter of this doctoral work presents an evidence-informed framework of recommendations to guide and optimize meaningful and just adolescent engagement in chronic disease prevention decision-making. This thesis provides evidence that adolescents' engagement in chronic disease prevention decision-making is feasible and empowering, builds adolescent capacity, and has the potential to tailor chronic disease prevention efforts targeted at adolescents. Further research is needed to assess the efficacy of the youth engagement recommendations made in this thesis on chronic disease prevention research, policy, and guideline development.

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APPENDICES

APPENDIX A

Systematic Scoping Review of the Peer-reviewed Literature- Supplementary File 1: Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2,3
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3,4,5,6
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	5,6,7,8

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if available, provide registration information, including the registration number.	6
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	6 (protocol),7,8
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	7,8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	24 (Additional file 2. Supplementary table 1. Medline search strategy)
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	7,8,9 (figure 1. Prisma flow diagram)
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any	8,9,24 (Additional file 3. Supplementary table 2. Data extraction table)

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		processes for obtaining and confirming data from investigators.	
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	7,8,9,24 (Additional file 3. Supplementary table 2. Data extraction table)
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	Not applicable
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	8,9
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	9, (figure 1. Prisma flow diagram)
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	24 (additional file 3)
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	Not applicable

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	24 (Additional file 3. Supplementary table 2. Data extraction table)
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	10-16
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	16-20
Limitations	20	Discuss the limitations of the scoping review process.	20
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	21
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	23

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA ScR): Checklist and Explanation. *Ann Intern Med.* 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).

Systematic Scoping Review of the Peer-reviewed Literature- Supplementary Table 1:

Medline Search Strategy (17.02.2020)

#	Searches	Results
1	(nutrition* or diet* or “physical activity” or health*).mp. [MP=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	4393981
2	((“over weight” or obesity or “pediatric obesity” or “paediatric obesity” or “lifestyle risk factors” or “non-communicable diseases” or “noncommunicable disease”) and prevention).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	49261
3	(youth or adolescen* or teen*).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, unique identifier, synonyms]	2087732
4	(participat* or involvement or engagement or “co-design” or “co design” or “decision making” or “decision-making”.mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, protocol supplementary concept	1195048

	word, rare disease supplementary concept word, unique identifier, synonyms]	
5	(research or guidelines or policy or policies or “action research”).mp. [mp=title, abstract, original title, name of substance word, subject heading word, floating sub-heading word, keyword heading word, organism supplementary concept word, protocol supplementary concept word, protocol supplementary concept word, rare disease supplementary concept word, unique identifier, synonyms]	10639503
6	1 and 2 and 3 and 4 and 5	999
7	Exp Humans/	18302997
8	6 and 7	962
9	Health Promotion/ or Community-Based Participatory research/ or Health Services Research/ or participatory .mp. or Health Knowledge, Attitudes, Practice/	220050
10	8 and 9	443
11	10 and 1995:2020.(sa_year).	438

Systematic Scoping Review of the Peer-reviewed Literature- Supplementary Table 2: Data extraction table of included studies.

				Adolescent Participation in the Research Cycle					Adolescent engagement: Mode of participation					Participatory Outcomes measured (characterised by empowerment & influence)-				Chronic Disease Related Outcomes					
Reference	Study Design/ Methods	Main Chronic disease or risk factor	Socio-ecological Setting	1. Identification of topic	2. Design & Development	3. Conduct	4. Analyses	5. Dissemination	Consultative	Collaborative	Adolescent-led	Other: Adolescents engaged but views did not influence design or development of the intervention	Model/ theory/ conceptual framework	Sense of self-worth/ self-esteem/ efficacy	Being taken seriously	Making decisions	Public/civic engagement	Increased awareness	Program/ intervention	Policy change	Environmental change (facilities, safe spaces, accessibility to healthier food choices)	Behaviour change (Diet/ physical activity)	Health status/risk factors change (e.g., weight change, BP change, etc)
Anselma et al, 2018 Netherlands (1) Anselma et al, 2019 Netherlands (2) Anselma et al, 2019 Netherlands (3) Anselma et al, 2020 Netherlands (4)	Qualitative Needs assessment Focus groups Intervention Mapping (IM)	Overweight/ obesity	Local community	☑	☑	☑	☑	☑	Y				Multiple model (incl. participatory-YPAR))	☑	☑	☑	☑	☑	☑	☑		Physical activity water policy	
Arlinghaus et al, 2017, USA (5)	RCT Adolescent health mentors/ leaders	Obesity	Institution (secondary education)					☑			Y		NR	NR	NR	NR	NR					☑	☑
Bailey et al, 2018, Australia (6)	Qualitative Focus groups	Overweight/ Obesity	Local community		☑				Y				Participatory	NR	NR	NR	NR		☑				
Balvanz et al, 2016, USA (7)	Qualitative Photovoice- Youth advocacy	Obesity	Local community	☑	☑	☑	☑	☑	Y				Multiple model (incl. CBPR)	NR	NR	NR	NR	☑	☑		☑		

Bardwell et al, 2009, USA (8)	Qualitative Questionnaire Participatory activities	Obesity	Family & Local community	☒	☒	☒			Y			Participatory (CBPR)	NR	NR	NR	NR	☒									
Uyeda et al, 2009, USA (9) Goh et al, 2009, USA (10) Bogart et al, 2011, USA (11) Bogart et al, 2014, USA (12) Bogart et al, 2016, USA (13) Bogart et al, 2018, USA (14)	Mixed methods + RCT Focus groups/ Questionnaires/Peer leadership/ Peer advocacy/ Marketing	Obesity	Institution (secondary education)	☒	☒	☒		☒	Y			Multiple theory incl. participatory (CBPR), SCT	NR	NR	NR	NR	☒	☒	☒	☒			☒		☒	☒
Christianson, et al. 2019, USA (15)	Qualitative Social marketing Focus groups	Wellness	Institution (tertiary education)	☒	☒	☒	☒	☒	Y			Multiple theory (incl. participatory (CBPR))	NR	NR	NR	NR	☒	☒								
Chae, et al, 2016, Republic of Korea (16)	Qualitative Focus groups	Overweight/obesity	Institution (secondary education)	☒					Y			Ecological model	NR	NR	NR	NR	☒									
Cassidy et al, 2013, USA (17)	Mixed methods Focus groups Questionnaires Role plays	Overweight/obesity/	Local community	☒	☒				Y			Multiple theory (incl. participatory (CBPR))	NR	NR	NR	NR	☒	☒								
Brown et al, 2010, USA (18) Brown et al, 2013, USA (19)	Qualitative Focus groups/ Interviews	Diabetes	Local community	☒	☒				Y			Multiple theory (incl. participatory (CBPR), SGT)	NR	NR	NR	NR	☒	☒								
Diez-Canseco, 2015, Peru (20)	Qualitative Peer promotion (education, training & feedback) Focus groups	Non-communicable diseases. (NCD)	Institution (Secondary education)	☒	☒	☒		☒	Y			Participatory	NR	NR	NR	NR	☒	☒					☒			
Correa et al, 2017, Canada (21) Rajaraman et al, 2015, Canada (22)	Qualitative Focus groups	Overweight/obesity	Adolescent (Individual)	☒					Y			Multiple/co complex theory	NR	NR	NR	NR										
Cueva et al, 2019, USA (23)	Qualitative Photovoice	Obesity	Local community	☒		☒			Y			Multiple theory incl.	NR	NR	NR	NR	☒									

	Discussions												participatory (CBPR)										
DeBar et al, 2011, USA (24) DeBar et al, 2009, USA (25) HEALTHY study group, 2005,2009, USA (26, 27) Siega-Riz et al., 2011, USA (28) Venditti, et al 2005, 2009, USA (29, 30) Marcus et al, 2013, USA (31)	RCT Focus groups Peer leadership Public commitment activities Social marketing	Obesity, Diabetes	Institution (secondary education)	☒	☒	☒		☒		Y			NR	NR	NR	NR	NR	☒			☒	☒	☒
de Vet, et al, 2013, Netherlands (32)	Qualitative Cross-sectional survey	Overweight/ obesity	Institution (secondary education)	☒						Y			NR	NR	NR	NR	NR						
Edwardson et al, 2015, UK (33) Harrington et al, 2018, UK (34)	RCT Questionnaires Peer tutoring peer modelling peer leadership marketing Focus groups	Poor physical activity	Institutions (secondary education)			☒		☒		Y			Social, Cognitive Theory	NR	NR	NR	NR	☒				☒	
Ewan et al, 2015, USA (35)	Qualitative Concept mapping.	Obesity	Institution/ local community	☒						Y			Multi-model (Participator y & Social ecological model of health)	NR	NR	NR	NR	☒			☒		
Findholt, et al, 2010, USA (36)	Qualitative Photovoice	Obesity	Local community	☒	☒	☒	☒	☒			Y		Participatory (CBPR)	NR	NR	NR	NR	☒					
Frerichs et al, 2012, USA (37) Frerichs et al, 2015, USA (38)	Qualitative Interviews Social marketing (including youth generated branding) & Social Media, Youth advocacy	Obesity	Local community		☒	☒		☒			Y		Multi-model (incl. SCT)	NR	NR	NR	NR	☒	☒		☒		
Frerichs et al, 2018, USA (39)	Qualitative Surveys Discussions-	Obesity	Local community			☒	☒	☒	Y				Multi-model (incl. Participatory	NR	NR	NR	NR	☒					

Lewis et al, 2018, USA (56)	Qualitative Surveys Helped plan summer enrichment camp activities	Obesity	Institution (secondary education)	☒				Y				Participatory -CBPR	NR	NR	NR	NR					☒	
Linton et al, 2014, USA (57) Milstein et al, 2016, USA (58)	Qualitative Surveys Community assessment Youth advocacy	Obesity	Local community	☒	☒	☒		☒	Y			Multi-theory (incl. SCT)	☒		☒	☒	NR	☒	☒		☒	
Livingood et al, 2017, USA (59)	Qualitative Youth advisory board Photovoice Focus group Interviews	Obesity	Local community	☒	☒	☒	☒	☒		Y		Multi-theory (incl. participatory -CBPR, eco model)	NR	NR	NR	NR		☒				
Llaurado et al, 2015, Spain (60) Tarro et al, 2017, Spain (61) Aceves-Martins, 2017, Spain (62) Tarro et al, 2019, Spain (63) Llaurado et al, 2018, Spain (64)	RCT Peer-led Focus groups Social marketing	Obesity	Institution (secondary education)	☒	☒	☒		☒	Y			Multi-model (incl. social)	NR	NR	NR	NR	☒	☒		☒	☒	
Loman, 2008, USA (65)	Qualitative Focus groups and interviews	Overweight/obesity	Local community	☒					Y			SCT	NR	NR	NR	NR		☒				
Mauriello et al, 2006, USA (66) Mauriello et al, 2010, USA (67)	Qualitative Surveys Focus groups, Interviews	Obesity	Institution (secondary education)	☒	☒				Y			Complex model Transtheoretical Model framework)	NR	NR	NR	NR		☒			☒	
Maynard et al, 2009, UK (68) Rawlins et al, 2013, UK (69) Maynard et al, 2017, UK (70)	MIXED Focus groups Interviews Questionnaires	Obesity	Local community	☒	☒				Y			Multi/complex models	NR	NR	NR	NR	☒				☒	
McGee et al, 2017, USA (71)	Qualitative Focus groups	Obesity	Local community	☒					Y			The Social Cognitive Theory (SCT)	NR	NR	NR	NR	☒					
McKinney et al, 2014, USA (72)	Qualitative Peer educators Surveys	Obesity	Institution (secondary education)		☒			☒	Y			Multi- model (incl. Participatory	NR	NR	NR	NR		☒			☒	

