

WALKING THE TALK: DESIGNING YOUTH ADVOCACY & ENGAGEMENT WITH YOUNG PEOPLE

WHITE PAPER: ENGAGING WITH YOUNG PEOPLE IN HEALTHCARE HOW ARE WE DOING?

2022



Association for the Wellbeing
of Children in Healthcare



Acknowledgement of Country

The Association for the Wellbeing of Children in Healthcare acknowledges the Traditional Custodians of the lands on which we work, the Wallumedegal people, who form part of the wider Aboriginal nation known as the Eora Nation. We recognise their continuing connection to the lands and waters of this Country. We also pay our respects to Elders past and present.



Association for the Wellbeing
of Children in Healthcare

The Association for the Wellbeing of Children in Healthcare (AWCH) is a national not-for-profit organisation that has been advocating for the needs of children, young people, and their families within the healthcare system in Australia since 1973.

AWCH works in partnerships with children, young people, their families, health professionals, peak bodies, and the broader community, to ensure that the psycho-social needs of children, young people, and their families are recognised and met.



Health Consumers NSW (HCNSW) is a membership-based, independent, not-for-profit organisation promoting and practicing consumer engagement in the NSW health sector. HCNSW creates meaningful partnerships between consumers, the health sector, and policy-makers.



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Contents

Contents.....	4
Executive Summary.....	6
Aims.....	7
Methodology	7
Australia’s Young People	8
Who Counts as ‘Young’?	8
Demographics	8
What’s Important to Young Australians?	9
Important Issues.....	9
Do Young People <i>Want</i> to be Engaged?	10
Where do Young People fit into the Healthcare System?	11
Barriers to Healthcare	11
Priorities and Recommendations.....	12
COVID-19	13
Literature Review	15
Power, Adultism & Active Citizenship	15
Preventing Tokenism	17
Co-design & Co-Production	18
Intersectionality & Marginalised Youth	20
Models of Engagement & Participation.....	24
Hart’s Ladder (1992)	24
Treseder’s Degrees of Participation (1997)	25
Shier’s Pathways to Participation (2001).....	26
Typology of Youth Participation & Empowerment Pyramid (2010)	27
Cahill & Dadvand’s (2018) P7 Model	28
Existing Resources.....	29

'Amplifying the Youth Voice: Health Consumers Queensland Youth Engagement Framework 2021'	30
'Wellbeing Health & Youth Engagement Framework'	32
'Better Together: A practical guide to effective engagement with young people'	33
'How to Partner with Young People'	34
'Co-designing with Young People'	35
'Engaging Children and Young People in Your Organisation'	36
'Youth Matter: A Practical Guide to Increase Youth Engagement and Participation in Tasmania'	37
Key Themes	39
Gaps	40
Intersectionality.....	40
Sharing Power.....	40
Co-authorship	40
Follow Up & Sustainability	41
Putting It Together	42
Actionable Findings.....	43
References.....	46

Executive Summary

This report serves as a preliminary scoping report for the Walking the Talk (WTT) project. WTT is a collaboration between the Association for the Wellbeing of Children in Healthcare (AWCH) and Health Consumers NSW (HCNSW), and young people, with the goal of engaging with, supporting, and working alongside young people to identify and target gaps in current approaches to youth engagement.

The aims of this report included identifying 'young people' as a distinct demographic and exploring current data regarding their experiences and priorities, identifying key themes and gaps throughout literature and current youth engagement resources, and lastly, identifying actions to be taken by WTT based on the findings of this report. This was achieved by reviewing current, relevant data regarding young Australians, current academic literature, relevant models of youth engagement, and current youth engagement resources, drawing out themes and gaps within each area in order to shape the next steps of the project.

It was found that young people in Australia continue to face numerous challenges and barriers to engagement, both on a consumer level, and a service delivery and design level. Further, many young people continue to feel unheard and dismissed as relevant stakeholders in society, particularly in the midst of the COVID-19 pandemic. The literature reviewed mirrored these findings, identifying several areas of consideration for youth engagement. Several common themes were identified within current youth engagement resources such as mutual trust and respect, accessibility, and flexibility. Four main gaps were identified, offering areas for opportunity for WTT. The gaps identified were:

- The need for an intersectional lens with regard to young people's identities, experiences, and needs
- The need for improved follow up and sustainability of engagement
- The need for improved collaboration and sharing of power between adults and young people
- The need for improved acknowledgement of young people's work as co-designers/producers/authors

Lastly, next steps for WTT were developed based on the findings. The next steps fall into the same four main areas as the identified gaps, giving WTT the opportunity to address these gaps within the engagement processes throughout the project.

Aims

The goal of this report is to identify the most effective and respectful ways to engage with young people within an engagement and health advocacy setting. To achieve this, the following aims have been developed:

- To define the demographic of 'young people' and identify the challenges faced by this group.
- To identify key themes within existing youth engagement resources, and to use these as a basis on which to build, drawing out gaps and areas in need of further attention and inclusion in engagement discourse.
- To review existing literature pertaining to youth engagement, youth participation, tokenism, and co-design.
- To conclude with specific, practical actions to be undertaken based on the information gathered, with a focus on healthcare.

Methodology

This preliminary report utilised data collection in three distinct areas.

1. National research and data regarding young Australians as a distinct demographic. This section includes a review of data regarding population characteristics and groups, current issues of concern for young Australians, current challenges faced by young people within the healthcare system, and the impacts of COVID-19 on Australia's young people.
2. Current resources which are focused on youth engagement. This section includes review of existing frameworks, toolkits, and guidelines with the goal of finding common themes, areas of opportunity and gaps in need of further research and focus.
3. Available academic literature on tokenism, co-design, youth engagement and participation, and youth-led research and engagement.

Australia's Young People

Who Counts as 'Young'?

There is currently little continuity among resources with regard to what age range constitutes 'young people'. For the purpose of this report, 'young people' will be defined as those aged 14-25 years. Particularly due to the ongoing impacts of the COVID-19 pandemic, more so than ever, many young people are living at home with family well into their 20s (Australian Institute of Health and Welfare, 2021). This, coupled with the often-tumultuous nature of early adulthood, provides a solid foundation for identifying those up to 25 years of age as 'young people'. This offers the opportunity for specific consideration for this age group, in which many people find themselves remaining reliant on a parent or other family, still developing their sense of self and identifying their passions, wants, and needs, as well as attempting to navigate systems such as the healthcare system, employment, and housing, for the first time.

Currently, over 4.4 million young people are living in Australia, with 1.3 million of those living in New South Wales (NSW) (Australian Bureau of Statistics, 2021; Youth NSW, 2019). It is therefore integral that services, organisations, and governments engage effectively and meaningfully with young people. Without this, we may be overlooking, dismissing, and failing to meet the needs of over 4 million Australians.

Before we examine the various engagement frameworks and strategies currently available, let's look at the various characteristics of young Australians, as well as the issues and challenges facing them currently.

Demographics

According to the Australian Institute of Health and Welfare (AIHW) (2021), 25% of Australia's young people aged 15-24, were born overseas, 5.1% were Aboriginal and/or Torres Strait Islander, 9.3% had a disability, and 75% lived in 'major cities' and fewer than 1.6% lived in 'remote' or 'very remote' areas.

Additionally, according to the Australian Bureau of Statistics (ABS):

- On a scale of 1 to 10, young people aged 15-24 reported an overall life satisfaction of 6.9 in 2020 (ABS, 2020).
- Of those aged 15-24, 35.8% of males and 39.3% of females had one or more chronic conditions (including mental health conditions) (ABS, 2018).

- Only 28% of young people aged 18-24 always find it easy to actively engage with healthcare providers (ABS, 2019).

New South Wales specific data, as of 2016, indicates that almost 31.5% of Australia's young people aged 12-25 live in NSW. Of young NSW residents, 30.5% were born overseas, and 4.5% are Aboriginal and/or Torres Strait Islander (Youth NSW, 2019).

The importance of intersectionality will be discussed in the literature review of this report, acknowledging the immense impact of belonging to one or more marginalised groups on access, engagement and participation.

What's Important to Young Australians?

Important Issues

According to Mission Australia's Youth Survey 2021, which surveyed 20,207 young people aged 15-19 years, the top three most important issues in Australia identified by participants were COVID-19 (identified by 45.7% as one of the most important issues in Australia), the environment (38%), and equity and discrimination (35.4%) (Tiller et al., 2021).

Mission Australia's survey also identified many areas of engagement utilized by young people (Tiller et al., 2021). The data gathered indicated that more than four in 10 (41.1%) respondents reported they had participated in volunteer work in the past year, one-third (33.9%) of young people indicated they had taken part in student leadership activities, 24.5% in youth groups/activities, 19.2% in environmental groups/activities, and 9.3% in political groups/activities.

Additionally, the Association for the Wellbeing of Children in Healthcare's (2021) report titled "'Too Young': An Exploration of Youth Ageism' offers significant findings. For this report, 61 young people aged 12-24 were surveyed with regard to their opinions, attitudes, and experiences of ageism both in general society and specifically within healthcare settings. The relevant findings of this report include the following.

- When asked their level of agreement with the statement "Young people are often overlooked as a group with unique needs, experiences and voices", **91.8%** of respondents agreed or strongly agreed.
- With regard to frequency of experiences, in response to the statement, "My opinions have been dismissed or ignored because of my age" **83.6%** of respondents reported that this had occurred 'Several times' or 'Usually'.

