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Title: Inside the black box of youth participation and engagement: Development and implementation of an organisation-wide strategy for a national youth mental health organisation in Australia

Running title: Youth participation and engagement

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Abstract

Aim

The involvement of young people in the development, implementation and evaluation of youth mental health services, policy and research programs is essential to ensure they are appropriate and responsive to the need of young people. Despite the increasingly central role that youth engagement and participation plays internationally, such activities are rarely described in detail. This paper aims to provide a thorough description of the development and implementation of an organisation-wide, three-year Youth Engagement and Participation Strategy for a national youth mental health organisation in Australia.

Methods

A descriptive account of the development and implementation of the Strategy, with detailed examples of programs and initiatives.

Results

The Strategy was developed based on available evidence, focus groups with key stakeholders, and best practice principles. The implementation of the Strategy resulted in a number of programs being delivered that involved a range of young people from across Australia. Despite being successful overall, a number of challenges

were experienced and ongoing considerations include ensuring diversity of partnerships, 'raising the bar' of youth participation, and creating meaningful pathways.

Conclusions

Youth participation and engagement within a youth mental health context is best seen as an evolving ambition that must remain flexible to the needs of all stakeholders. Despite some challenges and ongoing fine-tuning, it is possible to successfully implement youth participation and engagement across all areas, including service design and delivery, research and translation, and youth mental health policy.

Key words: youth mental health, early intervention, youth participation, consumer involvement, youth involvement

Introduction

Mental ill-health disproportionately affects young people, representing 45% of the global burden of disease in 10-24 year olds (Gore et al., 2011). However, youth are less likely than other age groups to seek professional help (Australian Institute of Health and Welfare, 2011). The World Health Organization recognises the need to consult with young people to develop adolescent friendly services (World Health Organization, 2012). Young people are the most appropriate stakeholders to ensure services are accessible and youth friendly, credible, less intimidating, accountable and responsive to young people's needs (Barry, 2014; James, 2007). Youth participation is required for research, research translation, policy, and practice (P. McGorry, Bates, & Birchwood, 2013).

Young people involved in meaningful engagement benefit from personal growth, a greater understanding of their future direction, and develop skills in teamwork, communication and consultancy (Howe, Batchelor, & Bochynska, 2011). Young people may also experience increased social and cognitive competency, skills and knowledge, social connectedness, and sense of community (Oliver, Collin, Burns, & Nicholas, 2006). Meaningful involvement can also be an important step in recovery (Howe et al., 2011).

A number of approaches inform current practice in youth participation. One paper assessed 14 different definitions, and defined youth participation as: “a process where young people, as active citizens, take part in, express views on, and have decision-making power about issues that affect them.” (Farthing, 2012). Hart’s Ladder of Participation was an early framework for youth participation activities, and defines eight levels of participation and non-participation (Hart, 1992). More recent approaches recognise that levels may change, and the highest level may not always provide the most effective or meaningful outcomes (Kellett, 2011). There is a paucity of research on youth engagement models (Monson & Thurley, 2011).

One recently developed approach is the McCain Youth-Adult Implementation Model (Heffernan et al., 2017), developed based on a literature review, discussion about goals for engagement, and “trial-and-error in engaging young people” (page 1184). Key attributes include flexibility, mentorship, authentic decision making, and reciprocal learning. The model was deemed successful based on demand for youth engagement facilitators, diversity of activities and youth involved.

Although youth participation and engagement are central to the ethos of early intervention, there is a critical gap in our knowledge about how to plan and flexibly implement these activities. This paper provides a description of the development and implementation of an organisation-wide, three-year Youth Engagement and

Participation Strategy ('Strategy') for a national youth mental health organisation in Australia.

Methods

Setting

Orygen is an Australian youth mental health organisation. A core strategic priority is to partner with young people and families, ensuring that clinical services, research and translational activities are appropriate. This builds upon the work of Orygen's specialist clinical program who developed Platform, a group composed of past and present clients who hold consumer advocacy and advisory roles, deliver peer support in the inpatient and outpatient unit, and provide community education (James, 2007).