	Focus groups											-CBPR + SCT)									
McPherson, and Lindsay, 2012, Canada (73)	Qualitative Focus groups	Obesity	Institution (hospital)	☒					Y			NR	NR	NR	NR						
Morales-Campos, et al, 2015, USA (74)	Qualitative Community advisory board partners Surveys Intervention planning Photo mapping	Obesity	Local community	☒	☒	☒	☒	☒		Y		Multi theory (incl. Participatory -CBPR + SCT)	NR	NR	NR	NR	☒	☒			
Mosavel, et al, 2018, USA (75)	Qualitative Asset mapping (part of a needs assessment)	Obesity	Local community	☒		☒	☒			Y		Participatory - CBPR	NR	NR	NR	NR	☒				
Muturi et al, 2018, USA (76)	Qualitative Survey	Obesity	Adolescent (Individual)	☒					Y			Multi-theory (incl. participatory)	NR	NR	NR	NR		☒			
Ncheles et al, 2007, USA (77)	Qualitative Photovoice Interviews Social marketing Youth advocacy	Health issues, health behaviours, unhealthy food, obesity	Local community	☒	☒	☒	☒	☒			Y	Multi-theory (incl. participatory - CBPR)	NR	NR	NR	NR	☒	☒		☒	
Nguyen et al, 2017, Vietnam (78) Tang et al, 2020, Vietnam (79)	Qualitative, Planned Pilot- RCT Peer education, Peer support, Focus groups, Interviews	Obesity	Institution (secondary education)	☒	☒				Y			Multi-theory (incl. SCT)	NR	NR	NR	NR		☒			
Partridge et al, 2019, Australia (80) Partridge et al, 2020, Australia (81)	Mixed methods RCT Co-design of text messages Survey	Over wight/ obesity	Adolescent (Individual)	☒	☒	☒				Y		Behavioural	NR	NR	NR	NR		☒			

Perry and Hoffman, 2010, USA (82)	MIXED Community advisory board (1 youth taking part) Study planning Surveys Focus groups	Obesity	Local community	☒	☒				Y			Participatory - CBPR	NR	NR	NR	NR	☒	☒	☒	☒	
Power et al, 2010, USA (83) Bindler et al, 2011, USA (84) Steele et al, 2011, USA (85) Wordell et al, 2012, USA (86)	MIXED Focus groups Peer mentoring component Questionnaires	Obesity	Institution (secondary education)	☒	☒				Y			Multi/complex- theory (incl. SCT)	☒	NR	NR	NR	☒	☒	☒	☒	
Renzaho et al, 2015, Australia (87)	Qualitative Discussions Interviews Focus groups	Obesity	Local community	☒					Y			Multi-theory (incl. participatory)	NR	NR	NR	NR	☒	☒			
Robbins et al, 2003, USA (88) Robbins et al, 2006, USA (89) Pfeiffer et al, 2019, USA (90)	Qualitative RCT Questionnaire Focus groups	Overweight/Obesity	Institution (secondary education)	☒					Y			Complex model (Transtheoretical model)	NR	NR	NR	NR	☒	☒		☒	
Martin Romero & Francis, 2020, USA (91)	Qualitative, Focus groups Discussions Participatory activities	Obesity	Family			☒			Y			Multi-theory (incl. Participatory + ecological)	NR	NR	NR	NR	☒				
Briancon et al, 2010, France (92) Saez et al, 2018, France (93)	RCT Peer mentors/facilitators Focus groups	Overweight/obesity	Institution (secondary education)	☒	☒	☒				Y		SCT	NR	NR	NR	NR		☒		☒	
Gittelsohn et al, 2014, USA (94) Sato et al, 2016, USA (95) Ruggiero et al, 2018, USA (96)	RCT + Qualitative Interviews, Focus groups, Youth leaders	Obesity	Local community	☒	☒	☒		☒	Y			Multi-theory (incl. SCT)	NR	NR	NR	NR	☒	☒	☒	☒	
Schwarte et al, 2010, USA (97)	Qualitative Photovoice	Obesity	Local community			☒		☒	Y			Complex model	NR	NR	NR	NR		☒	☒		

Shepherd et al, 2006, USA (98)	Qualitative Interviews	Obesity	Adolescent (individual)	☒					Y				NR	NR	NR	NR	NR							
Sherman et al, 2011, Canada (99)	Qualitative Focused ethnography Interviews Focus groups Educational play	Type 2 diabetes	Local community	☒	☒				Y				Multi/compl ex-model (incl. participatory)	NR	NR	NR	NR	☒	☒					
Spaulding et al, 2015, USA (100)	Mixed Discussions Focus groups	Overweight	Institution (secondary education)	☒					Y				NR					☒	☒					
Swanson et al, 2013, USA (101)	Qualitative Focus groups Interviews Co-design	Overweight/ obesity	Local community	☒					Y				Ecological model	NR	NR	NR	BR	☒						
Thompson et al, 2012, USA (102) Cullen et al, 2013, USA (103)	Qualitative RCT Focus groups Interviews Co-design Questionnaires	Obesity	Adolescent (individual)	☒	☒				Y				SCT	NR	NR	NR	NR		☒			☒		
Swinburn et al, 2007 (Aust, NZ, Fiji, Tonga) (104) Schultz et al, 2007 (Fiji) (105) Utter et al, 2010, NZ (106) Mattews et al, 2010, Aust (107) Millar et al, 2011, Australia (108) Swinburn et al, 2011 Australia (109) Fotu et al, 2011, Fiji (110)	MIXED Interviews Questionnaire and Workshop development Focus groups	Obesity	Local community & Institution (secondary education)	☒	☒			☒	Y				SCT	NR	NR	NR	NR	☒	☒	☒	☒		☒	☒
Vangeepuram et al, 2015, USA (111) Vangeepuram et al, 2017, USA (112)	RCT Peer-led Workshops Interviews Focus groups	Type 2 diabetes	Local community	☒	☒				Y				Multi-theory (incl. participatory - CBPR & SCT)	NR	NR	NR	NR	☒	☒			☒	☒	
Woodgate & Sigurdson 2015, Canada (113)	Mixed Focus groups Interviews	Cardiovascular health	Institution (secondary education)	☒	☒	☒		☒			Y		SCT	NR	NR	NR	NR	☒	☒					

Lems et al, 2019, The Netherlands (126)	Qualitative Interviews Co-creation sessions	Over-weight/ obesity	Local community	☒	☒					Y				Participatory - PAR	☒	NR	NR	NR		☒	☒					
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Abbreviations:

Y: Yes

Incl.: including

NR: Not Reported

RCT: Randomised Control Trial

YPAR: Youth Participatory Action Research

CBPR: Community Based Participatory Research

SCT: Social Cognitive Theory

APPENDIX B

Scoping Review of the Policy and Guideline Literature- Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews (PRISMA-ScR) Checklist

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
TITLE			
Title	1	Identify the report as a scoping review.	1
ABSTRACT			
Structured summary	2	Provide a structured summary that includes (as applicable): background, objectives, eligibility criteria, sources of evidence, charting methods, results, and conclusions that relate to the review questions and objectives.	2
INTRODUCTION			
Rationale	3	Describe the rationale for the review in the context of what is already known. Explain why the review questions/objectives lend themselves to a scoping review approach.	3-4
Objectives	4	Provide an explicit statement of the questions and objectives being addressed with reference to their key elements (e.g., population or participants, concepts, and context) or other relevant key elements used to conceptualize the review questions and/or objectives.	4
METHODS			
Protocol and registration	5	Indicate whether a review protocol exists; state if and where it can be accessed (e.g., a Web address); and if	4-5

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
		available, provide registration information, including the registration number.	
Eligibility criteria	6	Specify characteristics of the sources of evidence used as eligibility criteria (e.g., years considered, language, and publication status), and provide a rationale.	5-7
Information sources*	7	Describe all information sources in the search (e.g., databases with dates of coverage and contact with authors to identify additional sources), as well as the date the most recent search was executed.	7-8
Search	8	Present the full electronic search strategy for at least 1 database, including any limits used, such that it could be repeated.	8-9
Selection of sources of evidence†	9	State the process for selecting sources of evidence (i.e., screening and eligibility) included in the scoping review.	9
Data charting process‡	10	Describe the methods of charting data from the included sources of evidence (e.g., calibrated forms or forms that have been tested by the team before their use, and whether data charting was done independently or in duplicate) and any processes for obtaining and confirming data from investigators.	9-11
Data items	11	List and define all variables for which data were sought and any assumptions and simplifications made.	9-11
Critical appraisal of individual sources of evidence§	12	If done, provide a rationale for conducting a critical appraisal of included sources of evidence; describe the methods used and how this information was used in any data synthesis (if appropriate).	N/A

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
Synthesis of results	13	Describe the methods of handling and summarizing the data that were charted.	9-11
RESULTS			
Selection of sources of evidence	14	Give numbers of sources of evidence screened, assessed for eligibility, and included in the review, with reasons for exclusions at each stage, ideally using a flow diagram.	11-12
Characteristics of sources of evidence	15	For each source of evidence, present characteristics for which data were charted and provide the citations.	12-13
Critical appraisal within sources of evidence	16	If done, present data on critical appraisal of included sources of evidence (see item 12).	N/A
Results of individual sources of evidence	17	For each included source of evidence, present the relevant data that were charted that relate to the review questions and objectives.	12-20
Synthesis of results	18	Summarize and/or present the charting results as they relate to the review questions and objectives.	15, 16, 19
DISCUSSION			
Summary of evidence	19	Summarize the main results (including an overview of concepts, themes, and types of evidence available), link to the review questions and objectives, and consider the relevance to key groups.	21-24
Limitations	20	Discuss the limitations of the scoping review process.	24-26
Conclusions	21	Provide a general interpretation of the results with respect to the review questions and objectives, as well as potential implications and/or next steps.	26

SECTION	ITEM	PRISMA-ScR CHECKLIST ITEM	REPORTED ON PAGE #
FUNDING			
Funding	22	Describe sources of funding for the included sources of evidence, as well as sources of funding for the scoping review. Describe the role of the funders of the scoping review.	27

JB1 = Joanna Briggs Institute; PRISMA-ScR = Preferred Reporting Items for Systematic reviews and Meta-Analyses extension for Scoping Reviews.

* Where *sources of evidence* (see second footnote) are compiled from, such as bibliographic databases, social media platforms, and Web sites.

† A more inclusive/heterogeneous term used to account for the different types of evidence or data sources (e.g., quantitative and/or qualitative research, expert opinion, and policy documents) that may be eligible in a scoping review as opposed to only studies. This is not to be confused with *information sources* (see first footnote).

‡ The frameworks by Arksey and O'Malley (6) and Levac and colleagues (7) and the JBI guidance (4, 5) refer to the process of data extraction in a scoping review as data charting.

§ The process of systematically examining research evidence to assess its validity, results, and relevance before using it to inform a decision. This term is used for items 12 and 19 instead of "risk of bias" (which is more applicable to systematic reviews of interventions) to include and acknowledge the various sources of evidence that may be used in a scoping review (e.g., quantitative and/or qualitative research, expert opinion, and policy document).

From: Tricco AC, Lillie E, Zarin W, O'Brien KK, Colquhoun H, Levac D, et al. PRISMA Extension for Scoping Reviews (PRISMA-ScR): Checklist and Explanation. *Ann Intern Med*. 2018;169:467–473. doi: [10.7326/M18-0850](https://doi.org/10.7326/M18-0850).

APPENDIX C

The Youth Engagement Study Ethics Approval



Research Integrity & Ethics Administration HUMAN RESEARCH ETHICS COMMITTEE

Thursday, 9 December 2021

Dr Stephanie Partridge
Health Sciences; Faculty of Medicine and Health
Email: stephanie.partridge@sydney.edu.au

Dear Stephanie,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.: 2021/864
Project Title: The Youth Engagement Study
Authorised Personnel: Partridge Stephanie; Cheng Hoi Lun (Helen); Mandoh Mariam; Phongsavan Philayrath; Redfern Julie; Mhrshahi Seema;
Approval Period: 09/12/2021 to 09/12/2025
First Annual Report Due: 09/12/2022

Documents Approved:

Date Uploaded	Version Number	Document Name
07/12/2021	Version 1	Phase 2 Recruitment Invitation & Advertising
07/12/2021	Version 1	Phase 1 Recruitment Advertising
07/12/2021	Version 1	Focus group guide-clean
18/10/2021	Version 1	Youth Engagement Study Protocol- Version1- 10/10/21
18/10/2021	Version 1	YE-Main Survey-Version 1- 18/10/21
18/10/2021	Version 1	YE-Survey-Participant Info Statement-Version 1-17/10/21
18/10/2021	Version 1	YE-Survey Consent form_Version 1- 18/10/21
18/10/2021	Version 1	YE Focus Group Consent form-Version 1- 18/10/21
18/10/2021	Version 1	YE-Focus groups-Participant details survey-Version1-18/10/21
18/10/2021	Version 1	YE-Focus group-Participant Info Statement-Version1- 17/10/21
18/10/2021	Version 1	YE- Survey-Participant details survey-Version 1 18/10/21

Special Condition/s of Approval

It will be a condition of ethics approval that all people listed on this project (including researchers, students, university staff and volunteers) have a current/valid Working with Children Check (WWCC) prior to undertaking any research activity with children. The WWCC must be valid for the duration of the research activity. Evidence must be kept on file as part of your study records and be made available to the University when requested. You do not need to provide a copy to the Ethics Office.