- Further, in response to the statement, “I have been talked down to or looked down on because of my age”, **88.5%** reported that this had occurred ‘Several times’ or ‘Usually’.

These findings show that many young people recognise when they are overlooked due to their age, and many understand the ramifications of this. This report also offers insight into young people’s desire to engage and have their voices heard, making changes to the systems that they feel overlook and dismiss them.

Do Young People Want to be Engaged?

The survey utilised for the report by AWCH (2021) ended with an optional open-ended question for respondents to share their specific experiences. Over one third of respondents chose to do so, sharing some insightful and often extremely challenging experiences with ageism and the healthcare system. This willingness to engage and be open with researchers is promising, and may speak to a wider desire among young people to be heard, valued, and taken seriously by the adults in their lives; on personal, community, and government levels.

Additionally, the Australian Department of Health’s (2019) ‘Youth Taskforce Interim Report’ outlines various issues in line with the above findings. When examining what issues are most personally important to Australia’s young people, the report found that mental health, equity, equality and discrimination, financial constraints, and not being heard, taken seriously and lack of trust in the government, were most frequently cited. These findings are consistent with those published by Mission Australia in 2021, thus remain relevant today.

The ‘Youth Taskforce Interim Report’ also focused on engagement and young people’s views on, and experiences with, engaging with governments and policy makers. The report states that young people’s increasing disenfranchisement with government was clear through various consultations with young people. However, these consultations also contained a sense of great need with regard to engagement, participation, and collaboration in decision making and policy design. Young people spoken to for this report indicated their strong desire for genuine engagement, to be truly heard and valued. The consultees identified positive aspects of engagement such as being made aware of the outcomes of their engagement through follow ups from the body they worked with, transparency and clear communication, and remuneration for participants time and energy.

Through this report's consultations with young people, it is clear that many recognise the often tokenistic nature of their engagement, leading to cynical views of governments, organisations, and the engagement process itself. It is therefore critical that future engagement is evidence-based, as well as truly collaborative, or better yet, youth-led.

Where do Young People fit into the Healthcare System?

Barriers to Healthcare

Several resources indicate a need for systemic change and improvement with regard to the Australian healthcare system and young people's place within it. The Association for the Wellbeing of Children in Healthcare's (2021) report exploring young people's experiences of ageism within the healthcare system indicates several areas of concern that arise when young people engage with the healthcare system. Key themes drawn out in this report exhibit various barriers including dissatisfaction with the system and with care received, difficulties in navigating the system (particularly moving between public and private as well as from paediatric healthcare to adult healthcare), and structural barriers such as financial barriers and a lack of accessibility (AWCH, 2021). Findings include:

- Respondents were asked to rate their overall experience with the healthcare system on a scale of 1 (worst) to 10 (best), the average of all responses was 5 out of 10 (with 7 out of 10 being the most frequently reported response).
- In response to the statement "Overall, healthcare professionals do not understand young people's needs and experiences well enough", 60.7% 'agreed' or 'strongly agreed'.
- In response to the statement "Healthcare services generally feel friendly and welcoming to me, as a young person", 44.3% 'disagreed' or 'strongly disagreed' and 39.3% 'neither agree nor disagreed'. Only 16.4% 'agreed' with this statement, and none 'strongly agreed'.
- In response to the statement "I have had to strongly push to be heard or taken seriously by a healthcare professional", 59% responded "several times" or "usually".

These findings indicate significant concerns for the quality and efficacy of the healthcare young people are receiving. Further, the need for self-advocacy by young people within the healthcare system is clear. Several other aspects impacting young people's experiences with the healthcare system were identified within this research including issues navigating a confusing and complex healthcare system for the first time as a young

person, an absence of quality care due to a lack of understanding of the specific and complex needs of young people, feelings of being stereotyped by healthcare professionals due to age, and the perception of not being heard or taken seriously within healthcare settings. All of these aspects of young people's engagement with the healthcare system can, and have, led to misdiagnosis, and mistreatment. This impacts not only the young person but the healthcare system itself, potentially leading to issues such as the development or worsening of chronic conditions, disability, and hospitalisations.

Priorities and Recommendations

AWCH's (2021) report outlines several recommendations that parallel other reports such as the Australian Department of Health's (2019) 'National Action Plan for the Health of Children and Young People: 2020-2030' and the Youth Health Forum's (2021) 'Life Transitions and Youth Pathways to Health Services'. The recommendations outlined in AWCH's (2021) report include future research specific to young people, organisational involvement and collaboration between services and organisations, co-design and collaboration with young people, and overhaul of the healthcare system in order to address structural barriers, navigation issues, and the disconnect experienced between public and private services and systems.

The Department of Health's (2019) action plan identifies several priority areas relevant to young people including improving health equity across populations, and strengthening the health workforce in order to ensure specific and appropriate care for young people. The action plan goes on to outline actionable steps and structural aspects required to support the action plan. These include ongoing research and evidence gathering, increased cohesion and consistency throughout the healthcare system, centring young people at all points of design, implementation, and evaluation, and active engagement in collaboration and collective efforts between organisations, services, governments, and consumers.

Similarly, the Youth Health Forum's (2021) report also outlines several key challenges with regard to young people's engagement with the healthcare system, particularly when transitioning between the paediatric system to the adult system. The six challenges outlined in this report are trusting healthcare services, transitioning to adult healthcare, navigating the healthcare system, delivering digital healthcare, building a more equitable system, and developing health literacy. This report also contains recommendations based on its findings. These include navigation support, affordable access, digital healthcare delivery, inclusive delivery, and youth age consistency across jurisdictions.

It is clear across these three reports that numerous themes emerge. Most notably, the need for collaboration between services, organisations, governments, and the young people they are attempting to serve and support. It is hoped that through this report and ensuing project that best practice with regard to youth engagement, co-design, and developing and supporting youth-led research and engagement will be established.

COVID-19

UNICEF Australia's 'Living in Limbo' (2021) report surveyed 1007 young people aged 13-17 and provides incredible insight into young Australian's experiences with the COVID-19 pandemic. Issues including mental health, resilience, and participation and decision making were prevalent.

This survey found that when asked about coping within the context of COVID-19, 45% of participants reported that they were able to cope 'well'. This has almost halved from 81% as reported by UNICEF Australia in 2020. Further, one quarter of participants reported feeling isolated and unsure of how or where to access support.

UNICEF Australia gathered compelling data regarding young people's perspectives and experiences with regard to being heard, being considered as stakeholders, and being considered as essential workers (where relevant) through this important study. The survey found that one quarter of participants felt that children and young people are not considered to be stakeholders equal to other groups in society within the context of the national COVID-19 response. Additionally, 40% of participants felt that many of the conversations about children and young people were more focused on the impact on parents and caregivers than the children and young people themselves, believing that children and young people should be a primary consideration within such conversations.

Another issue reported by participants was a lack of recognition of young people as part of the demographic of 'essential workers'. Of the participants in UNICEF Australia's survey, 20% worked a job that could place them at risk of being exposed to COVID-19, i.e. front-line, or essential workers. In conjunction, 44% of participants felt that there has been little acknowledgement and recognition that many young people are among the essential workers who have been risking their health to serve the community throughout the COVID-19 pandemic.

Lastly, and arguably most importantly, 26% of the young people surveyed believe that there is "no clear way for children and young people to feed into the discussion about who has been affected and how the virus, its impact, and responses are being

communicated" (UNICEF Australia, 2021, p.13). This speaks to the significant lack of opportunity afforded to young people to have their voices heard, and their ideas and opinions taken seriously. This is integral to acknowledge within future youth engagement and participation.

These relevant and highly current findings suggest that young people continue to be left out of the conversation. While it is clear through the existence of these various reports that effort is being made to gather information regarding young people's experiences of being unheard and dismissed, more work must be done to ensure genuine and meaningful engagement with young people in order to begin to effectively address the issues and challenges facing this group.

Literature Review

This section will examine current academic literature focused on areas such as tokenism, co-design with young people, and youth-led engagement. By reviewing existing literature, and comparing and contrasting various findings, arguments, and recommendations, a sound foundation for future development of youth engagement processes and resources can be developed.

Power, Adulthood & Active Citizenship

Young people are often characterised as 'adults-in-formation' or 'citizens-in-the-making', with the explicit implication that they are not yet ready to participate in society on the same level as adults (Gordon, 2007; Hickey & Pauli-Myler, 2019). This notion of young people as 'future citizens' is supported and perpetuated throughout most aspects of society. From socialisation within the family, to the education system and the media, young people are taught that they are better 'seen and not heard', leaving them not only voiceless but unknowingly complacent in that voicelessness (Gordon, 2007).

DeJong and Love (2015) conceptualise young people as a social identity group, and youth oppression as the result of the subordination of this group. The authors define youth oppression, also referred to as adulthood, as the "systematic subordination of younger people as a targeted group, who have relatively little opportunity to exercise social power... through restricted access to the goods, services, and privileges of society, and the denial of access to participation in the economic and political life of society" (p. 490). When we conceptualise youth in this way, it becomes clear that the way in which society is built by and for adults, places young people in positions of powerlessness, reinforced through the stereotypes, biases, and attitudes born from an adult-based society. This, in turn, leads to the idea that only adults should make decisions and hold power, even with regard to issues, decisions and services that only impact children and young people (DeJong & Love, 2015). This offers a significant perspective with regard to youth engagement and participation, particularly in the healthcare system. By understanding this conceptualisation of youth oppression and thus being acutely aware of adult power and domination within society, we can work towards changing this.