Results

Development process

At the time of developing the Youth Engagement and Participation Strategy, the Orygen's Strategic Plan listed "Partnering with young people and families" as an overarching strategy. Within this, a dedicated strategy for youth participation and engagement was developed with key stakeholders to provide a framework that outlined Orygen's organisation-wide commitment and approach to youth engagement, build an appreciation for the importance and potential of meaningful youth engagement across the organisation and to provide practical guidance and

strategies for working in partnership with young people. An external consultant was engaged to undertake preparatory work, which included a review of youth participation literature, existing approaches, and consultations with both local and international youth mental health organisations. Consultations included two focus groups with internal staff about the barriers and enablers to meaningful youth participation at Orygen, two focus groups with young people, one with Platform and another with a national mental health organisation. The strategy adopted and youth-adult approach to partnerships and focused on creating a framework for planned activities, but also allowed for new activities to be developed with young people, allowing for them to be involved in decision making. A simplified overview of the planned activities and how they related to the organisational structure is provided in Figure 1.

[Insert Figure 1 about here]

Overarching principles

In reviewing the academic and grey literature on youth participation and engagement, a number of guiding principles were agreed upon and are presented in Box 1. These principles have been used to inform the development of all initiatives. Young people without a lived experience of mental-ill health were included to ensure diverse perspectives were represented. Not all young people who are passionate about youth

mental health identify as having a lived experience. It also reflects the early intervention approach of the organisation, which conducts research and provides clinical care to those with emerging mental ill-health and potentially less experience with service use. The age ranges for each activity differed; however, they all fell within 12-25 years old.

[Insert Box 1 about here]

Leveraging existing staff members and the creation of new roles

Strong support and endorsement from organisational leadership was essential to promote culture change and funding for implementation. A full-time *Youth Engagement Program Manager* role was created to coordinate and deliver the strategy and act as a central support for all young people and staff. *Youth Engagement Champions* were recruited from different specialist areas (research, research translation, clinical and policy) to enhance implementation and facilitate youth partnership activities in their areas. These roles have been undertaken by a number of different staff members of varying levels of seniority. Although having a certain level of authority has helped in some cases, a sound knowledge of both the area of the organisation and youth participation have been the key factors to success for these roles. An existing staff member took on the role *Youth Partnerships in Research Coordinator* to provide additional support in this area.

Youth leadership across the organisation: Youth Advisory Council

The Youth Advisory Council (YAC) is composed of nine young Australians with and without a lived experience of mental ill health. The role of the YAC is primarily advisory. They provide advice on the implementation of the youth participation strategy and the programs within to the organisation, facilitated by the Youth Engagement Program Manager. The YAC also provide project-specific advice to different functional areas of the organisation as issues emerge. Within the YAC, decision-making is based on a majority. While the expertise of council members is highly valued, decisions are also made *with* staff to ensure Orygen is able to achieve organisational objectives. It is worth noting that when young people opt in to other, one-off opportunities, the level of decision making may change based on the nature of the activity. Depending on availability and interests, individual members may also opt-in to additional opportunities such as contributing to Orygen-led policy papers, national campaigns (e.g. advocacy, media), and assisting in the development of new youth participation initiatives. YAC members meet each month using online teleconferencing software, and meet in-person with the Youth Research Council (see below) twice yearly over a two-year tenure. YAC members are paid an honorarium for the face-to-face meetings, with meeting costs (e.g. travel, accommodation, catering) covered. YAC members are also reimbursed for each monthly meeting to cover both preparation and actual meeting time.

Internships

Two types of internships were implemented. The first internship was a short-term, voluntary work-experience program that involved four young people having brief exposure to all aspects of the organisation over 12 days during a four-week period. The second program involved a more intensive paid internship, whereby interns were recruited to work on mutually agreed upon projects over 12 weeks in specific areas of the organisation.

Valuing lived experience and shared stories: the 'Live It, Speak It' program

Live it, Speak it is a speakers bureau of young people with diverse experiences who are trained and supported to share their lived experience in meetings, conferences, fundraising events, with community groups and the media.

Research: Youth Research Council

Along with the organisation-wide initiatives, more specialist programs were established to provide support to specific areas. Like the YAC, the Youth Research Council (YRC) appointed nine young Australians for a two-year tenure. Members included those with a lived experience of mental ill health, those interested in research, young emerging researchers, or people with an interest in how young people could contribute to research. YRC members have contributed to individual

projects, throughout all stages of the research process. For example, YRC have held research 'pitch' events to deliver early-stage feedback to researchers; been involved in research design and methodology; intervention development; recruitment and data collection approaches; data analysis, interpretation, and dissemination; and research translation activities. Although YRC members have been engaged in a wide variety of research projects and processes, inaugural members worked to create a mechanism by which all research at Orygen had some form of youth involvement. Box 2 describes two ways in which the YRC set up processes to ensure youth participation occurred across all research studies. The national councils work alongside one another, with the YAC providing advice as to *how* young people can be involved and mechanisms to support a diverse range of voices across all areas of the organisation, whilst the YRC works more closely with research teams to advise on specific studies, encourage participatory research, translation of results and increase accessibility and understanding of research to young people in the community. Both councils meet separately and then come together for the twice-yearly face-to-face meetings and other events.