Condition/s of Approval

- ☐ Research must be conducted according to the approved proposal.
- ☐ An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- ☐ You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
 - II Serious or unexpected adverse events (which should be reported within 72 hours).
 - II Unforeseen events that might affect continued ethical acceptability of the project.

Research Integrity & Ethics Administration
Research Portfolio
Level 3, F23 Administration Building
The University of Sydney
NSW 2006 Australia

T +61 2 9036 9161
E human.ethics@sydney.edu.au
W sydney.edu.au/ethics

AEN 15 211 513 464
CRICOS 00026A



- ☐ Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- ☐ Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.
- ☐ Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- ☐ Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- ☐ Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- ☐ The Ethics Office may conduct audits on approved projects.
- ☐ The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,

Associate Professor Mark Arnold
Chair, Human Research Ethics Committee (HREC 2)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) [National Statement on Ethical Conduct in Human Research \(2018\)](#) and the NHMRC's [Australian Code for the Responsible Conduct of Research \(2018\)](#)

The Youth Engagement Study Survey: Participant Information Sheet

Page 1

Participant Information: The Youth Engagement Study SURVEY

Who is running the study?

This survey is being conducted by researchers from The University of Sydney. Our names are Stephanie Partridge, Mariam Mandoh, Julie Redfern, Philayrath Phongsavan, Helen Cheng and Seema Mhrshahi.

Mariam Mandoh designed the survey and is conducting this study as a component of her Doctor of Philosophy (Medicine and Health) research degree at The University of Sydney under the supervision of Dr Stephanie Partridge.

What is this study about?

We want to hear from young people about their perceptions and any experiences with health research relating to chronic diseases such as obesity, heart disease and diabetes. We are doing a survey to find out more about how young people, 13-18 years old are currently participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease and diabetes.

By 'youth participation' we mean young people, individually or together, forming and expressing their views and influencing matters of importance to them. The survey includes questions about your personal health including your height and weight and your views and experiences with participation in activities that encourage young people to be healthy.

Who can take part in the study?

To participate in this survey, you need to:

Be aged between 13 and 18 years old
Live in Australia
The survey will take about 10 minutes to complete. It asks you about your opinion and experience with engagement in activities that encourage young people to eat better, be more physically active or prevent chronic diseases such as obesity, heart disease and type 2 diabetes. Your responses are completely anonymous.

The online survey can be completed only once on any device connected to the internet.

At the end of the survey, you can enter a prize draw to win one of 20 Gift Vouchers, each valued at \$50.

If you have any questions, please contact Stephanie from the research team at stephanie.partridge@sydney.edu.au.

The University of Sydney Ethics Approval Number: 2021/86

Would you like to see additional details about the study?

☐ Yes
☐ No

Additional Information: The Youth Engagement Study SURVEY

This additional information tells you what we will ask you to do if you decide to join the study. Knowing what is involved will help you decide if you want to take part in the research. Please read it carefully so that you can make up your mind about whether you want to take part.

Do I have to be in the study? Can I withdraw from the study once I've started?

The survey is completely voluntary. You can decide if you want to take part in it or not. Participation is completely up to you. You can stop at any time.

Submitting your completed questionnaire is an indication of your consent to participate in the study. You can withdraw your responses any time before you have submitted the questionnaire. Once you have submitted it, your responses cannot be withdrawn because they are anonymous and therefore, we will not be able to tell which one is yours.

What will the study involve for me?

If you decide that you want to be in our study, we will ask you to:

Complete one 10-minute online survey about your perceptions and any experience participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease and diabetes. When we ask you questions, you can choose which ones you want to answer. If you don't want to answer something, that's ok. You can click 'prefer not to answer' or stop the survey.

What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

The survey does not ask for your name, so your responses will be completely anonymous. They will be combined with hundreds of other responses so no one will know your individual answers. We will only request your contact details at the end if you want to:

Be included in the prize draw
Want to know about the study results once it is finished
Be willing to be contacted for future research
However, these details are kept separate from the survey and will not be linked in any way to the answers you provide.

All the information you provide to us during the study will be kept confidential and stored securely and your identity/information will be kept strictly confidential. We will write a report about the study, which may be published later and key findings from the report shared on social media. However, we will not mention your name anywhere in the report or key findings on social media, and no one will know that you took part in the study

How long will the study take?

The survey will take about 10 minutes to complete.

Are there any benefits associated with being in the study?

By participating in the study, you will be helping us do our research which focuses on adolescent health. There are no direct benefits from participating in the survey. However, by taking the survey you can choose to enter the prize draw for a chance to win one of 20 x \$50 Gift Vouchers for The Iconic or JB Hi-Fi.

Are there any risks or costs associated with being in the study?

This study will take up some of your time, we do not expect that there will be any risks or costs associated with participating in the study.

16/08/2025 1:15pm

projectredcap.org

REDCap[®]

taking part in this study. Some questions ask about your personal health including your height and weight, and about your experience with participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease and diabetes.

If any of these questions or other questions make you feel distressed or upset, we recommend that you stop the survey and first contact your General Practitioner. Here are other contacts you can talk to and websites you can access if you feel distressed or upset, if that is what you want to do.

Kids Helpline: T: 1800 551 800 W: kidshelpline.com.au

The Butterfly Foundation: T: 1800 334 673 W: thebutterflyfoundation.org.au

ReachOut: W: au.reachout.com

HeadSpace: W: headspace.org.au

Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

What if I have any questions or would like further information about the study?

If you have any questions about the study, you can ask us or your family or someone else who looks after you. If you want to, you can call Stephanie Partridge on +61 2 8890 8187.

Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by the end of the survey, which asks you if you would like to receive a summary of the study results. If you answer 'Yes', when we finish the study, we will tell you what we learnt by emailing you a one-page summary. If you select 'Yes', you will receive this feedback after the study is finished.

What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (2021/864). As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you are not happy with how we are doing the study or have any complaints about the way the study is conducted, then you or the person who looks after you can contact the university using the details outlined below. Please tell them the study title and protocol number.

Call the university on +61 2 8627 8176 or Write an email to ethics@sydney.edu.au

This sheet is for you to keep. Click to download a copy.

[Attachment: "Youth Engagement Study Survey- Participant Information Statement.pdf"]

Would you like to go to the consent form now?

☐ Yes
☐ No

The Youth Engagement Study Survey: E-consent Form

Page 1

The Youth Engagement Study SURVEY: E-Consent Form

You should only consent to being in the study once you have read and understood what the study is about, and you want to be in it. If you do not want to participate in our study, select "no" in the form below.

In giving my consent I state that:

I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved. I have read the Participant Information Sheet and my questions have been answered by either the Participant Information Sheet, my parent/guardian or the researchers and I am happy with the answers. I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney now or in the future. I understand that I can withdraw from the study at any time by stopping the survey. I understand that my questionnaire responses cannot be withdrawn once they are submitted, as they are anonymous and therefore the researchers will not be able to tell which one is mine. I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

-
- 1) I am providing consent ☐ Yes
☐ No

The Youth Engagement Study Survey

Page 2

Which main language (other than English) do you speak at home?

- ☐ Arabic
- ☐ Cantonese
- ☐ Greek
- ☐ Hindi
- ☐ Italian
- ☐ Korean
- ☐ Mandarin
- ☐ Spanish
- ☐ Tagalog
- ☐ Tamil
- ☐ Vietnamese
- ☐ Other

Other, please specify

Please indicate the highest level of education completed for each parent/guardian: Parent/guardian 1

- ☐ Some high school
- ☐ Completed high school
- ☐ Currently studying for degree or diploma
- ☐ Completed a trade or technical qualification
- ☐ Completed a degree or diploma
- ☐ Completed a post graduate degree
- ☐ Other
- ☐ Don't know
- ☐ Prefer not to say

Other, please specify

Parent/guardian 2 (if applicable)

- ☐ Some high school
- ☐ Completed high school
- ☐ Currently studying for degree or diploma
- ☐ Completed a trade or technical qualification
- ☐ Completed a degree or diploma
- ☐ Completed a post graduate degree
- ☐ Other
- ☐ Don't know
- ☐ Prefer not to say

Other, please specify

Are you currently attending school?

- ☐ Yes
- ☐ No

What is your current school year?

- ☐ Year 7
- ☐ Year 8
- ☐ Year 9
- ☐ Year 10
- ☐ Year 11
- ☐ Year 12

What is your highest level of education?

- ☐ Currently enrolled in year 10 or below
- ☐ Completed year 10 school certificate or equivalent
- ☐ Completed year 12 Higher school certificate or equivalent
- ☐ Enrolled in Diploma/Technical course
- ☐ Enrolled in University undergraduate degree
- ☐ Other

Other, please specify

What is your current height? (in cm)

What is your current weight? (in kg)

Perceptions of Health

What do you think is the biggest health issue facing youth? (Select one)

- ☐ Mental health disorders (e.g., depression, anxiety, etc)
- ☐ Alcohol use
- ☐ Drug use
- ☐ Obesity
- ☐ Bullying
- ☐ Suicide
- ☐ Asthma
- ☐ Other

Other, please specify

What do you think are the top three risk factors for chronic diseases (such as obesity, type 2 diabetes and heart disease)? (select three)

- ☐ Unhealthy diet
- ☐ Low physical activity levels
- ☐ Social media/ technology
- ☐ Bullying (including cyber bullying)
- ☐ Mental health
- ☐ Cost/ access to healthy food
- ☐ Safety of active transport (walking, riding a bike/scooter/ skateboard) to school/other destination
- ☐ Access to parks/ safe outdoor spaces
- ☐ Peer pressure
- ☐ Stigma
- ☐ Other

Other, please specify

For this section a health 'intervention' is defined as an activity or strategy designed to promote or improve health of individuals or a population. Examples of public health interventions include public health messaging, health resources developed for young people, health education programmes and community health promotion campaigns.

How important do you think healthy diet and lifestyle interventions are for young people?

- ☐ Very important
- ☐ Important
- ☐ Unsure
- ☐ Not important
- ☐ Very unimportant

Please tell us why you selected that response

Participation For this section 'youth participation' is defined as young people (individually or together) forming and expressing their views/ opinions and influencing matters of importance to them.

In the last 12 months, did you do any unpaid, voluntary work? (e.g., coaching, refereeing, school canteen, Clean-up Australia, community group, religious group/church, youth service/mentoring, etc)

- ☐ Yes
☐ No

Please specify the nature of any unpaid, volunteer work that you have done in the last 12 months

How often did you do unpaid, volunteer work?

- ☐ At least once a week
☐ At least once a fortnight
☐ At least once a month
☐ At least once a year

In the last 2 years, have you ever been involved in any activities that promote young people to eat better, be more physically active or prevent chronic diseases (such as obesity, type 2 diabetes and heart disease)?

- ☐ Yes
☐ No
☐ Unsure/ Can't remember

Please specify the nature of the activity/activities (e.g., involvement in a research study, community event, sport club, etc)

How did you participate? (select all that are relevant)

- ☐ Questionnaire (where you were asked for your view/opinion on a health topic)
☐ Focus/ discussion group
☐ Interview
☐ Co-design workshop
☐ Photovoice/ photography
☐ Youth/ peer advocacy
☐ Peer leader/ mentor/ educator
☐ Youth advisory group/ board/ committee
☐ Social media
☐ Community event
☐ I can't remember/ I don't know
☐ Other

Other, please specify

Thinking about your experience (if you've had more than one, think about the most impactful)

In which setting did you participate? (select all that are relevant)

- ☐ Primary school
☐ Secondary school
☐ Tertiary education (college, TAFE, university)
☐ Community (workplace, community centre, faith group, etc)
☐ Social clubs
☐ Other

Other, please specify

When involved in this activity did you feel your contribution was:

- ☐ Very meaningful
☐ Somewhat meaningful
☐ Not meaningful
☐ Unsure

How would you describe your participation (involvement in this activity)?

- ☐ I felt my views or opinions were not considered and I had no ability to influence the process
☐ Adult-led (my views or opinions were considered, but I had no other influence over the decision-making)
☐ Equal partnership (I felt there was equal partnership between adults and young people involved)
☐ Youth-led (I had the capacity to make decisions that controlled the process and outcomes)

Why have you never been involved in any activities that promote young people to eat better, be more physically active or prevent chronic diseases (such as obesity, type 2 diabetes and heart disease)?