This is mirrored in the work of Hickey and Pauli-Myler (2019) and Gordon (2007). Hickey and Pauli-Myler (2019) examined the ways in which young people were constrained in their power, decision making, and ability to create change within a local government context. The authors attended an initiative run by a local government in Queensland. This

involved the formation of a 'youth leaders council', consisting of 12 young people aged between 13 and 24, with the goal of engaging young people in government decision-making. Through observation as well as consultation with the young people involved, the authors found that despite the explicit goal of the initiative being to engage young people in decision making and policy formation, the opposite occurred. Despite being told that the council was 'theirs' to share thoughts and ideas, the young people felt unwelcome, unheard, and highly constrained by the adult-built bureaucracy of government. Further, the authors remark that the experiences outlined in this study are not rare, in fact, according to many of the participants, they are the norm. This is likely due to the pervasive and unrecognised nature of adultism in society. The authors conclude by acknowledging that constraints such as those placed on young people do not exist inherently, they are upheld and enacted, and thus can be subject to disruption. This offers hope with regard to future youth participation, and guidance for adults looking to engage ethically and genuinely with young people.

Similarly, Gordon (2007) examines the presence of ageism (or adultism) within youth engagement and activist settings, and the ways in which young people recognise and respond to age inequality. The author examined two youth activist organisations, observing, and comparing young people's conceptualisation of adultism, and the ways in which they respond and organise in order to overcome it. Gordon (2007) also discusses the notion of 'citizens-in-the-making', and the ways in which this leaves systems, services, and decisions both "unquestioned and unchallenged" (p. 635), thus upholding the status quo of adult domination and youth subordination, as described by DeJong and Love (2015). The author's examination of two youth activist organisations showed that, by defying the 'be seen and not heard' expectation of young people and moving into political and activist spaces, young people found themselves becoming keenly aware of their social position as 'youth', thus subordinate to the dominant 'adult'. Through this awareness, young people both politicise and criticise adultism, utilising this to develop strategies and mechanisms for undermining adult power, increasing youth autonomy, and creating allies out of the adults in their lives. The author concludes: whether adults recognise or deny age as a source of oppression can influence the ways in which young people understand and respond to adult power, including whether young people choose to engage at all, or if they do, whether engagement is sustained in the future.

Corney et al. (2021) also discuss the impacts of adultism, describing it as a hindrance to youth participation. The authors describe adultism as "based in a web of cultural norms

that continually and ubiquitously affirms and reinforces the superior position of the adult, relative to the young person" (p. 4). They go on to outline various assumptions and stereotypes pervading our society that reflect this; young people characterised as impulsive, naive, impressionable, and vulnerable, while adults are generally characterised as not impulsive, sensible, wise, and capable. Through this, the authors conceptualise youth participation as an "on-going struggle against adultism" (p. 4). The authors also acknowledge that young people, particularly those under the legal voting age of their country of residence, are politically disenfranchised. This leaves young people powerless over decision making and political involvement unless 'welcomed' into the space by adults. They conclude by stating that while governments espouse the need for and use of youth participation, there is little to suggest that young people under the age of enfranchisement will have a significant political voice in Australia any time soon (Corney et al., 2021).

Preventing Tokenism

In his work for UNICEF, Hart (1992) describes children as "undoubtedly the most photographed and the least listened to members of society" (p. 9). Hart (1992) describes the ways in which children are often brought into organisations, initiatives, and events as carefully selected, controlled, and often viewed as representative of 'all' children. This notion of false representation, and lack of voice and influence, can be understood as tokenism. Hart (1992) defined tokenism as instances in which children are said to be given a voice, but have little or no choice or opportunity for actual influence. Hart's Ladder (1992) is one of the most widely utilised models of public participation since its inception. The ladder consists of eight rungs, labelled in ascending order from, ostensibly, least participatory to most. The bottom three rungs of the ladder, in ascending order, 'Manipulation', 'Decoration', and 'Tokenism', are grouped as 'non-participation'. From here the rungs are, in ascending order, 'Assigned but informed', 'Consulted and informed', 'Adult-initiated, shared decisions with young people', 'Initiated and directed by young people', and 'Initiated by young people, shared decisions with adults'.

The final five rungs are grouped as 'participation'. It is clear that this model is a linear spectrum from non-participation to most involved participation. However, Hart (1992) points out that the goal of participation does not always have to be the highest rung. The most important aspect is choice, if one ensures that participants have the freedom to

choose the extent of their participation, this is ideal. For example, youth engagement may be initiated by adults but be as open as possible to young people's input and influence. This would fall on the 6th rung of Hart's Ladder, but still be ethical, empowering, and capable of subverting adult power structures typical of much youth participation. Many authors, including Hart (1992), have remarked that participation at the 7th and 8th rung levels is very rare. This is unsurprising when we consider the conceptualisation of youth as a social identity group subject to oppression and subordination (DeJong & Love, 2015; Gordon, 2007; Hickey & Pauli-Myler, 2019). This notion is echoed by Warming (2011) who examines the same concept of children and young people as 'future adults', contrasting adults as human *beings* and young people as human *'becomings'*. With this concept of young people as *future* citizens and thus currently non-citizens, it is no surprise that few instances of youth participation are youth-initiated. If you have been socialised and conditioned by all aspects of society to be seen and not heard, how do you know you have a voice, let alone the capacity to initiate change?

Co-design & Co-Production

Co-design, at its core, involves working *with* people rather than *for* them (McKercher, 2020). McKercher (2020) defines co-design as "an approach to designing with, not for, people... typically works best where people with lived experience, communities and professionals work together to improve something that they all care about" (p. 14). Co-design is a process that involves a team of people sharing power, sharing experiences, building relationships, and building capacity. It is essential to recognise that co-design is an active and ongoing process, not a product or 'one-off'. Similarly to Hart's (1992) clarification of the highest rung of the ladder as not necessarily the ideal goal, McKercher and Gardner (2021) argue that co-design is not at the top of a hierarchy of 'good' participation. The term co-design has almost become synonymous with ethical and 'good' participation. However, as McKercher and Gardner (2021) state "not all participatory practice is co-design, and not all co-design is good, fair or participatory" (para. 9). It is essential, therefore, to think deeply and critically about approaches to participation.

Farr (2017) defines co-production as a process through which participants (co-producers) play an active role in producing policy, resources, services and so on, that are of consequence to them. This has potential for immense impact on young people's involvement in healthcare engagement and advocacy. Farr (2017) outlines key aspects of

co-production as building capabilities and skills, ensuring equal partnerships, and mutuality and reciprocity. Just as McKercher (2020) outlines with regard to co-design, Farr (2017) describes the need for co-production to involve the sharing of power, i.e. transferring power from organisations and professionals onto their fellow co-producers. However, Farr (2017) acknowledges the gap between theory and practice with regard to enacting this transference of power. To address this, they refer to the need for continuous critical reflective practice in order to avoid falling back into adult power and dominance. Similarly, Liddard et al. (2019) explore co-design and co-production in work with disabled¹ young people, through a co-authored article. The authors assert that research is inherently political, thus holding the power to empower or exploit. Therefore, it is essential to co-design and co-production that dominant and traditional power relations generally present in academic research are destabilised. As Farr (2017) describes, this requires ongoing critical reflection on power, privilege, and position. Further, Carter and Coyne (as cited by Liddard et al., 2019) emphasise the need for a foundational and core commitment among adults (researchers, organisations, and so on) to the idea that children and young people can and will shape the work, often challenging dominant ideas and constructing their own agendas within the work. It is only through this commitment, the authors assert, that tokenism can be truly countered, and meaningful co-design and co-production can take place. Additionally, Lillard et al. (2019) echo the notion expressed by McKercher (2020) of co-design and co-production as conducted *with* and *by* participants, rather than *about* and *for* them. This is the very basis of co-design and must be at the forefront of researchers and organisations minds when engaging with young people, particularly with regard to healthcare.

Lastly, work by Bevan Jones et al. (2020) and Thabrew et al. (2018) explore the process of co-designing and co-producing health technologies with young people. Bevan Jones et al. (2020) conducted a review of literature pertaining to the co-design of digital health technologies with children and young people, in order to identify and explore principles of co-design. The authors identified 25 articles and 30 digital health technologies designed and produced with children and young people. The themes identified included principles of co-design including creative collaboration and the stages of involvement,

¹ Both identity-first and person-first language are accepted in Australia (People with Disability Australia, 2021), thus identity-first language is used here, as it is used in the article by Liddard et al. (2019). Further, this is underpinned by repeated calls from the disabled community to destigmatise the use of identity-first language (Hayden, 2021; Kellgren-Fozard, 2019; Ladau, 2021).

methods of engagement including collaborative activities and techniques to engage participants, and lastly, co-designing the prototype including aspects such as mapping the prototype and engaging with diversity within the participant group. The authors also identified common challenges to co-design including flexibility, funding, and time. Further, a significant consideration was the number of participants, acknowledging the difficulty in representing a wide range of experiences and demographics within an average co-design initiative. Lastly, the authors found that only five of the 25 articles described a process of evaluation of the co-design process. These findings offer insight into the co-design process with young people, echoing the need for accountability, evaluation, feedback, and flexibility.