Would you like to participate in activities that promote young people to eat better, be more physically active or prevent chronic diseases?

- ☐ Yes
☐ No
☐ Not sure

If given the opportunity, HOW would you like to participate in activities that promote young people to eat better, be more physically active or prevent chronic disease? (select all that apply)

- ☐ Participate in research about young people
☐ Be consulted in guideline development for young people (e.g., school canteen strategy, dietary guidelines, physical activity guidelines)
☐ Be consulted in policy development for young people (e.g., national obesity strategy)
☐ A learning role (educational talks/ seminars)
☐ Other

Other, please specify

In which setting would you prefer to participate in activities that promote young people to eat better, be more physically active or prevent chronic diseases? (select one)

- ☐ Online
☐ In-person
☐ Hybrid (online and in-person)
☐ Other

Other, please specify

Of the participatory methods listed below which do you
feel would give youth the most influence? (select one)

- ☐ Questionnaire
- ☐ Focus/discussion group
- ☐ Interview
- ☐ Co-design activities
- ☐ Youth/peer advocacy
- ☐ Peer leader/mentor
- ☐ Youth advisory group
- ☐ Social media/marketing
- ☐ Other

Other, please specify

To what extent do you feel that participating and being involved in activities that promote young people to eat better, be more physically active or prevent chronic diseases will help improve your:

	Very unlikely	Unlikely	Unsure	Likely	Very likely
Sense of self-worth/self-esteem/self-efficacy	☐	☐	☐	☐	☐
Sense of being taken seriously	☐	☐	☐	☐	☐
Confidence in decision making	☐	☐	☐	☐	☐
Confidence in public/community engagement	☐	☐	☐	☐	☐

To what extent do you feel that youth participation in activities that promote young people to eat better, be more physically active or prevent chronic diseases can add value to:

	Very unlikely	Unlikely	Unsure	Likely	Very likely
Health research (e.g., contribution to knowledge, understanding scientific knowledge)	☐	☐	☐	☐	☐
Health intervention development	☐	☐	☐	☐	☐
Improving decision making for health policy development	☐	☐	☐	☐	☐
Raising awareness of healthy diet and lifestyle among peers, family or community	☐	☐	☐	☐	☐
Improving health promoting environments/ facilities	☐	☐	☐	☐	☐
Improving healthy lifestyle behaviours	☐	☐	☐	☐	☐
Improving health outcomes	☐	☐	☐	☐	☐

If given the opportunity to participate in activities that promote young people to eat better, be more physically active or prevent chronic diseases what would you like to gain out of the experience?

- ☐ Skill development
☐ Research experience
☐ Networking
☐ Payment
☐ A gift voucher
☐ Other

Other, please specify

Participant details

Thank you for completing the survey

We appreciate your insight!

Please select all that apply to you:

- ☐ I am interested in participating in further research about youth engagement in research
- ☐ I am interested in participating in further research about adolescent health in the digital world
- ☐ I would like to receive a summary of this survey study
- ☐ I would like to be considered in the prize draw
- ☐ None of the above

To be contacted about future research or to receive a summary of this survey study please provide your contact details below.

These details will not be stored or linked to your responses in any way. The information you provide here will not be used to personally identify you.

First name

Last name

Email

Mobile

The Youth Engagement Study Focus Group: Participant Information Sheet

Page 1

Participant Information: The Youth Engagement Study FOCUS GROUPS

Who is running the study?

The study is being conducted by researchers from The University of Sydney. Our names are Stephanie Partridge, Mariam Mandoh, Julie Redfern, Philayrath Phongsavan, Helen Cheng and Seema Mhrshahi.

Mariam Mandoh designed the focus group guide and is conducting this study as a component of her Doctor of Philosophy (Medicine and Health) research degree at The University of Sydney under the supervision of Dr Stephanie Partridge.

What is this study about?

We want to hear from young people about their perceptions and experiences in health research relating to chronic diseases such as obesity, heart disease and diabetes. We are conducting focus groups to find out more about how young people, 13-18 years old are currently participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases.

By 'youth participation' we mean young people, individually or together, forming and expressing their views and influencing matters of importance to them. The focus groups include questions about your personal views or any experiences with participation in activities that encourage young people to eat better, be more physically active or prevent chronic diseases.

Who can take part in the study?

To participate in a focus group, you need to:

Be aged between 13 and 18 years old Live in Australia

The focus groups will be held online using Zoom (Zoom Video Communications, Inc) and will take about 45 minutes to complete. You will be asked about your opinion and any experience with engagement in activities that encourage young people to eat better, be more physically active or prevent chronic diseases such as obesity, heart disease and diabetes. Your responses are completely anonymous and audio recordings will be de-identified.

You can only take part in one focus group.

Participants who complete a focus group will be reimbursed for their time with a \$25 gift voucher.

If you have any questions, please contact Stephanie from the research team at stephanie.partridge@sydney.edu.au.

The University of Sydney Ethics Approval Number: 2021/864

16-08-2023 2:08pm

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Would you like to see additional details about the study?

☐ Yes
☐ No

Additional Information: The Youth Engagement Study

This additional information tells you what we will ask you to do if you decide to join the study. Knowing what is involved will help you decide if you want to take part in the research. Please read it carefully so that you can make up your mind about whether you want to take part.

Do I have to be in the study? Can I withdraw from the study once I've started?

The study is completely voluntary. You can decide if you want to take part or not. Participation is completely up to you. You can stop at any time.

Participants can withdraw from the focus group at any time without giving a reason. However, you will be informed at the beginning of the focus group that if you withdraw after the start of the focus group any contribution to the discussion prior to withdrawal will not be able to be removed from the recording/written transcript.

What will the study involve for me?

If you decide that you want to be in our study, we will ask you to:

Take part in one 45-minute online focus group about your perceptions and any experience participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease and diabetes. When we ask you questions, you can choose to contribute to the group discussion. If you don't want to contribute or feel that you don't have anything else to express, that's okay.

What will happen to information about me that is collected during the study?

By providing your consent, you are agreeing to us collecting personal information about you for the purposes of this research study. Your information will only be used for the purposes outlined in this Participant Information Statement, unless you consent otherwise.

The focus group will involve a brief introduction of the group participants at the beginning. All responses and discussion in the focus group will be kept confidential within the group. We will only request your contact details at the end if you want to:

Receive your gift voucher Want to know about the study results once it is finished Be willing to be contacted for future research

However, these details are kept separate from the survey and will not be linked in any way to the answers you provide.

All the information you provide to us during the study will be kept confidential and stored securely and your identity/information will be kept strictly confidential. We will write a report about the study, which may be published later and key findings from the report shared on social media. However, we will not mention your name anywhere in the report or key findings on social media, and no one will know that you took part in the study

16-08-2023 2:08pm

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How long will the study take?

The online focus group will take about 45 minutes to complete.

Are there any benefits associated with being in the study?

By participating in the study, you will be helping us do our research which focuses on adolescent health. There are no direct benefits from participating in a focus group. However, by taking part you will be reimbursed for your time with a gift voucher each valued at \$25 for The Iconic or JB Hi-Fi.

Are there any risks or costs associated with being in the study?

This study will take up some of your time, we do not expect that there will be any risks or costs associated with taking part in this study. Some questions ask about your personal experience with participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease and diabetes.

If any of these questions or other questions make you feel distressed or upset, we recommend that you stop participation in the focus group and first contact your General Practitioner. Here are other contacts you can talk to and websites you can access if you feel distressed or upset, if that is what you want to do.

Kids Helpline:	T: 1800 551 800	W: kidshelpline.com.au
The Butterfly Foundation:	T: 1800 334 673	W: thebutterflyfoundation.org.au
ReachOut:		W: au.reachout.com
HeadSpace:		W: headspace.org.au

Can I tell other people about the study?

Yes, you are welcome to tell other people about the study.

What if I have any questions or would like further information about the study?

If you have any questions about the study, you can ask us or your family or someone else who looks after you. If you want to, you can call Stephanie Partridge on +61 2 8890 8187.

Will I be told the results of the study?

You have a right to receive feedback about the overall results of this study. You can tell us that you wish to receive feedback by completing the 'participant details' form, which asks you if you would like to receive a summary of the study results. If you answer 'Yes', when we finish the study, we will tell you what we learnt by emailing you a one-page summary. If you select 'Yes', you will receive this feedback after the study is finished.

What if I have a complaint or any concerns about the study?

Research involving humans in Australia is reviewed by an independent group of people called a Human Research Ethics Committee (HREC). The ethical aspects of this study have been approved by the HREC of the University of Sydney (2021/864). As part of this process, we have agreed to carry out the study according to the National Statement on Ethical Conduct in Human Research (2007). This statement has been developed to protect people who agree to take part in research studies.

If you are not happy with how we are doing the study or have any complaints about the way the study is conducted, then you or the person who looks after you can contact the university using the details outlined below. Please tell them the study title and protocol number.

Call the university on +61 2 8627 8176 or Write an email to ethics@sydney.edu.au This sheet is for you to keep. Click to download a copy.

[Attachment: "Youth Engagement Study Focus Group- Participant Information Statement.pdf"]

The Youth Engagement Study Focus Group: Participant E-consent Form

Page 1

The Youth Engagement Study: Focus Group Participant E-consent Form

You should only consent to being in the study once you have read and understood what the study is about, and you want to be in it. If you do not want to participate in our study, select "no" in the form below.

In giving my consent I state that:

I understand the purpose of the study, what I will be asked to do, and any risks/benefits involved. I have read the Participant Information Statement and my questions have been answered by either the Participant Information Statement, my parent/guardian or the researchers and I am happy with the answers. I understand that being in this study is completely voluntary and I do not have to take part. My decision whether to be in the study will not affect my relationship with the researchers or anyone else at the University of Sydney now or in the future. I understand that my participation will be audio recorded. I understand that I can withdraw from the study at any time by exiting the focus group. I understand that if I choose to withdraw from the focus group after it has begun, my contribution to the discussion prior to withdrawal cannot be removed from the recording/written transcript. I understand that personal information about me that is collected over the course of this project will be stored securely and will only be used for purposes that I have agreed to. I understand that the results of this study may be published, and that publications will not contain my name or any identifiable information about me.

I am providing consent

☐ Yes
☐ No

Participant Name

Signature

Email Address

Phone Number

Date:

The Youth Engagement Study Focus Group: Registration Form

Page 1

This online survey is designed to be completed in approximately 3 minutes. Your responses will be kept confidential and we will not store any information which can personally identify you.

We are interested in hearing about your perceptions and experiences in health research and activities that encourage young people to eat better, be more physically active or prevent chronic diseases.

This registration survey includes demographic questions and day/time options for the 45-minute online focus group.

Demographics

What is your age?

☐ 13
☐ 14
☐ 15
☐ 16
☐ 17
☐ 18
☐ Other

Are you living in Australia?

☐ Yes
☐ No

What best describes your gender identity?

☐ Male
☐ Female
☐ Non-binary/ gender diverse
☐ Prefer not to say
☐ Other

Other, please specify

What is the postcode of the suburb where you live?

Do you speak a language other than English at home?

☐ Yes
☐ No

What language (other than English) do you speak at home?

☐ Arabic
☐ Cantonese
☐ Greek
☐ Hindi
☐ Italian
☐ Korean
☐ Mandarin
☐ Spanish
☐ Tagalog
☐ Tamil
☐ Vietnamese
☐ Other

Other, please specify

16-08-2023 1:45pm

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Day and time options for the 45-minute online focus groups

What day(s) of the week are you available to participate in an online group discussion? (select all that apply)

- ☐ Monday
- ☐ Tuesday
- ☐ Wednesday
- ☐ Thursday
- ☐ Friday
- ☐ Saturday
- ☐ Sunday

What time(s) are you available to participate in an online group discussion? (select all that apply)

- ☐ 4.15pm-5pm (AEST)
- ☐ 5.15pm-6pm (AEST)
- ☐ 6.00pm-6.45pm (AEST)
- ☐ I am not located in the same time zone as Sydney (please specify times which would suit below)

What other time(s) suit you?

Participant details

Thank you for completing the focus group registration survey!

Please select all that apply to you:

- ☐ I am interested in participating in further research about youth engagement in research
- ☐ I am interested in participating in further research about adolescent health in the digital world
- ☐ I would like to receive a summary of this focus group study
- ☐ None of the above

Please provide your contact details below to be contacted for future research or receive a summary of the focus group study.

These details will not be stored or linked to your focus group responses in any way. The information you provide here will not be used to personally identify you.

First name

Last name

Email

Mobile

Youth Engagement Study Focus Group Guide

The Youth Engagement Study- Focus groups
Page 1

YES Focus Group Guide

Record ID

Focus Group Discussion Guide: Youth Engagement

Introductions

Moderator to briefly introduce themselves and mention anyone assisting and/or observing the session.

Inform the need to audio record the session and remind participants the session will not be video recorded so they can keep their cameras on if they would like to and feel comfortable to do so.

Explain that participants can withdraw from the focus group at any time; however, any contribution to the discussion prior to withdrawal cannot be removed from the recording or written transcript.

Introductions

Have young people introduce themselves

Explain the purpose of the project and bring up respectful discussion

Main purpose

Explain purpose of project

We are a research group at The University of Sydney conducting a research project to look at if and how you are currently participating in any activities that encourage young people to eat better, be more physically active or prevent chronic diseases, like obesity, heart disease and type 2 diabetes. We are interested in hearing about your level of participation and how you would like to participate in future activities. The group discussion that we will be having will last approximately 45 minutes and we will take short breaks to stretch and check everyone is doing ok. Respectful discussion

Explain the importance of everyone contributing respectfully to the discussion, particularly if they feel differently to the person next to them:

When you feel like you have something to say, please do so. There are many of you in the group and it is important that you all get a chance to express your views. Please stay on mute when you are not talking so we can hear everyone clearly and unmute yourself when you have something to say. There are no right or wrong answers; you do not have to agree with the views of other people in the group. You do not have to speak in any particular order. While I want to hear what each one of you has to say, it is important that only one person speaks at a time. Please keep what is said in this group confidential, by that we mean do not disclose any personal information that is disclosed within the focus group to anyone else. Please keep your mobile phones on 'silent mode' Does anyone have any questions before we start our group discussion? We will check in with everyone at various points during the session.

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Project: Youth Engagement

REDCap[®]

interaction to see how everyone is going

Overall- Perceptions of Chronic Diseases

What comes to mind when you think of chronic diseases such as obesity, type 2 diabetes, and heart disease?

a. Prompt: stigma, sick, unfit, unhealthy, old, normal

Do you notice chronic diseases in society?

a. Prompt: If so, where?

b. Prompt: Do you think it is a problem for young people? Or older people?

What do you think are some of the main risk factors for chronic diseases such as obesity, type 2 diabetes and heart disease?

a. Prompt: diet, inactivity, lifestyle choices, family history/genetics

Do you think eating healthy and being physically active is important?

a. Prompt: Why?

b. Prompt: maintain good health, prevent illness, fitness, etc

*** CHECK IN – MAKE SURE EVERYONE IS OK AND OFFER BREAK OUT ROOMS IF NEEDED***

For this discussion 'health promoting activities' refers to activities or strategies that promote young people to eat better, be more physically active or prevent chronic diseases such as obesity, type 2 diabetes and heart disease.

And,

For this discussion, 'youth participation' or 'engagement' is defined as young people (individually or together) forming and expressing their views and influencing matters of importance to them.

Youth Engagement- Insights

Do you think that young people have a role to play in health promoting activities for young people?

a. Prompt: How? Relevance, acceptability, leadership, confidence

How do you think young people can be involved in improving health promoting activities?

a. Prompt: giving advice, planning, marketing, advocacy, leading,

Which setting do you think is best for engaging young people?

a. Prompt: Online, in-person, mixed (online/ in-person), school, community, social clubs, etc

How engaged do you think young people should be in decision-making for health promoting activities?

a. Prompt: In the development stages, throughout the entire process, in the final implementation stages

*** CHECK IN – MAKE SURE EVERYONE IS OK AND OFFER BREAK OUT ROOMS IF NEEDED***

Reminder: for this discussion, 'youth participation' or 'engagement' is defined as young people (individually or together) forming and expressing their views and influencing matters of importance to them.

Youth Engagement- experience

Have you or one of your friends ever participated in the decision-making for activities or strategies that promote young people to eat better, be more physically active or prevent chronic diseases?

a. Prompt: such as school canteen policy, school PDHPE curriculum planning, youth advisory group, etc

If you have been engaged in an activity which aimed to improve youth health,

What was it? / what was your role?

a. Prompt: questionnaire, youth advisory group, a project/ needs assessment/ asset mapping (e.g., photovoice), focus/ discussion group, ...

b. Prompt: role- passive participant, assistant, advisor/consultant, leader, mentor, advocate.

How did the experience make you feel?

a. Prompt: empowered, confident, influential, used.

If you haven't had the experience of participating in decision-making for health promoting activities- were there any barriers to participation?

a. Prompt: no opportunity/ exposure, time, location (accessibility), financial (incl. work commitments),

Reminder: for this discussion 'health promoting activities' refers to activities or strategies that promote young people to eat better, be more physically active or prevent chronic diseases such as obesity, type 2 diabetes and heart disease.

Youth Engagement- preferences for future participation

If given the opportunity, how would you like to be involved in health promoting activities?

a. Prompt: in a leadership role, as an advisor, as part of a research team, etc

What kind of role do you think young people should have in the decision-making process in health promoting activities?

a. Prompt: consultative (give advice but no control over the process), collaborative (partners, limited control), adolescent-led (full control, adults support them)

b. Prompt: should the level of participation always be the same? Or should it depend on the type of health promoting activity/ strategy?

What kind of role do you think young people should have in the decision-making process in health promoting activities?

a. Prompt: consultative (give advice but no control over the process), collaborative (partners, limited control), adolescent-led (full control, adults support them)

b. Prompt: should the level of participation always be the same? Or should it depend on the type of health promoting activity/ strategy?

Conclusions

If given the opportunity to participate in health promoting activities, what would you like to gain out of the experience?

a. Prompt: Skill development, Research experience, Networking, payment, etc

*** CHECK IN – MAKE SURE EVERYONE IS OK AND OFFER BREAK OUT ROOMS IF NEEDED***

Are there any final comments you would like to make about the content we have discussed today?

Many thanks for your time and contribution

Youth Engagement Study- Supplementary Table 1. Explanation and descriptive summary of the eight independent categorical explanatory variables considered for inferential analysis.

Variable label (variable name)	Definition	Categories	N (%)
Gender (gender)	What best describes your gender identity? (categories combined)	Male	151 (30.1)
		Female	308 (61.5)
		Other gender*	39 (7.8)
Geographical classification (PC_classified_c2)	What is the postcode of the suburb where you live? (classified based on the Australian Department of Agriculture, Fisheries and Forestry (DAFF) ⁴⁰⁹)	Rural/regional	118 (23.6)
		Metropolitan	383 (76.4)
Socioeconomic status (SES) (SES_Quin)	Based on IRSAD quintiles derived from postcode data	Q1	40 (8.0)
		Q2	41 (8.2)
		Q3	86 (17.2)
		Q4	87 (17.4)
		Q5	238 (47.5)
CALD (lang_NonEng)	Do you speak a language other than English at home?	No	318 (63.5)
		Yes	183 (36.5)
Current school year_c5 (school_yr_c5)	What is your current school year?	Year 7 or 8	25 (5.0)
		Year 9	41 (8.2)
		Year 10	95 (19.0)

		Year 11	141 (28.1)
		Year 12	157 (31.3)
Highest level of education (edu_level)	What is your highest level of education?	Currently enrolled in year 10 or below	156 (31.1)
		Completed year 10 school certificate or equivalent	282 (56.3)
		Completed year 12 higher school certificate or equivalent	24 (4.8)
		Enrolled in a diploma or technical course	7 (1.4)
		Enrolled in a university undergraduate degree	31 (6.2)
At least one Parent/guardian with tertiary education (P1P2_highest_P_Ed_c2)	Please indicate the highest level of education completed for each parent/ guardian**	No parent/ guardian with tertiary education	111 (22.2)
		At least one parent/guardian	390 (77.8)

		with tertiary education	
Previous volunteer work (unpaid_vol_work)	In the last 12 months, did you do any unpaid, voluntary work? (e.g., coaching, refereeing, school canteen, Clean-up Australia, community group, religious group/ church, youth service/ mentoring, etc)	No Yes	226 (45.1) 275 (54.9)
* ‘Other gender’ includes ‘non-binary/gender diverse’ and ‘My gender identity isn’t listed’			
** Deduced from the original variables for parent/guardian 1 and 2 education.			

Youth Engagement Study- Supplementary Table 2. Exploring the relationship between participation and socio-demographic characteristics

Socio-demographic characteristics		% ‘participated’ in health promoting activities
Gender	Male	29.0
	Female	64.0
	Other gender	7.0
Geographical classification	Rural/regional	24.0
	Metropolitan	76.0
Socioeconomic status (SES)	Quintile 1	7.1
	Quintile 2	11.2
	Quintile 3	13.3
	Quintile 4	25.5
	Quintile 5	42.9
Language other than English	No	63.0
	Yes	37.0
Current school year	Year 7 or 8	4.3
	Year 9	8.6
	Year 10	20.4
	Year 11	30.1
	Year 12	36.6
Highest level of Education	Enrolled in year 10 or below	28.0
	Completed year 10	56.0

Socio-demographic characteristics		% 'participated' in health promoting activities
	Completed year 12	8.0
	Enrolled in a Diploma/ Technical course	2.0
	Enrolled in University	6.0
Parent/guardian education	No tertiary education	19.0
	At least one parent with tertiary education	81.0
Previous volunteer work	No	27.0
	Yes	73.0

Youth Engagement Study- Supplementary File 1. Multivariable Binary Logistic

Regression Model

Categorical Variables Codings			Parameter coding			
		Frequency	(1)	(2)	(3)	(4)
Socioeconomic status (SES)	Q1	40	.000	.000	.000	.000
	Q2	41	1.000	.000	.000	.000
	Q3	86	.000	1.000	.000	.000
	Q4	87	.000	.000	1.000	.000
	Q5	238	.000	.000	.000	1.000
Previous volunteer work	No	222	.000			
	Yes	270	1.000			

Block 0: Beginning Block

Classification Table^{a,b}

Observed		Predicted		Percentage Correct
		Participation		
Step 0	Participation	No/ Unsure	Yes	
	No/ Unsure	394	0	100.0
	Yes	98	0	.0
Overall Percentage				80.1

a. Constant is included in the model.

b. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 0	Constant	-1.391	.113	151.933	1	<.001	.249

Variables not in the Equation

			Score	df	Sig.
Step 0	Variables	Socioeconomic status (SES)	7.628	4	.106
		Socioeconomic status (SES)(1)	1.339	1	.247
		Socioeconomic status (SES)(2)	1.507	1	.220
		Socioeconomic status (SES)(3)	5.151	1	.023
		Socioeconomic status (SES)(4)	1.491	1	.222
	Overall Statistics		7.628	4	.106

Block 2: Method = Forward Stepwise (Likelihood Ratio)

Omnibus Tests of Model Coefficients

		Chi-square	df	Sig.
Step 1	Step	17.784	1	<.001
	Block	17.784	1	<.001
	Model	17.784	1	<.001

Model Summary

Step	-2 Log likelihood	Cox & Snell R Square	Nagelkerke R Square
1	473.501 ^a	.036	.056

a. Estimation terminated at iteration number 5
because parameter estimates changed by less than
.001.

Classification Table^a

			Predicted		
			Participation		
	Observed		No/ Unsure	Yes	Percentage Correct
Step 1	Participation	No/ Unsure	394	0	100.0
		Yes	98	0	.0
	Overall Percentage				80.1

a. The cut value is .500

Variables in the Equation

		B	S.E.	Wald	df	Sig.	Exp(B)
Step 1 ^a	Previous volunteer work (1)	1.008	.250	16.270	1	<.001	2.741
	Constant	-2.020	.209	93.667	1	<.001	.133

a. Variable(s) entered on step 1: Previous volunteer work.

Model if Term Removed

Variable	Model Log Likelihood	Change in -2 Log Likelihood	df	Sig. of the Change
Step 1 Previous volunteer work	-245.642	17.784	1	<.001

APPENDIX D

The HAPYUS Youth Advisory Group Evaluation Study: Ethics Approval Form



Research Integrity & Ethics Administration HUMAN RESEARCH ETHICS COMMITTEE

Wednesday, 27 October 2021

Dr Stephanie Partridge
Health Sciences, Faculty of Medicine and Health
Email: stephanie.partridge@sydney.edu.au

Dear Stephanie,

The University of Sydney Human Research Ethics Committee (HREC) has considered your application.