The findings of Thabrew et al. (2018) parallel those of Bevan Jones et al. (2020). The authors examined three examples of co-design of eHealth interventions with young people and found similar challenges, benefits, and techniques. Creativity is espoused as highly relevant and beneficial to the co-design process. It may be essential to co-design, particularly with young people, to welcome ambiguity, allowing the work to potentially take a different turn than initially expected. This type of environment can help to share power between co-designers, encourage creativity and out-of-the-box thinking, and support co-designers to voice their ideas (Thabrew et al., 2018). The authors also outline ways in which to gain and maintain engagement of young people including the use of comfortable and appropriate environments, familiar games and icebreakers, optimal duration times of activities, and consideration of wellbeing such as providing refreshments. These findings are significant considerations for future engagement in co-design with young people.

Intersectionality & Marginalised Youth

The integration of intersectionality is a vital component for successful, and respectful, research and engagement. Various groups and identities remain marginalised under current systems, and the intersecting nature of such can have significant impacts on areas such as engagement, participation, and the seeking of various services including healthcare. This is particularly true of young people, with age being another aspect of identity through which marginalisation can occur, particularly with regard to engagement (Hickey & Pauli-Myler, 2019). Young people belonging to marginalised groups such as First Nations young people, LGBTQI+ young people, those experiencing homelessness,

refugees and asylum seekers, and young people with disabilities and/or chronic health conditions are traditionally viewed as 'hard to reach' in comparison to non-marginalised youth (Iwasaki, 2016). Often youth, particularly those belonging to one or more marginalised groups, are seen as 'disengaged' or disconnected from systems and services. However, placing the onus of engagement on young people rather than the systems and services themselves only fosters harmful stereotypes and attitudes that may cause youth to feel disconnected in the first place.

Additionally, a significant amount of literature exists to suggest that compounding, or 'multiple', marginalisation among young people leads to increased barriers to healthcare, negative health outcomes, and increased difficulty with regard to healthcare system navigation (Robards, Kang, Tolley, et al., 2018; Robards et al., 2019; Robards et al., 2020). This evidence of barriers to access and engagement with the healthcare system mirrors findings regarding a wider issue of access and engagement in general for marginalised young people, including in research, organisational participation, decision making, and policy and service development (Iwasaki, 2016; Robards, Kang, Tolley, et al., 2018; Robards, Kang, Usherwood, et al., 2018).

Robards et al. (2019) conducted research using multiple (2-4) interviews with each participant over the course of 6-12 months. 41 young people were interviewed, all of whom were New South Wales residents aged between 12 and 24 years. Participants belonged to one or more of the following marginalised groups; those living in rural and remote areas, those experiencing homelessness, sexuality and/or gender diverse, refugee, and Indigenous.

Findings from this study suggest that when choosing to access services, young people were not in a position to be able to choose the best, most appropriate care for them. Instead, they had to prioritise other aspects like affordability, thus forgoing optimal care. This is of particular concern for marginalised groups, as appropriate care may mean access to service providers who are knowledgeable about essential aspects of the young person's life. For example, due to inaccessibility or lack of affordability, a young trans person may not be able to access care from a provider who is knowledgeable on trans health and wellbeing. This may lead to medical mistreatment, discrimination, mental health concerns, and a lack of access to appropriate resources for the young person. In the context of engagement and participation, this may be mirrored. For example, if an organisation's engagement process appears inaccessible, too time consuming, or too complex, many young people with intersecting needs may forgo participating. This can

lead to the process of engagement, and the results of such, being ineffective and non-representative of diverse groups.

Robards et al. (2019) found four other main themes:

1. Technology offers opportunity for connection and engagement
2. Marginalised young people experience various forms of discrimination leading them to choose not to access care
3. Marginalisation compounds making healthcare engagement and navigation even more challenging, and finally,
4. The fragmented nature of the healthcare system impacts young people significantly and may be addressed through adequate navigational support for consumers as well as increasing consumer knowledge of the system.

All four of these themes can be present in engagement and participation also.

Technology offers accessibility and other opportunities to engage, discrimination can lead to marginalised young people disengaging, multiple marginalisation could make participation more complex or even impossible, and intersecting needs/identities can make navigating engagement and participation settings more difficult. This indicates a need for an in depth understanding of marginalisation and the impacts of such on young people as participants.

Ansara's (2022) findings, while not focused only on young people, mirror much of this data. This report utilised qualitative methods to gain insight into the experiences of healthcare consumers with intersectional identities and needs. This included gender identity, sexuality, disability, culture, ethnicity, citizenship status, and other marginalised life experiences such as homelessness, previous incarceration, low/no income, and long-term health conditions. Key findings from this report, while in reference to engaging with the healthcare system, can also directly parallel with engagement and participation in research. Findings included barriers to access such as hidden bureaucracy, safety concerns such as exclusionary practices and policies, concerns regarding respect (such as the presence of stigma), discrimination, gaps in policy and training, and concerns regarding information and communication such as ineffective communication from healthcare professionals and lack of understanding and consideration for logistical factors that can impact communication. Further concerns reported included a lack of consideration of the importance of flexibility and responsiveness on the part of healthcare professionals and services, concerns regarding privacy such as privacy breaches, and

barriers to providing feedback such as concern regarding the risk of retaliation (e.g., service denial) if concerns or complaints are submitted. This is of particular concern for those with intersectional needs, as there may be fewer services able to meet their needs and losing access to said service may lead to inadequate, discriminatory, or entirely forgone care, due to a lack of options of services.

Again, these barriers and concerns can almost be directly translated to a youth engagement context. Concerns regarding privacy, bureaucracy, flexibility, partnership, communication, and feedback provision are all highly relevant to youth engagement and participation, and the ways in which these are shown to be impacted by intersectional needs and experiences is just as relevant.

This report concludes with five main areas of recommendation including systemic-level co-design, systemic-level feedback pathways, and increased awareness of inter-systemic intricacies and consequences. That is to say, the ways in which systems, like healthcare, can impact on other systems, policies, and processes such as housing, employment, and education. These recommendations are significant and speak to a need for change, not only within the healthcare system, but all systems, to better serve people with intersecting needs. Within a youth engagement and participation context, these recommendations are pertinent and may indicate the presence of similar barriers and concerns within the engagement processes currently utilised by organisations, particularly when engaging with marginalised young people.

Models of Engagement & Participation

Various models of youth engagement exist to guide researchers, organisations, and governments to engage effectively with young people within many sectors including health. From Hart's (1992) Ladder and Shier's (2001) Pathways to Participation, to the Typology Of Youth Participation And Empowerment Pyramid by Wong et al. (2010) and Anderson's (2017) Pedagogical Political Participation Model, each model offers a valuable contribution to the youth engagement and participation landscape. This section will outline the main models of youth engagement and participation, drawing out areas of opportunity for any future models.

Hart's Ladder (1992)

As discussed in the literature review, Hart (1992) developed this model to serve as a foundation for thinking about children and young people's participation in projects, and the wider world. This model remains highly relevant today, offering a definitive spectrum of youth participation (or non-participation).

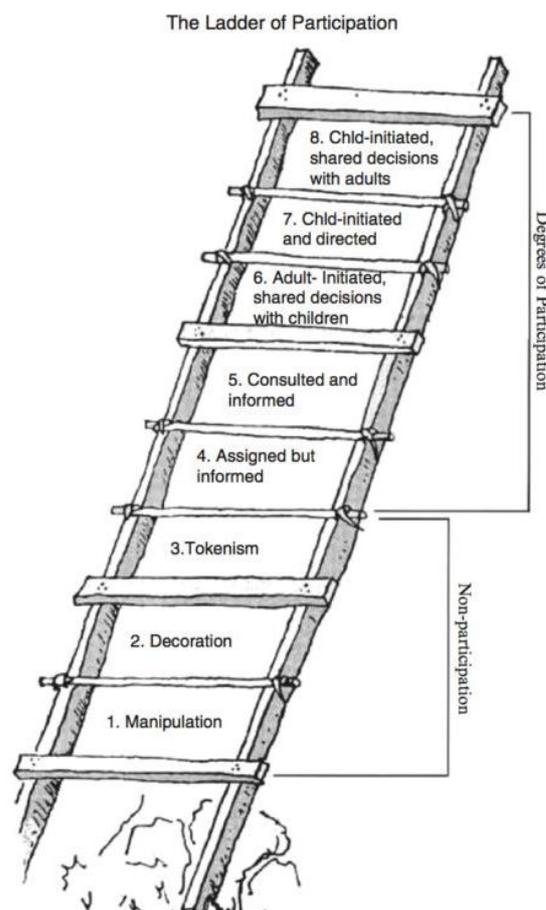


Figure 1 - Hart's Ladder (1992)

Treseder's Degrees of Participation (1997)

This model draws on the top five levels of Hart's (1992) Ladder. However, critically, Treseder (1997) shifts away from the hierarchical nature of Hart's (1992) Ladder, allowing each of the five levels to exist without implying an ideal.