I am pleased to inform you that after consideration of your response, your project has been approved.

Details of the approval are as follows:

Project No.: 2021/749
Project Title: Engaging youth in health research to prevent chronic disease: protocol for the youth advisory group evaluation study
Authorised Personnel: Partridge Stephanie; Phongsavan Philayrath; Raeside Rebecca; Redfern Julie; Cheng Hoi Lun (Helen); Jia Si; Mandoh Mariam; Mhrshahi Seema;
Approval Period: 27 October 2021 to 27 October 2025
First Annual Report Due: 27 October 2022

Documents Approved:

Date Uploaded	Version Number	Document Name
29/09/2021	Version 2	Protocol clean
29/09/2021	Version 2	Semi-structured interview Clean
29/09/2021	Version 2	PIS clean
29/09/2021	Version 2	PCF clean
29/09/2021	Version 2	Demographics survey clean
01/09/2021	Version 1	Recruitment email
01/09/2021	Version 1	YLLS Survey
01/09/2021	Version 1	GSE Survey
01/09/2021	Version 1	Leadership SE Survey

Condition/s of Approval

- ☐ Research must be conducted according to the approved proposal.
- ☐ An annual progress report must be submitted to the Ethics Office on or before the anniversary of approval and on completion of the project.
- ☐ You must report as soon as practicable anything that might warrant review of ethical approval of the project including:
 - ☐ Serious or unexpected adverse events (which should be reported within 72 hours).
 - ☐ Unforeseen events that might affect continued ethical acceptability of the project.
- ☐ Any changes to the proposal must be approved prior to their implementation (except where an amendment is undertaken to eliminate *immediate* risk to participants).
- ☐ Personnel working on this project must be sufficiently qualified by education, training and experience for their role, or adequately supervised. Changes to personnel must be reported and approved.

Research Integrity & Ethics Administration
Research Portfolio
Level 3, F23 Administration Building
The University of Sydney
NSW 2006 Australia

T +61 2 9036 9161
E human.ethics@sydney.edu.au
W sydney.edu.au/ethics

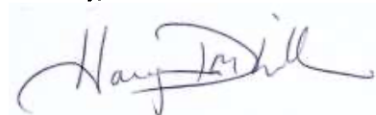
ABN 15 211 513 464
CRICOS 00026A

- ☐ Personnel must disclose any actual or potential conflicts of interest, including any financial or other interest or affiliation, as relevant to this project.
- ☐ Data and primary materials must be retained and stored in accordance with the relevant legislation and University guidelines.
- ☐ Ethics approval is dependent upon ongoing compliance of the research with the *National Statement on Ethical Conduct in Human Research*, the *Australian Code for the Responsible Conduct of Research*, applicable legal requirements, and with University policies, procedures and governance requirements.
- ☐ The Ethics Office may conduct audits on approved projects.
- ☐ The Chief Investigator has ultimate responsibility for the conduct of the research and is responsible for ensuring all others involved will conduct the research in accordance with the above.

This letter constitutes ethical approval only.

Please contact the Ethics Office should you require further information or clarification.

Sincerely,



Dr Haryana Dhillon
Chair
Human Research Ethics Committee (HREC 3)

The University of Sydney of Sydney HRECs are constituted and operate in accordance with the National Health and Medical Research Council's (NHMRC) [National Statement on Ethical Conduct in Human Research \(2018\)](#) and the NHMRC's [Australian Code for the Responsible Conduct of Research \(2018\)](#)

The HAPYUS Youth Advisory Group Evaluation Study: Demographics survey

Timepoints: Baseline

Platform: REDCap

References:

- Australian Bureau of Statistics. Census of Population and Housing (2016)
- Australian Bureau of Statistics. Socio-Economic Indexes for Areas (SEIFA): 2033.0.55.001 2018. Canberra, Australia.
- The Australian Bureau of Statistics. The Australian Statistical Geography Standard: Remoteness Structure, 2019.

1. How old are you?

- ☐ Younger than 13 → STOP
- ☐ 13
- ☐ 14
- ☐ 15
- ☐ 16
- ☐ 17
- ☐ 18
- ☐ Older than 18 → STOP

2. What best describes your gender identity?

- ☐ Male
- ☐ Female
- ☐ Non-binary / gender diverse
- ☐ My gender identity isn't listed
 - ☐ (Branching question) I identify as: _____
- ☐ Prefer not to say

3. Do you live in NSW?

- ☐ Yes
- ☐ No → STOP

4. What suburb or town do you live in? _____

5. What is your postcode? _____

6. Are you currently attending school?

- ☐ Yes → Go to question 7
- ☐ No → Go to question 8

7. What year are you in?

- ☐ Year 6
- ☐ Year 7
- ☐ Year 8
- ☐ Year 9
- ☐ Year 10
- ☐ Year 11
- ☐ Year 12

8. What best describes your current situation?

- ☐ Completed Year 10 School certificate
- ☐ Completed Year 12 Higher school certificate
- ☐ Enrolled in Diploma/Technical
- ☐ Enrolled in University undergraduate
- ☐ Other (please state)

9. What is the main language spoken in your home? (tick one)

- ☐ English
- ☐ Arabic
- ☐ Cantonese
- ☐ Greek
- ☐ Hindi
- ☐ Italian
- ☐ Korean
- ☐ Mandarin
- ☐ Spanish
- ☐ Tagalog
- ☐ Tamil
- ☐ Vietnamese
- ☐ Other, please specify _____

10. Are you of Aboriginal or Torres Strait Islander origin?

- ☐ No
- ☐ Yes, Aboriginal
- ☐ Yes, Torres Strait Islander
- ☐ Yes, both Aboriginal and Torres Strait Islander
- ☐ Prefer not to answer

The HAPYUS Youth Advisory Group Evaluation Study: General Self-Efficacy Scale (GSE)

Timepoints: Baseline, 6-months, 12-months

Platform: REDCap

References:

- Schwarzer, R., & Jerusalem, M. (1995). Generalized Self-Efficacy scale. In J. Weinman, S. Wright, & M. Johnston, Measures in health psychology: A user's portfolio. Causal and control beliefs (pp. 35-37). Windsor, UK: NFER-NELSON.

Reliability: Internal reliability for GSE = Cronbach's alphas between .76 and .90

Validity: The General Self-Efficacy Scale is correlated to emotion, optimism, work satisfaction. Negative coefficients were found for depression, stress, health complaints, burnout, and anxiety.

Scoring: The total score is calculated by finding the sum of all the items. For the GSE, the total score ranges between 10 and 40, with a higher score indicating more self-efficacy.

	Not at all true	Hardly true	Moderately true	Exactly true
All questions	1	2	3	4

#	Statement	Not at all true	Hardly true	Moderately true	Exactly true
1	I can always manage to solve difficult problems if I try hard enough	☐	☐	☐	☐
2	If someone opposes me, I can find the means and ways to get what I want.	☐	☐	☐	☐
3	It is easy for me to stick to my aims and accomplish my goals.	☐	☐	☐	☐
4	I am confident that I could deal efficiently with unexpected events.	☐	☐	☐	☐
5	Thanks to my resourcefulness, I know how to handle unforeseen situations.	☐	☐	☐	☐
6	I can solve most problems if I invest the necessary effort.	☐	☐	☐	☐
7	I can remain calm when facing difficulties because I can rely on my coping abilities.	☐	☐	☐	☐
8	When I am confronted with a problem, I can usually find several solutions.	☐	☐	☐	☐
9	If I am in trouble, I can usually think of a solution	☐	☐	☐	☐
10	I can usually handle whatever comes my way.	☐	☐	☐	☐

The HAPYUS Youth Advisory Group Evaluation Study: Leadership/ Teamwork Self-Efficacy Scale (LTSES)

Timepoints: Baseline, 6-months, 12-months

Platform: REDCap

References:

- Deemer ED, Sharma P and Xu C. Leadership/Teamwork Self-Efficacy Scale: Longitudinal Confirmatory Factor Analysis in the Context of an Energy Science Intervention. Journal of Career Development 2020: DOI: 10.1177/0894845320953899.
- Chemers, M. M., Zurbriggen, E. L., Syed, M., Goza, B. K., & Bearman, S. (2011). The role of efficacy and identity in science career commitment among underrepresented minority students. Journal of Social Issues, 67, 469–491. <https://doi.org/10.1111/j.1540-4560.2011.01710.x>

Reliability: Excellent test–retest reliability (All factor loadings from this analysis exceeded .50). Items 1, 2, 3, 5, and 10 are teamwork factors, and items 4, 6, 7, 8, and 9 are leadership factors.

Validity:

Scoring: 1, 2, 3, 5, 10 are teamwork factors and 4, 6, 7, 8, 9 are leadership factors.

	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
All questions	1	2	3	4	5

#	Statement	Strongly disagree	Disagree	Neutral	Agree	Strongly agree
1	I know how to cooperate effectively as a member of a team.	☐	☐	☐	☐	☐
2	I find it easy to follow instructions or take orders from others.	☐	☐	☐	☐	☐
3	I have high confidence in my ability to function as part of a team.	☐	☐	☐	☐	☐
4	I can provide strong support for other team members of any team I am on.	☐	☐	☐	☐	☐
5	I know how to be a good team member.	☐	☐	☐	☐	☐
6	I know a lot about what it takes to be a good leader.	☐	☐	☐	☐	☐
7	I know what it takes to help a team accomplish its task.	☐	☐	☐	☐	☐
8	I am confident of my ability to influence a team I lead.	☐	☐	☐	☐	☐
9	I know how to encourage good team performance.	☐	☐	☐	☐	☐

10	I am able to allow other team members to contribute to the task when leading a team.	☐	☐	☐	☐	☐
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The HAPYUS Youth Advisory Group Evaluation Study: Youth Leadership Life Skills

Development Survey (YLLSDS)

Timepoints: 6-months, 12-months

Platform: REDCap

References:

- Morris, J. C. (1996). Self-perceived youth leadership life skills development among Iowa 4-H members. Retrospective Theses and Dissertations. Paper 11122.
- Seevers, B. S., Dormody, T., J., & Clason, D. L. (1995). Developing a scale to research and evaluate youth leadership life skills development. Journal of Agricultural Education, 36, 28-34.

Reliability: High reliability (internal consistency $\alpha > .90$)

Validity: Face validity, Construct validity, Content validity

Scoring: The total score is calculated by finding the sum of all the items.

Subscales Communication Skills (2) I am a good listener;

Decision Making Skills (5) I consider all choices before making a decision;

Skills in Getting Along with Others (7) Consider the needs of others;

Learning Skills (4), I can use information to solve problems;

Management Skills (3) I can delegate responsibility;

Skills in Understanding Yourself (6) I am sure of my abilities;

Skills in Working with Groups (3) I trust other people.

	No gain	Slight gain	Moderate gain	A lot of gain
All questions	0	1	2	3

#	Statement	No gain	Slight gain	Moderate gain	A lot of gain
1	Can determine community needs	0	1	2	3
2	Am able to rely on my strengths	0	1	2	3
3	Respect what I am good at	0	1	2	3
4	Can set realistic goals	0	1	2	3
5	Can be honest with others	0	1	2	3
6	Can use information to solve problems	0	1	2	3
7	Understand stress from being a leader	0	1	2	3
8	Can set priorities.	0	1	2	3
9	Am sensitive to others	0	1	2	3
10	Am open-minded.	0	1	2	3
11	Consider the needs of others.	0	1	2	3
12	Show a responsible attitude	0	1	2	3
13	Willing to speak up for my ideas	0	1	2	3
14	Consider input from all group members.	0	1	2	3
15	Can listen effectively	0	1	2	3
16	Can make alternative plans	0	1	2	3
17	Recognize the worth of others	0	1	2	3
18	Create an atmosphere of acceptance	0	1	2	3

#	Statement	No gain	Slight gain	Moderate gain	A lot of gain
19	Can think about alternatives	0	1	2	3
20	Respect others' feelings	0	1	2	3
21	Can solve problems as a team	0	1	2	3
22	Can handle mistakes	0	1	2	3
23	Can be tactful	0	1	2	3
24	Flexible when making team decisions	0	1	2	3
25	Get along with others	0	1	2	3
26	Can clarify my values	0	1	2	3
27	Use rational thinking	0	1	2	3
28	Understand what it takes to be a leader	0	1	2	3
29	Have good manners	0	1	2	3
30	Trust other people	0	1	2	3

The HAPYUS Youth Advisory Group Evaluation Study: Semi-Structured Interview Guide

Timepoints: Baseline, 6-months, 12-months

Platform: Phone/Zoom

References:

- UNICEF. Conceptual Framework for Measuring Outcomes of Adolescent Participation. 2018.
- Baum F, MacDougall C, Smith D. Participatory action research. J Epidemiol Community Health 2006;60:854–7.
- Smith, J. and J. Firth, Qualitative data analysis: the framework approach. Nurse researcher, 2011. 18(2): 52-62.
- Gale, N.K., Heath, G., Cameron, E. et al. Using the framework method for the analysis of qualitative data in multi-disciplinary health research. BMC Med Res Meth 13, 117 (2013)

Transcription: Microsoft word auto transcription function

Analysis: Interviews will be digitally recorded and transcribed verbatim and will be independently parallel coded into themes in two iterative stages by two researchers based on the Framework approach using NVivo version 12.0 (QSR International). Codes will be constantly compared with previously coded data and combined or expanded until no new concepts or themes emerged. Direct quotations will be used to illustrate consensus among the participants and individual opinions.

Baseline semi-structured interview guide

Introduction:

- A reminder that your responses are private and confidential.
- Being in this study is completely voluntary and you do not have to take part if you do not wish to.
- Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.
- I will be audio recording the interview.
- You may choose not to answer any questions that you do not wish to answer.
- You may withdraw at any time during the interview.
- If you choose to withdraw, we will not collect any more information from you.
- Please let us know at the time you withdraw what you would like us to do with information we have collected about you up to that point.

We will start with some general questions about your previous experience.

- Have you been involved in a youth advisory group before?
 - o If yes, would you mind sharing who ran the group and how you contributed?
 - o How did the experience make you feel?
- Have you or one of your friends ever participated in the decision-making for activities or strategies that promote young people to eat better, be more physically active or prevent chronic diseases?
 - o Prompt: such as school canteen policy, school PDHPE curriculum planning, youth advisory group, etc
- If you have been engaged in an activity which aimed to improve youth health, what was it? / What was your role?
 - o Prompt: questionnaire, youth advisory group, a project/ needs assessment/ asset mapping (e.g., photovoice), focus/ discussion group, ...
 - o Prompt: role- passive participant, assistant, advisor/consultant, leader, school leadership, mentor, advocate.
- How did the experience make you feel?
 - o Prompt: empowered, confident, influential, used.
- If you haven't had the experience of participating in decision-making for health promoting activities- were there any barriers to participation?
 - o Prompt: no opportunity/ exposure, time, location (accessibility), financial (incl. work commitments)
- What is your main reason for joining this youth advisory group?
 - o Prompt: What do you hope to get out of this experience? Do you have an interest in pursuing careers in research or health? Incentives?

I'd like to focus now on your research skills

- Do you have any previous experience in health research?
 - o Prompt: as a research participant, contributing to a research study in other ways (e.g. ethics, consent and assent, research design, advocacy, literature searching, research translation, consumer engagement, funding)
- How would you describe your research skills?
 - o Prompt: taught in school?
- Do you feel like gaining skills in research is important to you?
 - o Why/ why not?

Next, I'd like to ask you about your confidence

- Do you feel like your views are worth listening to?
 - o Why/ why not?
- Do you feel like you can make a difference in the world?
 - o Why/ why not?
- Do you feel confident expressing my views?
 - o Why/ why not?

I'd like to focus now on your experience of being listened to and taken seriously

- Why do you feel it's important for young people to be involved in obesity prevention research/ health research?
- Do you feel like you are listened to and taken seriously?
 - o Prompt: which settings e.g., home, school, community?

Next, I'd like to ask you about making decisions

- Did you decide if I want to join this youth advisory group?
 - o Prompt: did you ask your parents/guardian for permission?

Last, I'd like to ask you about your sense of engagement

- How do you feel you can contribute to this youth advisory group?
- Do you feel you are able to act on issues that matter to you?

This is all the questions I have for the interview today. Would you like to make any additional comments?

Thank you for taking the time to participate in the interview.

6/12-month semi-structured interview guide

Introduction:

- A reminder that your responses are private and confidential.
- Being in this study is completely voluntary and you do not have to take part if you do not wish to.
- Your decision will not affect your current or future relationship with the researchers or anyone else at The University of Sydney.
- I will be audio recording the interview.
- You may choose not to answer any questions that you do not wish to answer.
- You may withdraw at any time during the interview.
- If you choose to withdraw, we will not collect any more information from you.
- Please let us know at the time you withdraw what you would like us to do with information we have collected about you up to that point.

We will start with some general questions about your experience over the last 6/12-months.

- What did you hope to achieve during first 6-months/12-months of the youth advisory group?
- Given your experience, what did you find least helpful about the youth advisory group?

- Could we now focus on any positives about the youth advisory group? What did you like about it if anything? What did you find the most helpful?
- In general, what do you think of youth advisory group?
 - o Prompt: What are your views of the delivery methods?
- Do you have an interest in pursuing careers in research or health?

I'd like to focus now on your research skills

- How would you describe your research skills now after participating in the youth advisory group?
 - o Prompt: what do you think of the skill development sessions?
- Do you feel like gaining skills in research is important to you?
 - o Why/ why not?
- Have you been able to apply these skills to other aspects of your life?
 - o Prompt: which aspect? Can you tell me more about that?

Next, I'd like to ask you about your confidence. Thinking about your experience over the last 6/12-months.

- Do you feel like your views are worth listening to?
 - o Why/ why not?
- Do you feel like you can make a difference in the world?
 - o Why/ why not?
- Do you feel confident expressing my views?
 - o Why/ why not?

I'd like to focus now on your experience of being listened to and taken seriously. Thinking about your experience over the last 6/12-months.

- Do you feel like you are listened to and taken seriously as a member of this youth advisory group?
- Why do you feel it's important for young people to be involved in obesity prevention research/ health research?

Next, I'd like to ask you about making decisions. Thinking about your experience over the last 6/12-months.

- Do you feel like you are able to take on responsible roles within the youth advisory group?
 - o Prompt: What made it easy? What made it hard?

Last, I'd like to ask you about your sense of engagement. Thinking about your experience over the last 6/12-months

- How did you feel you contributed to this youth advisory group?
- Do you feel you are able to act on issues that matter to you?
- Do you feel that as a member of this youth advisory group you can make changes?
- Do you feel that this youth advisory group promotes the rights of adolescents in research that is about adolescents?
- Do you feel like this youth advisory group has made an impact?
 - o What sectors of influence? Research, community, school, government

This is all the questions I have for the interview today. Would you like to make any additional comments?

Thank you for taking the time to participate in the interview.

Researcher comment on Youth Advisory Group (manuscript under review):

Engaging adolescents in chronic disease prevention research: insights from researchers about establishing and facilitating a youth advisory group

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ABSTRACT

Our comment discusses our experience establishing a youth advisory group focused on chronic disease prevention research. The comment highlights three key learnings: the need for researchers to adapt their working style, the importance of redefining the power dynamics, and the challenge of aligning traditional research structures with consumer-led research models.

Key words: Youth, adolescent, participatory research, advisory group, consumer, chronic disease prevention.

COMMENT

To complement the paper “Evaluating the effect of a 12-month youth advisory group on adolescent’s leadership skills and perceptions related to chronic disease prevention research: a mixed-methods study,” (1) this comment reflects on our experience in establishing and managing a youth advisory group. Our youth advisory group supported our research projects for 12 months in 2021/22 and co-authored a perspective on their experiences (2), providing practical insights into the meaningful engagement of adolescents in health research that affects them.

Adolescent health and well-being are gaining attention globally with the “1.8 Billion Young People for Change Campaign” leading to the 2023 Global Forum for Adolescents (3). Global organisations, including UNICEF, the World Health Organisation’s Partnership for Maternal, Newborn and Child Health, and the United Nations Convention on the Rights of the Child, recognise the need for younger generations to be involved in issues that impact them. In the face of intergenerational challenges such as the chronic disease epidemic, it is increasingly important for researchers to engage meaningfully with adolescents in research decision-making. In a prevention research context, adolescent engagement is a developing area of investigation with limited pragmatic evidence for researchers (4). Our systematic review found few studies in the chronic disease prevention field that meaningfully engaged adolescents as co-researchers, and fewer still evaluated their experiences in such a role (5).

To address the limited evidence for meaningfully engaging adolescents in chronic disease prevention research, we established the Health Advisory Panel for Youth at the University of Sydney (HAPYUS, pronounced ‘Happy Us’) in October 2021. Our research extends beyond healthcare services research and into areas such as the food environment and digital landscape

that are relevant to adolescent health and well-being. To engage adolescents as co-researchers, we focused on process motivators, such as learning new skills and gaining experience, over outcome motivators, such as improved health outcomes or health knowledge. This comment highlights three key learnings from our experience coordinating our youth advisory group.

Firstly, we needed to adapt our working style to establish and foster our youth advisory group. The group operated mostly online as the adolescents were recruited from a wide geographical area in New South Wales, Australia. We provided monthly payments to youth advisors and allocated researcher time to support the group. Online meetings were scheduled outside school hours to accommodate the youth advisors' schedules. We envisioned most of the research collaboration occurring during the scheduled monthly meetings. However, we realised that youth advisor attendance at these meetings was limited, with only half of the group attending on average. To address this, we adopted a tiered engagement approach, offering multiple avenues for youth advisors to contribute comfortably and safely. We also secured funding to host one full day in-person workshop with the program designed by the youth advisors. Costs covered travel for members residing in rural or regional areas to attend. We used Slack and linked collaborative tools such as Google Docs and Mural. As well, we made the meeting recordings available on Slack. We learned to be flexible and agile in our approach and adjust to group engagement changes and we recognise this approach is different to how traditional research teams operate. We recommend that researchers allocate a lead moderator to facilitate safe collaboration online and effectively communicate with the youth advisors.

Secondly, redefining the traditional power dynamic was crucial to engaging adolescents as co-researchers. Traditionally, adolescents are viewed as research participants rather than co-researchers. To shift this power gradient, we recruited them to include them in decision-making

processes and value their lived experiences. To sustain a successful co-researcher partnership, researchers need to provide opportunities for adolescents to feel empowered within the scientific community, such as co-authorship on publications and reports and presentation opportunities. Our approach was guided by youth participatory action research (YPAR) principles (4), and we started by asking the youth advisors to identify their top issues related to chronic disease prevention. This task resulted in a published essay in a scientific journal (6) and presentations at national conferences (e.g., Australian Medical Association 2022 National conference) empowering youth advisors and demonstrating the value of their perspectives in the scientific community.

Finally, challenging the traditional research structures, the principles of YPAR encourage adolescent involvement in the entire research cycle, from deciding on research questions to undertaking systematic research. However, this poses a dilemma when resources such as researcher time and funding are required to support the project, typically not readily available through conventional scientific systems. To overcome these obstacles, our team leveraged existing research grants and provided mentorship to develop the research skills of our youth advisors. Through this approach, they were able to contribute to the grant's objectives (e.g., youth-centred design of a digital health program (7)) while also exploring the issues that matter to them (6) and while generating evidence on the impact of youth advisory groups (YES! Project and HAPYUS evaluation). It will be challenging time frames, in our case, 12 months, to align with research structures and funding calls. YPAR remains a cyclical process of learning and action, but changes are necessary within scientific systems to accommodate such models of consumer-led research approaches and modernise the system itself.

CONCLUSIONS

In conclusion, our comment sheds light on the practical considerations of establishing and facilitating a youth advisory group in the context of chronic disease prevention and digital health research. The three key learnings from our experience include the need for researchers to adapt their working style, redefine the traditional power dynamic between adolescents and researchers, and challenge conventional research structures to align with models of consumer-led research, such as YPAR. Our successful collaboration between researchers and the youth advisors resulted in a youth designed digital health program, the publication of a scientific essay and future research ideas to explore. The global community recognises the importance of involving young people in issues that impact them. With growing attention on adolescent health and well-being, it is crucial for researchers to actively involve and support adolescents in making decisions about research that affects them.

List of abbreviations: Health Advisory Panel for Youth at the University of Sydney, HAPYUS; youth participatory action research, YPAR.