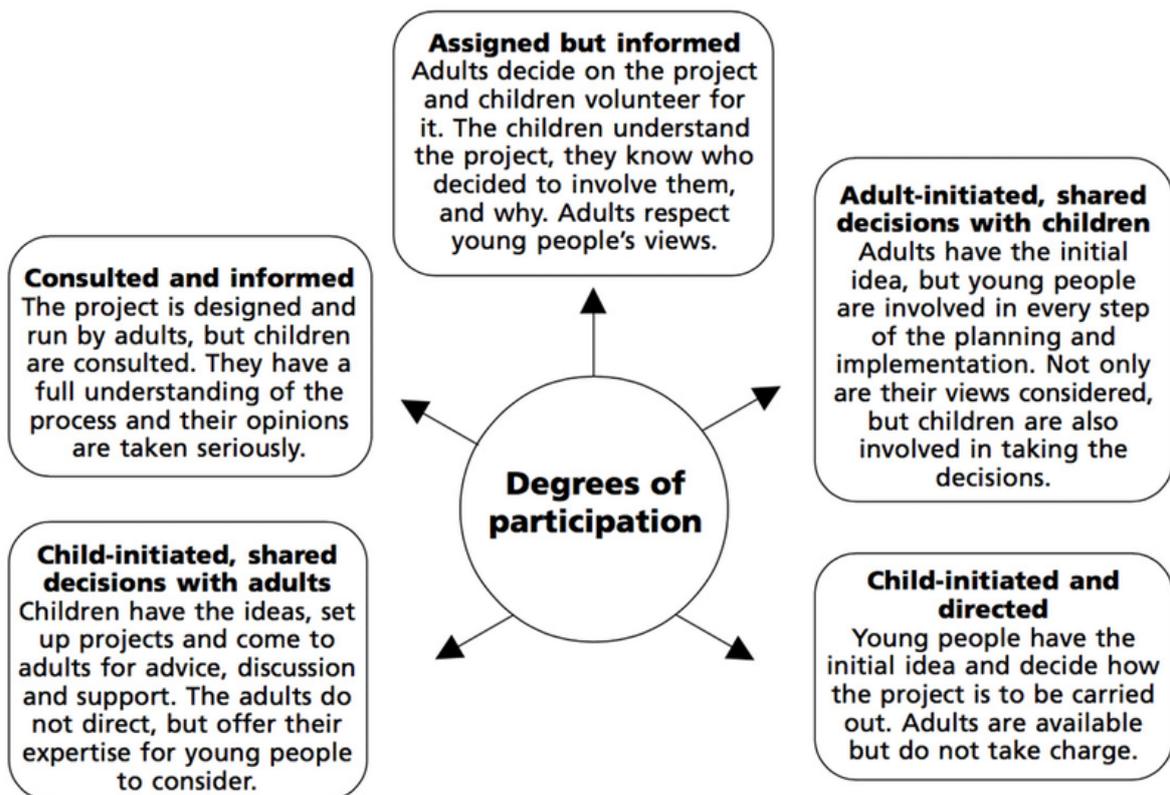


Figure 2 - Treseder's Degrees of Participation (1997)

Shier's Pathways to Participation (2001)

Shier's (2001) model is sequential and consists of five levels of participation:

1. Children are listened to
2. Children are supported in expressing their views
3. Children's views are taken into account
4. Children are involved in decision-making processes
5. Children share power and responsibility for decision-making.

Further, it is also broken into three stages of commitment at which each level of participation can operate: openings, opportunities, and obligations. This is a sequential model moving from least participatory to most.

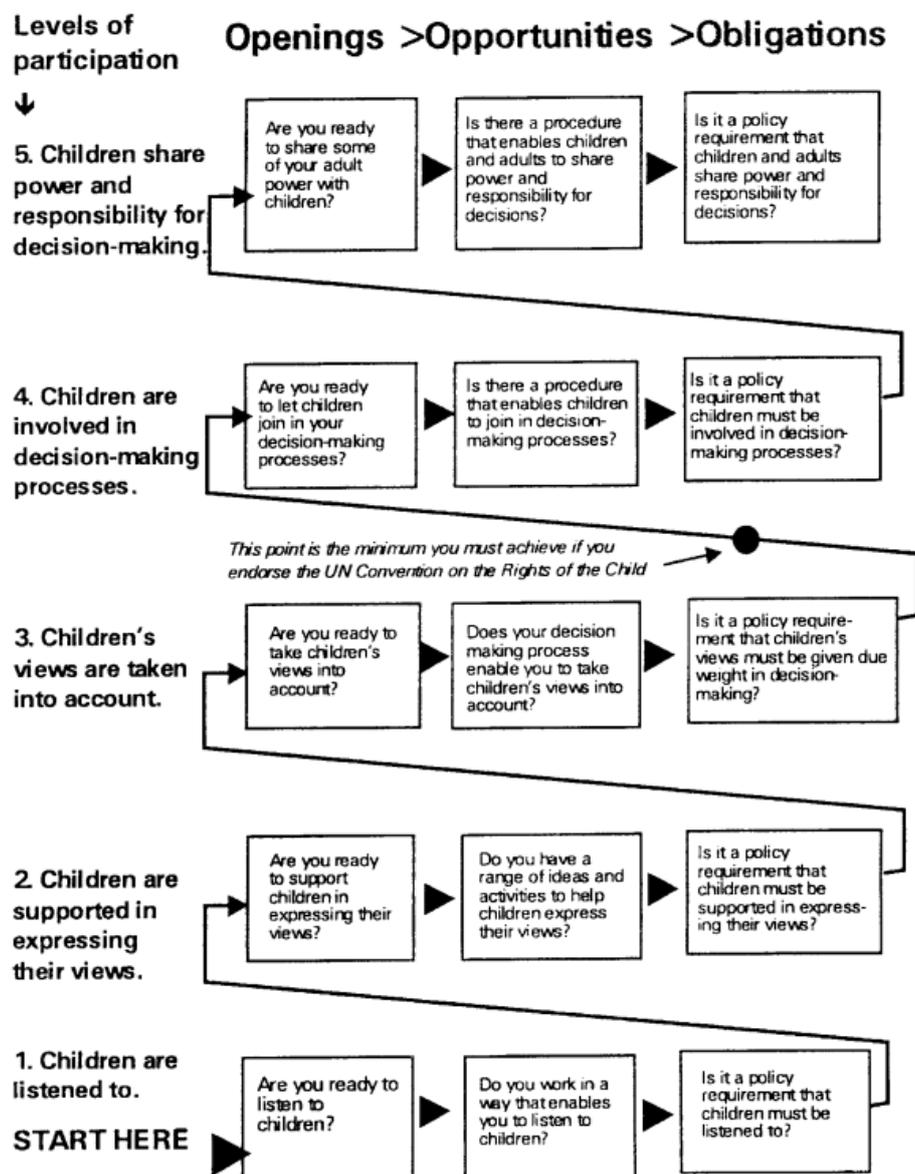


Figure 3 - Shier's Pathways of Participation (2001)

Typology of Youth Participation & Empowerment Pyramid (2010)

This model outlines 5 levels of participation, each placed at varying degrees of empowerment and control. This model is hierarchical in nature and suggests the most empowering level is 'pluralistic' where young people and adults share control.

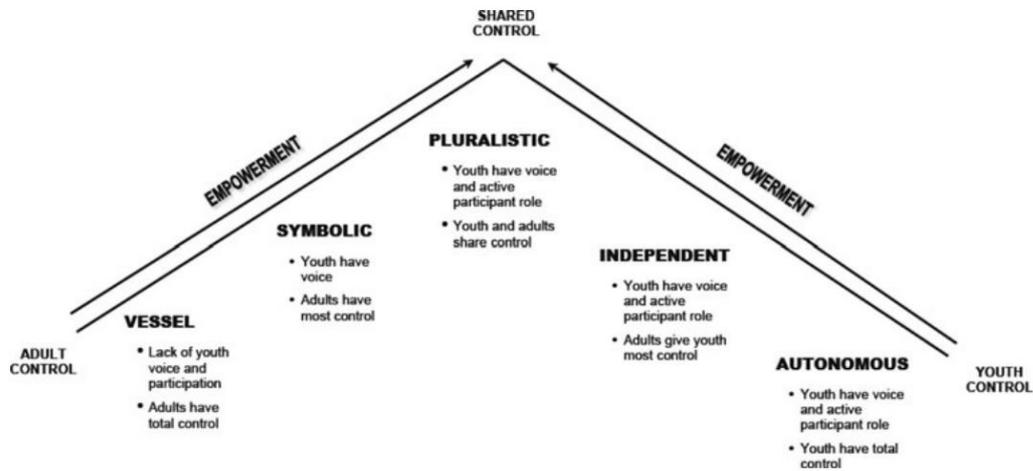


Figure 4 - Typology of Youth Participation and Empowerment Pyramid (Wong et al., 2010)

By examining models most widely used by researchers and organisations, it is clear that those of a sequential or a hierarchical nature are popular. However, as suggested by Cahill and Dadvand (2018), youth engagement and participation can be a highly fluid process, requiring significant flexibility. Thus, a model should reflect this while still providing a guide and framework to achieve optimal engagement. Cahill and Dadvand's (2018) proposed model attempts to achieve this through a more cyclical and interconnected framework. This model exhibits a holistic approach to youth engagement and participation, offering a significant foundation for future models.