DECLARATIONS

Ethics approval and consent to participate: This article provides comment on a study that was performed in line with the principles of the Declaration of Helsinki. This project received ethical approval by the Human Research Ethics Committee (HREC) of the University of Sydney, date: 27.10.2021, approval No. 2021/749. Informed consent for the participants below 16 was obtained from the participants and this approach was approved by the University of Sydney Human Research Ethics Committee.

Consent for publication: The authors affirm that no identifying information was used in the preparation of this article.

Availability of data and materials: All data generated or analysed during this study are included in this published article and its supplementary information files.

Competing interests: The authors declare that they have no competing interests.

Funding: HAPYUS was supported as part of a larger research project funded by the Australian Government Department of Health Medical Research Future Fund Primary Care Grant [2006315]. The Charles Perkins Centre funded the in-person HAYPUS workshop on 14th July 2022 at The University of Sydney. SRP is supported by a National Heart Foundation Future Leader Fellowship [Grant number: 106646]. RR is supported by a SOLVE-CHD PhD Scholarship and Supplementary Scholarship.

Authors' contributions: Conceptualisation, methodology and investigation (SRP, MM, AT, RR). Writing- original draft preparation (SRP). Writing- review and editing (SRP, MM, AT, RR). All authors have read and agreed to the published version of the manuscript.

Acknowledgements: The authors wish to thank all members of HAPYUS, Dominik Mautner, Radhika Valanju, Imeelya Al Hadaya, Meera Barani, Alexi Cross, Emily McMahon, Bowen Ren, Dominique Rose, Aviral Sharda, Alexander Sinnott, Fulin Yan and the research evaluation team, Professor Julie Redfern, Professor Philayrath Phongsavan, Associate Professor Seema Mahrshahi, Dr Hoi Lin Cheng, and Sara Wardak.

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5. Mandoh M, Redfern J, Mihrshahi S, Cheng HL, Phongsavan P, Partridge SR. Shifting From Tokenism to Meaningful Adolescent Participation in Research for Obesity Prevention: A Systematic Scoping Review. Frontiers in Public Health. 2021;9(2133).
6. Valanju R, Barani M, Mautner D, Hadaya IA, Cross A, Gunawardana M, et al. Youth perspective on chronic disease prevention. Lancet Child & Adolescent Health. 2022;6(7):456-8.
7. Raeside R, Spielman K, Maguire S, Mihrshahi S, Steinbeck K, Kang M, et al. A healthy lifestyle text message intervention for adolescents: protocol for the Health4Me randomized controlled trial. BMC Public Health. 2022;22(1):1805.

Youth comment on Youth Advisory Group (manuscript under review):

Experiences from Youth Advisors in Chronic Disease Prevention Research

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ABSTRACT

Engaging young people in research is a promising approach to tackling issues like chronic disease prevention. Our involvement provided valuable experiences, including being at the forefront of change and learning to work within a research team. Our experience provides greater insight and learnings for future youth engagement in research.

Keywords: Youth, adolescent, participatory research, advisory group, consumer, chronic disease prevention.

COMMENT

Chronic diseases in young people are rising at an alarming rate calling for research into possible preventative measures (1). There is growing evidence that health outcomes in young people may be improved through interventions that are targeted and youth-specific, e.g., using youth-relevant language, technology, and motivational cues (2). One promising approach is by including young people in appropriate research decision-making using a framework of collaboration informed by the Youth Participatory Action Research principles and processes and guidelines on adolescent participation and civic engagement (3, 4). As a result, the pilot Health Advisory Panel for Youth at the University of Sydney (HAPYUS, pronounced ‘Happy Us’) was established to enhance collaborations between young people and researchers as a vital step in improving current efforts in public health.

HAPYUS started as a group of 16 young people from across New South Wales Australia from diverse backgrounds and with different experiences, who share a passion for youth advocacy and youth health. During 2021/22, we engaged in discussion through a hybrid model of virtual meetings, online chat discussions and in-person workshops to tackle the issues of improving youth’s physical and mental health. Our research and development process involved the following stages:

1. Conceptualising: brainstorming top health issues by drawing from young people’s lived experiences as well as relevant research literature.
2. Refining: distilling the broad range of issues into the top three health concerns and research questions (5)
3. Prototyping: shaping initiatives and digital programs to support healthy behaviours in young people such as the “Health4Me” program (6) and “YES!” Project (unpublished)
4. Testing: scaling up of prototypes for use by adolescents; receiving feedback from participants as well as youth advisors

5. Communicating: presenting our perspectives and recommendation strategies through a written report, media releases, and further distribution via social media platforms

Working through a structured process enabled us as youth advisors to learn about various aspects of research and youth engagement. Furthermore, we gained valuable insights into the framework of modern collaboration and communication that utilises an array of subspecialties, which enhanced our efficiency as a team as well as our personal growth. We identified three main experiences as most valuable to us throughout the course of our roles at HAPYUS, 1) being at the forefront of change, 2) learning to work within a research team, and 3) communicating data and perspectives.

Being at the forefront of change

As youth advisors, we share a sense of scientific curiosity and proactive engagement for health issues. Working with researchers from the Faculty of Medicine and Health at The University of Sydney enabled our group to be at the forefront of a rapidly evolving landscape of youth and adolescent health research.

Having identified three top concerns regarding chronic disease prevention in young people (i.e., social media's inimical impact on young people, unbalanced nutritional intake, and rise of physical inactivity) (5), we realised that these issues were dynamically changing based on the multidimensional context of COVID-19 and growing concerns for youth mental health. We understood that existing concepts about youth mental and physical health needed modification due to restrictions posed by the pandemic and the rising prevalence of social media. Discussing these concerns with researchers gave us the opportunity to represent the perspective of young people whilst also collaborating on new ways to overcome adolescent health issues, such as with the following projects and our reflections presented in Table 1.

Table 1. Reflections on our involvement in adolescent health research projects]

Project	Our reflections
Health4Me: digital health program to support young people's nutrition and physical well-being	By considering the ever-growing presence of technology in the daily lives of youth, we recognised text messaging as a high yield avenue for reaching out to younger audiences. Using the identified top health issues, we collectively brainstormed text messages that would remind and encourage young people to complete short, health-related activities, to help improve their physical and mental health. By providing our input, we were able to construct text messages that we as young people felt would resonate with other teenagers and at the same time achieve potentially health-relevant modifications in behaviour. This represents a significant shift in conventional adolescent health research approaches by increasing youth involvement in the creation of meaningful health tools ("by youth, for youth"). The protocol for this study is now published and our contribution is acknowledged (6).
YES! Project Youth Engagement Study	Another oftentimes limiting aspect of current research regarding youth health is lack of feedback from young people on data collected about us. Thus, our collaboration on this project emphasised the analysis of youth responses, such as real-time viewpoints from youth on questions about civic engagement at all levels. Additional opportunities for us were also provided in shadowing focus groups by scribing key issues explored by participants. Thus, this project emphasised youth involvement at every stage through a multitude of roles for young people, from collaborators to participants, to effectively improve the feedback loop that shapes our understanding of perceptions of youth engagement. This project is ongoing, and we look forward to collaborating on the scientific manuscript.
Youth Advisory Group (YAG) Evaluation Study	Thirteen members of HAPYUS participated in an evaluation study that consisted of completing a written and verbal questionnaire about our experiences as part of HAPYUS in intervals of 6 months (7). This is an innovative approach to embed youth feedback into research studying the impact on youth collaborators, who are designing health tools, rather than studying the target group for the health tools (which is young people using the health applications). Additionally, reflecting on our communication, teamwork skills and confidence, most of us agreed that our research engagement helped us learn more about our holistic development as individuals.

Working within a research team

Despite our team being geographically distant and COVID-19 restrictions, we were able to collaborate within our advisory team as well as with the team of researchers via online platforms such as Slack and Mural. The diversity of our group, both culturally and geographically, proved valuable in identifying the complex interactions leading to disease in young people including barriers to

healthy living. To effectively delegate responsibilities based on strengths and interests, we divided ourselves into working teams and subsequently updated other working teams through a regular feedback system.

Within the HAPYUS advisory group, the team of co-chairs worked together on collating the experiences of all members culminating in a report and media releases, a process that involved regular regrouping. We also formed teams for consulting with the various state and federal parliamentarians, speaking at the Australian Medical Association conference, and for policy briefings. As a team with sixteen members, it was crucial that we distributed opportunities equally amongst ourselves to allow everyone to be involved in collaborations on both a small and large scale.

The most valuable aspect of working within this framework with the guidance of researchers was the dichotomous learning model which motivated us for constant improvement using feedback in areas of delegation and time management to ensure we worked together effectively. Learning those skills will also be important for the future, as in a rapidly changing workforce, online collaboration is expected to be an integral skill.

Communicating data and perspectives

Traditionally, young people have been distanced from both readership of academic literature (due to jargon that may be difficult for readers from non-research backgrounds and with limited awareness of relevant materials available regarding youth health issues) as well as co-authorship of academic literature (as research was considered strictly a domain of adult experts). HAPYUS represented to us as youth advisors an innovative path of youth involvement allowing us to use our own voice. To avoid tokenistic youth participation, we felt the need to create an authentic account that would be accessible to younger audiences throughout the world. Our group co-authored a perspective essay about the evolution of youth health contextualised by the pandemic, which was published by The Lancet Child

and Adolescent Health as “Youth perspective on chronic disease prevention” (5). As some of the youngest co-authors to be published in The Lancet, we achieved two important goals:

- Bridging the gap between youth and academia
- Presenting our concerns through synthesising research evidence and perspectives, leading to increased awareness of chronic disease in young people and potentially novel approaches for solutions.

Through the ensuing interest by national level media, we had an opportunity for further public discussions, such as through The Sydney Morning Herald (national Australian newspaper) and Sunrise (national Australian breakfast television program), raising awareness amongst the wider scientific community but also the public including younger audiences. Other opportunities included presenting at the Australian Medical Association Conference (the peak professional body for medical doctors in Australia), and discussions with policy advisors of the state and federal Government.

Data communication is becoming an increasingly sought-after skill and we as youth advisors greatly benefited from working through various modes of communication, from article writing to interviews and conference presentations. Through these opportunities, we gained invaluable experiences, but most importantly, we hopefully contributed in a meaningful way to youth health research and better health outcomes for young people.

CONCLUSIONS

In conclusion, our involvement in the HAPYUS has been influential in advancing youth engagement in chronic disease prevention research. We navigated dynamic health challenges, improved our collaboration skills, and bridged the gap between youth and researchers through effective

communication. Our experiences offer valuable insights for future youth involvement in addressing chronic disease prevention research.

List of abbreviations: Health Advisory Panel for Youth at the University of Sydney, HAPYUS

DECLARATIONS

Ethics approval and consent to participate: This article provides comment on a study that was performed in line with the principles of the Declaration of Helsinki. This project received ethical approval by the Human Research Ethics Committee (HREC) of the University of Sydney, date: 27.10.2021, approval No. 2021/749. Informed consent for the participants below 16 was obtained from the participants and this approach was approved by the University of Sydney Human Research Ethics Committee.

Consent for publication: All authors have provided consent for publication. No individual identifying information was used in the preparation of this article.

Availability of data and materials: All data generated or analysed during this study are included in this published article and its supplementary information files.

Competing interests: The authors declare that they have no competing interests.

Funding: HAPYUS is supported as part of a larger research project funded by the Australian Government Department of Health Medical Research Future Fund Primary Care Grant [2006315]. The Charles Perkins Centre funded the in-person HAPYUS workshop on 14th July 2022 at The University of Sydney.

Authors' contributions: Conceptualisation, methodology and investigation (DM, RV, IAH, MB, AC, EM, BR, DR, AS, AS, FY, SW). Writing- original draft preparation (DM, RV, SW). Writing- review and editing (DM, RV, IAH, MB, AC, EM, BR, DR, AS, AS, FY, SW). All authors have read and agreed to the published version of the manuscript.

Acknowledgements: The authors wish to thank the other HAPYUS members who contributed to various activities over the 12-month term and the guest speakers who attended our meetings to share their research. We also thank all members of the research team, Dr Stephanie Partridge (who proofread this comment and provided guidance in its preparation), Mariam Mandoh, Rebecca Raeside, Professor Julie Redfern, Professor Philayrath Phongsavan, Associate Professor Seema Mihrshahi and Dr Hoi Lun Cheng.

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