Cahill & Dadvand's (2018) P7 Model

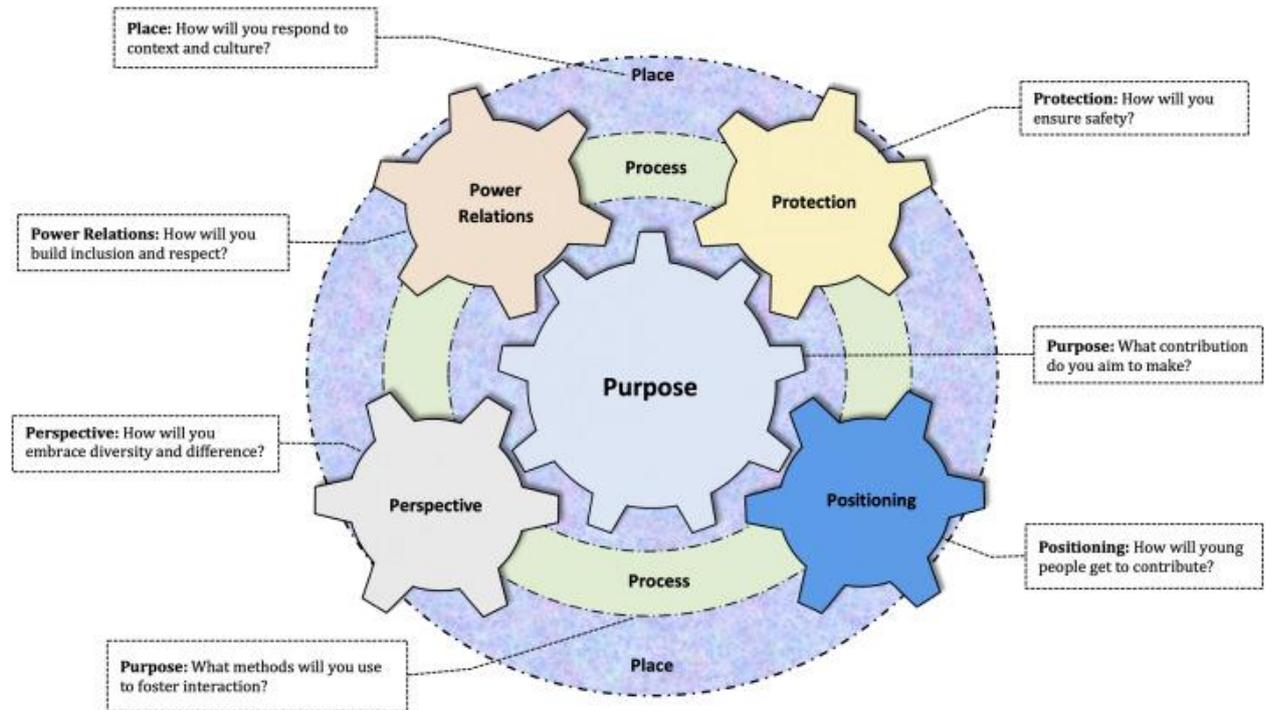


Figure 5 - The P7 Model (Cahill & Dadvand, 2018)

Existing Resources

There exists many frameworks, guidelines, and toolkits focused on youth engagement and advocacy. However, again, as current findings indicate, many young people continue to feel left out and unheard. It is the goal of this report to draw out overarching themes within the pool of current resources, extract and examine current 'best practice' within the youth engagement and advocacy environment, and identify any gaps or opportunities for improvement.

The following is a list of the resources discussed in this section:

- Health Consumers Queensland's (2021) '*Amplifying the Youth Voice: Health Consumers Queensland Youth Engagement Framework 2021*'
- The Government of South Australia's (2016) '*Better Together: A practical guide to effective engagement with young people*'
- Orygen's '*How to Partner with Young People*' (2016) and '*Co-designing with young people*' (2019)
- WH&Y's '*Wellbeing Health & Youth Engagement Framework*' (Tiller et al., 2019)
- The Office of the Advocate for Children and Young People's (2019) '*Engaging children and young people in your organisation*'
- The Department of Communities of Tasmania's (2019) '*Youth Matter*' guide

Each resource will be examined, with main themes outlined, and any indicators of success identified. The purpose of this is to capture the current landscape of youth engagement resources. Once all resources are examined, common themes will be discussed with regard to their relevance and importance in future youth engagement and the Walking the Talk project.

As these resources share similar aims and focus, several common themes can be found throughout. These themes will be discussed and explored in order to gain insight into young people's wants and needs as identified in existing resources.

'Amplifying the Youth Voice: Health Consumers Queensland Youth Engagement Framework 2021'

Health Consumers Queensland developed this framework with the input of a Youth Reference Group (2021). This group consisted of 17 young people from a range of backgrounds including Aboriginal and Torres Strait Islander young people, LGBTQI+ young people, young people with disabilities, young people from rural backgrounds, culturally and linguistically diverse young people, those with chronic conditions, and young carers.



This framework is aimed at improving engagement between young people and the healthcare system. The engagement principles listed in this framework, and the way in which each applies to young people, are as follows:

Principle	Application to Young People
Partnership	<ul style="list-style-type: none"> → Young people's engagement with healthcare organisations is built on collaboration and transparency. → Information is freely shared, and organisations and services ensure that young people are engaged in goal setting and decision making at all levels.
Respect and Dignity	<ul style="list-style-type: none"> → Young people's contributions, knowledge, and beliefs are valued, respected, and supported. → A safe and supportive environment is provided to young people.
Inclusive	<ul style="list-style-type: none"> → Accessibility, flexibility, and adaptability are present in order to meet the engagement needs of all young people. → Diversity is reflected within engagement and participation settings. → Various engagement tools available in order to engage with young people from all backgrounds and experiences.
Improvement	<ul style="list-style-type: none"> → Young people's contributions are valued and utilised to improve services, systems, and policies. → Ongoing training and other opportunities are offered to support young people in their engagement.

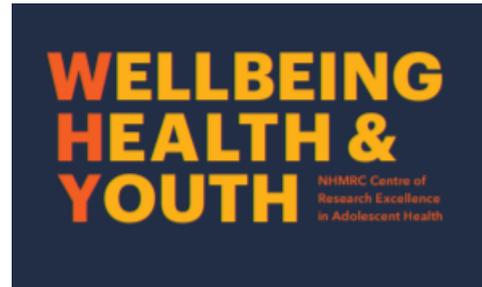
Indicators of success that the framework has positively impacted on various areas of healthcare are listed at the end of this framework, and are as follows:

1. More young people are confident about their ability to engage with the health system.
2. More young people take up consumer representative positions in Queensland.
3. Health staff are more confident to engage with young people.
4. Increased awareness of the proposed Youth Network by health consumers and health service employees.
5. Increased number of health consumers in leadership and decision-making roles helping to shape the health system in Queensland.

These indicators are comprehensive, though somewhat broad. Opportunities for more structured measures of success will be discussed in the 'Gaps' section of this report.

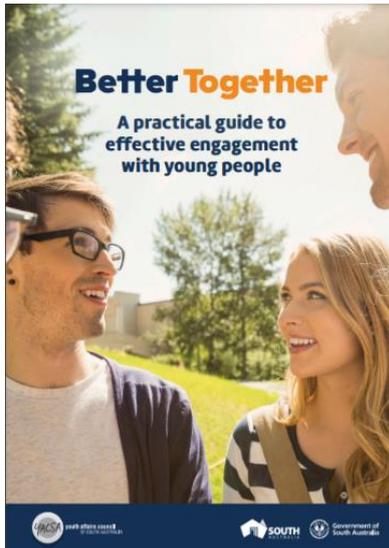
‘Wellbeing Health & Youth Engagement Framework’

The Wellbeing, Health, and Youth Engagement Framework was developed to inform engagement of young people in the health sector (Swist et al., 2019). This framework aims to provide a set of values and practical questions to foster ethical engagement with young people. The framework was developed in collaboration with young people and other experts.



The framework is outlined as follows:

Value	Key Questions	Application
Mutual Trust & Accountability	<p>Are young people supported to engage in meaningful ways?</p> <p>What ongoing opportunities are present?</p>	Embedding a shared intergenerational responsibility.
Diversity & Inclusion	<p>How can young people be best supported in the co-design of health research and translation?</p> <p>Is your co-designing approach youth-centred, strengths-based, and focused on maximizing opportunities for health and wellbeing?</p>	Co-designing projects, systems, and services.
Equity & Responsiveness	<p>Is communication clear, inclusive, and understandable for all young people?</p> <p>Are materials, documents, and activities inclusive and accessible for all young people?</p>	Producing a common language and meaningful technologies.



'Better Together: A practical guide to effective engagement with young people'

This resource was developed for the Government of South Australia, focusing on youth engagement with government. It is a comprehensive resource, outlining the importance and benefits of youth engagement, tips for successful engagement, and models and tools of engagement.

Better Together describes effective engagement as **continuous, representative, and meaningful**. Youth

engagement must ensure young people are effectively and continuously involved in areas such as decision making and service design.

This resource outlines six principles as the foundation of the engagement process. These are:

1. We know why we are engaging
2. We know who to engage
3. We know the history
4. We start together
5. We are genuine
6. We are relevant and engaging

The resource goes on to outline tips for successful youth engagement including be clear, be genuine, provide young people with skills, develop relationships, provide resources, consider timing and location, consider accessibility, consider out of pocket expenses, be accountable, be supportive, consider language, don't make assumptions, and avoid adults taking over.

Further, this resource discusses the utility of best practice models of engagement when looking to engage young people. Two models are outlined and discussed, Hart's Ladder of Child Participation, and the IAP2 Public Participation Spectrum. Both models outline different levels of engagement from least impactful to most. These are useful models to ensure the desired level of engagement is being met.

'How to Partner with Young People'

The first resource 'How to Partner with Young People' (Orygen, 2016) is a toolkit designed to offer various principles of youth participation as well as practical tips on how and when to partner with young people. The principles outlined are as follows:



- Have clear expectations
- Be flexible
- Value experience
- Involve more than one young person
- Mutual benefit
- Reimburse appropriately
- Support involvement
- Avoid tokenism
- Provide resources
- Provide feedback

The resource goes on to outline when and where young people can be partnered with, such as within specific studies, within organisations, and within the broader community. This can be achieved through four broad methods: participatory research, co-design and youth-led research, major contributions to research, and advice on research. Lastly, a checklist of talking points was included (see Figure 6). These offer a guideline for young people to ensure they are being engaged well and treated fairly.

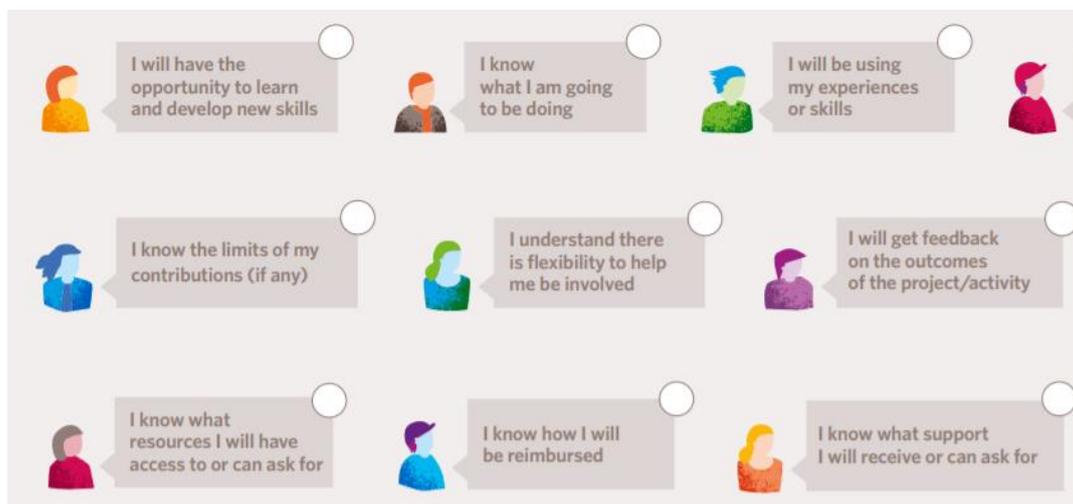


Figure 6 - A snippet from page 3 of Orygen's (2019) 'How to partner with young people'

‘Co-designing with Young People’

The second resource by Orygen, ‘Co-designing with Young People’ (2019), focuses on co-design and serves as a guide for healthcare services and organisations to optimally engage in co-design with young people.

This resource identifies core features of co-design as:

- Equal value given to expertise by lived experience and expertise by profession or education
- Sharing of decision-making power
- A design-led process
- Use of design methods to support active participation

This resource is comprehensive and offers great insight into the co-design process. It is acknowledged that ‘not all participation is co-design’, meaning services should not mistake lower-level engagement such as consulting to be co-design. Co-design can be understood as ‘doing with’ rather than ‘doing for’ or ‘doing to’. This resource highlights an alternative participation ladder, developed by The New Economics Foundation (Slay & Stephens, 2013 as cited in Orygen, 2019).

This resource then goes on to outline main principles offered in the previous resource ‘How to Partner with Young People’, as listed above (Orygen, 2016).

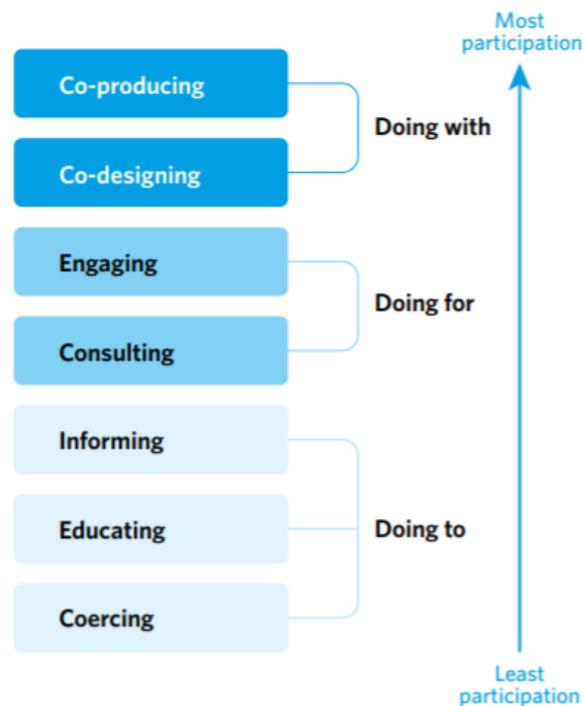


Figure 7 - An alternative participation ladder, developed by The New Economics Foundation (Slay & Stephens, 2013 as cited in Orygen, 2019)



‘Engaging Children and Young People in Your Organisation’

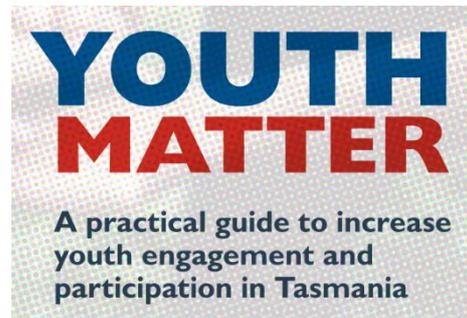
This resource was developed in 2019 to assist organisations to meaningfully engagement with young people. It created with the intention of a wide audience, from

experienced youth organisations to people with no experience working with young people on a participatory level. This resource is comprehensive and offers insight on several areas. Topics discussed in this resource include:

- Why should organisations include children and young people in decision making
- How to enable participation with young people, including information on different levels of participation, and capacity building of both organisations and of young people
- Practical information for youth participation, including tips regarding facilitation, location, methods, and feedback provision
- Ethical considerations, including duty of care, addressing power, privacy and confidentiality, remuneration, working with marginalised youth, and mandatory reporting
- Information for obtaining consent, including core principles of consent, parent/carer consent, info sheets and consent forms
- Evaluation of the participation process, including types and methods of evaluation, and external resources for evaluation

Overall, this is a comprehensive resource, covering many areas of youth engagement and participation. However, there is no mention of co-design or co-production, which may leave a significant gap in the potential impact of this resource.

‘Youth Matter: A Practical Guide to Increase Youth Engagement and Participation in Tasmania’



This resource was designed in 2019 to assist policy makers and service providers to engage with young service users, with the aim of young

people’s voices being heard and valued. This resource was developed in order to deliver on Action 26 of the Youth at Risk Strategy (2017) which was focused on improving youth participation. Communities Tasmania met with almost 400 young people aged 11-18 years, conducting both group sessions and one on one interviews.

It was identified by young people that the top way to increase youth participation and engagement was to ‘support, encourage and build their confidence’. The top barrier to youth participation identified was ‘fear, nervousness, shyness, and embarrassment’.

Youth engagement has a myriad of benefits for young people, their communities, and the organisations they partner with. This resource outlines these as follows:

Benefits for Young People	Benefits for Community & Organisations
Increased self-esteem	Improves trust between the community and policy makers
New relationships	Removed negative stereotypes of young people
Increased critical thinking skills	Development of skilled workers
Empowerment and have greater control over their lives	Increased public value for money, by distributing funds to programs and services that are required for young people to use
Services are improved and more relevant	Better informed planning and decision making

Findings from this research include:

- Young people define youth participation/engagement as ‘taking part’, ‘having an opinion’ and ‘being involved’
- When asked to describe a ‘bad experience participating’, 21% of young people said, ‘not being listened’, 18% said ‘nothing was done’, 15% said

'scared/uncomfortable'. 30% identified 'other' and described experiences including 'being forced', 'didn't make a difference', and 'nobody cared'.

- When asked to describe a 'good experience participating', 28% said 'being heard/listened to', 17% said 'getting action/something was done', 15% said 'helping people/making a difference'.

This resource goes on to outline 6 resources developed based on the feedback received from young people.

1. **Pathways to participation:** this is a tool similar to the IAP2 Public Participation Spectrum, outlining five levels of participation: inform, consult, involve, collaborate, and empower.
2. **Ladder of Participation:** this is a model based on Hart's Ladder (1992), detailing 8 different levels of participation.
3. **Principles of engagement with young people:** tool to show the foundations of engagement that should underpin all engagement with young people.
4. **Do's and Don'ts of youth engagement:** tool to specify what is 'good' engagement and what is 'bad' engagement.
5. **Youth engagement checklist:** tool to check each aspect of ethical engagement is being met. This includes sections such as purpose, past learnings, ethical considerations, and acknowledgment.
6. **Examples of how to engage with young people:** this resource outlines different methods of engagement such as arts programs, forums, interviews, social media, surveys, and reference groups, showing the level of participation associated with each, as well as estimated level of cost and time, advantages and disadvantages, tips, and examples of the methods in action.

Key Themes

It is the goal of this section to draw out common themes, discuss how and why they are important to youth engagement, and identify any areas for opportunity for future resources, models, and processes of engagement.

Several key concepts crop up repeatedly when examining existing resources, indicating their integral nature with regard to youth participation. These will be outlined in this section, however, the overall goal of this is to draw out aspects that are perhaps less recognised, or less discussed. We want to move past the essential foundations of what constitutes ethical and appropriate youth engagement and participation into what creates and fosters outstanding, genuine, effective, and sustained youth engagement.

The key themes that occur frequently throughout all of the resources examined in this report are as follows:

- Clarity and transparency (with regard to expectations, communication, language)
- Flexibility (with regard to manner of engagement, timing, location, level of engagement, and so on)
- Mutual trust and respect
- Accessibility (consideration of age, disability, language barriers, and so on)
- Inclusion/diversity
- Provision of support, resources, and feedback
- Reimbursement/Remuneration
- Avoid tokenism

While these principles offer a framework and a standard for organisations and researchers to set their sights on and be held to, our goal in examining the existing resources is to reach beyond the basics towards *optimal* youth engagement and participation. By identifying concepts that build upon the minimum ethical standard, we can strive for truly inclusive and genuine engagement. Aspects of engagement such as accountability, responsiveness, and sustainability were mentioned only once or twice in the existing resources. These offer a start to improving on the current landscape.



Gaps

So what's missing? While all of the resources examined are comprehensive and offer useful frameworks for engaging with young people, there exist some gaps that, if filled, could offer improved outcomes and results of engagement with young people.

Additionally, some resources, such as Communities Tasmania's (2019) 'Youth Matter' guide, are particularly comprehensive, and offer a blueprint for resources in New South Wales.

Intersectionality

As discussed in the literature review of this report, intersectionality and consideration of multiple marginalisation is integral to youth access, engagement, and participation. While many resources acknowledge the additional 'challenges' that may be present when engaging marginalised young people, acknowledgement of compounding marginalisation appears to be missing. This has the potential to leave a significant portion of the population, some of the most vulnerable in fact, out of the conversation. Through examination of the literature, it is clear that an intersectional lens is, in fact, absolutely critical to effective and meaningful engagement with young people (Robards et al., 2020).

Sharing Power

The concept of sharing power is touched on by multiple existing resources, however, it is clear through some of the literature that true balancing of power between researchers/organisations and participants is difficult and often not effectively achieved. This is particularly true for young participants, as not only does the professional/participant divide need to be bridged, but the adult/young person divide does too. As discussed by Liddard et al. (2019), this relinquishing of power to young people requires genuine commitment to the process. Adults must commit fully to the idea that young people will have influence, ideas, and make important decisions. To do this may take learning, listening, and loosening of red-tape (where possible) on the part of the adults involved.

Co-authorship

While most resources examined thanked those involved in the work, only one resource listed the members of their youth reference group by name within the resource document. As outlined in the literature review, co-design and co-production must involve equal partnership and sharing of power: working *with* not *for* (McKercher, 2020). Thus,

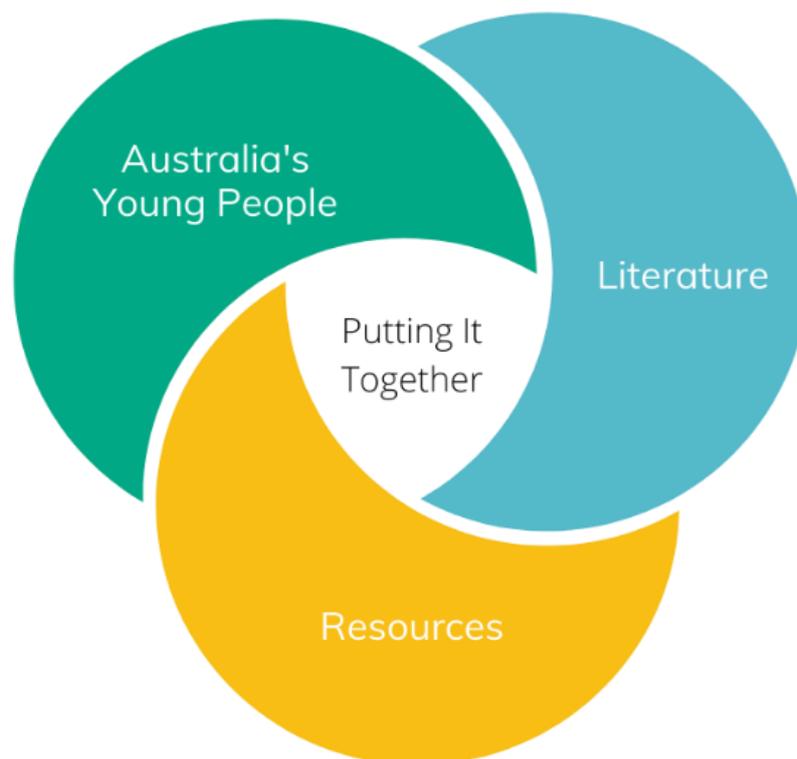
the core of co-design and co-production runs counter to the exclusion of co-designer's names alongside the researchers or organisations names. This is potentially only possible to a degree depending on the number of participants involved, as well as some likely choosing to remain anonymous or de-identified for privacy reasons. However, the option should be offered to be thanked, listed by name, or even listed as a co-author depending on the level of involvement in developing and writing the resource. This inclusion is likely to work to not only boost young people's motivation and empowerment in the short term but also lead to long term empowerment and thus sustained engagement in research, organisational change, politics, and so on.

Follow Up & Sustainability

As discussed, while a myriad of models and resources exist to guide youth engagement and participation, current findings suggest that young people remain feeling unheard and undervalued. It is integral to effective engagement and to young people's self-value, that they are involved at every stage of engagement, including after a project is complete. Young people should be provided with meaningful feedback, as well as longer term follow up to inform them of how their ideas, opinions, and experiences impacted on the final outcome. It is also essential that engagement does not simply identify issues but is actively working to be a part of the solution. Sustainability of organizational engagement means maintaining engagement with participants through regular updates, engaging in follow ups, providing resources and opportunities such as further training to participants, and supporting participants to continue their engagement into adulthood.

Putting It Together

With 1.3 million young people living in New South Wales, it is essential that their thoughts, ideas, and opinions are heard, respected, and acted upon in collaboration with them. As discussed in the first section, young people want to be involved, want to contribute to not only decisions that impact them but to the thriving of their communities as a whole. It is therefore critical that we utilise the literature and existing resources to strive for optimal youth engagement, now and into the future.



It is clear, through the data and findings outlined in this report, that young people are not completely satisfied with the current state of the healthcare system, nor of youth engagement and participation as a whole. It is the goal of the Walking the Talk project to engage with young people meaningfully in order to better both future youth engagement as a whole, and particularly engagement with healthcare-based organisations, and the healthcare system itself.

Actionable Findings

So, what should the future of youth engagement and health advocacy look like? The goal of the Walking the Talk project is to support and empower young people to engage in health advocacy, to listen to young people’s experiences of engaging with the healthcare system, and to identify and target gaps in current resources and support for young people engaging with the healthcare system. In order to achieve this, we must first engage with young people to discover what is important to them when it comes to engagement and participation, what works for them, and how they want to be involved. Key findings from this report will inform the next steps of the Walking the Talk project.

Findings	Actions
Young people experience many barriers to both receiving healthcare, and engaging with healthcare services on decision making, service design and delivery, and priority setting levels.	<ul style="list-style-type: none"> → Utilise all available knowledge of best practice youth engagement to bring together a diverse group of young people with the goal of co-designing a future for youth engagement and participation. → Opportunity to initially engage with a small group to gain insight into how to engage with a wider group of young people both effectively and meaningfully.
Young people are often viewed as ‘future citizens’ and thus encounter little opportunity to voice their thoughts, ideas, and opinions. They currently find that they have to strongly self-advocate in order to be heard in healthcare settings.	<ul style="list-style-type: none"> → Focus groups, interviews, and online forums are recommended to facilitate discussions with young people about how they would like organisations to engage with them.
Young people <i>want</i> to engage, want their voices heard, and their ideas taken seriously by organisations, services, and governments. Particularly with regard to the COVID-19 pandemic, many young people feel left behind and left out of important conversations.	<ul style="list-style-type: none"> → Provide a platform, support and resources for young people to lead the way in designing future engagement and participation methods, models, and resources.

<p>Co-design is an effective process for engaging with young people - however it is not necessarily the epitome of ethical participation. Consideration of the types of participation, as well as the timeframe and resources available, should be reflected upon before deciding if co-design should/will occur.</p>	<ul style="list-style-type: none"> → Commitment to the principles of the co-design/co-production process throughout the project. → Ensure all involved understand the meaning of co-design and commit to the process including sharing power and viewing young people as genuine co-designers and co-producers. → Utilise available resources such as the work of McKercher (2020) to ensure, throughout the engagement process, that co-design is taking place. → Co-authorship will be considered, co-designers will be acknowledged within final project outcomes.
<p>Intersectionality is an essential consideration for engagement and participation, particularly with regard to healthcare engagement. Intersecting identities, experiences, and needs have a significant impact on young people's lives, and this must be recognised and treated with sensitivity.</p>	<ul style="list-style-type: none"> → An intersectional lens will be utilised throughout the project. → Consider aspects such as accessibility, remuneration, interpreters, cultural considerations, mental health, and disclosure when engaging with young people with intersectional needs. → Consider the impact of intersectional needs on young people's lives - can lead to complex and challenging experiences, thus requiring sensitivity when engaging.
<p>Youth engagement requires follow up and a focus on sustainability. Engagement must not simply identify issues but commit to being a part of the solution. Young people deserve to know the impact of their involvement, ideas, and opinions, thus effective follow up with information regarding</p>	<ul style="list-style-type: none"> → A commitment to providing effective feedback, follow up and sustainability of engagement. → Discuss methods of follow up with young people <ul style="list-style-type: none"> ○ How should organisations follow up? ○ Why follow up is important to young people?

how they impacted final outcomes, is critical to best practice youth engagement.

- Is more clear information regarding follow up needed within the youth engagement context?
- Sustainability
- How can organisations better involve young people on an ongoing basis?
 - How can organisations support young people to remain engaged, and utilise the skills and experienced gained, as they age out of 'youth' focused engagement into adulthood?

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