[Insert Box 2 about here]

Research: Youth Partnerships in Research

An existing staff member was seconded to work as the Youth Partnerships in Research Coordinator and oversee activities aimed at increasing the number of young people that Orygen was partnering with across their research programs. The Youth Partnerships in Research Coordinator acted as a contact person for researchers needing assistance in establishing or maintaining partnerships with young people; maintained relationships with the YRC members to provide information about researchers and research projects; supported YRC members to develop and execute their own research, attend conferences and present their own work; supported YRC members to understand more about research and translation; and to better understand the barriers and enablers to youth partnerships in research (Faithfull, Brophy, Pennell, & Simmons, 2019). Based on these data, a toolkit to support both researchers and young people was co-developed with the YRC (Orygen The National Centre of Excellence in Youth Mental Health, 2017).

Research Translation

Young people have been involved in the development of training resources such as evidence summaries and clinical practice points, providing practical insight on topics such as engaging young people in assessment and sexual health.

Research Translation: Youth Educator Program

Another initiative specified in the strategy was the Youth Educator program. This program aimed to integrate young people into professional development programs delivered by Orygen. This program is yet to be implemented, but is included to demonstrate the challenges encountered. Whilst literature often focuses on the successes of youth participation, it is often a complex process with difficulties for both the young people involved and the organisation. Box 3 describes both the benefits and the challenges of attempting to implement this program. The lessons identified here include clarifying very early on what the objectives and timeframes of the initiative are; ensuring both staff and young people abide by deadlines; providing regular communication by phone/email for those based outside the organisation and; creating a transition/handover plan if young people have a limited term at the organisation.

[Insert Box 3 about here]

Clinical: Youth Advisory Groups

At the time of the strategy, Orygen was the lead agency for four headspace Centres (P. D. McGorry et al., 2007) in the north-western suburbs of metropolitan Melbourne (Glenroy, Sunshine, Craigieburn and Werribee). headspace Centres are enhanced primary care services that are designed to be 'one-stop shops', providing a range of service options to young people aged 12-25, including assessment and care provided

by allied health, medical and related (e.g. substance use, vocational support) professionals. Each Centre had a local Youth Advisory Group (YAG). YAGs provided ongoing support to strengthen ties to community, as well as advising and participating in both research and clinical initiatives and programs. YAG members also devised and implemented independent activities. Although there was no formal relationship between the local YAGs and the national YAC and YRC, members of all groups had the opportunity to network with each other at events and other organisation-wide opportunities.

Clinical: Peer Workforce

Building on a long history of youth peer work in the clinical program (Monson & Thurley, 2011), a key part of implementing youth participation within our clinical services was to increase the youth peer workforce. Youth peer workers were employed for a range of activities including traditional peer support, online peer support, peer education, and vocational support.

Policy development

Orygen produces a number of policy reports and submissions to provide advice to government, mental health service commissioners and providers. In one example, Orygen developed a major policy report on youth suicide in partnership with YAC and YRC members. A roundtable discussion with members identified the actions they

believed were most important to improve our response to suicide among young people. A member of the YAC and YRC was invited to join the project team and be engaged in all stages of report's development.

Communication: building awareness of opportunities for young people

Working with Orygen's communications and media staff, we engaged social media and existing youth-focused and youth-led organisations to connect with a wide range of Australian young people to promote opportunities (e.g. recruitment to Councils and internships), updates, and outcomes of programs and initiatives. This has allowed for broad and established engagement channels when special projects have occurred (e.g. design of a new building, see Box 4).

[Insert Box 4 about here]

Communication: helping young people connect with Orygen

Comprehensive documentation, guidelines and information has been produced to ensure the program consistently engages in safe and inclusive processes. Some examples include: 1) expression of interest forms that allowed young people to communicate what they were hoping to gain from such an opportunity; 2) wellness plans, to help young people communicate and document the support needed to participate; 3) terms of reference to detail expectations and parameters of roles and

opportunities; and 4) reimbursement guidelines to ensure all stakeholders were aware of the reimbursement arrangements.

Communication: helping Orygen staff members connect with young people

Through consultations with existing staff members, one main barrier to partnering with young people was being unsure about who to ask or how to connect with young people. An online form was devised that allowed staff to provide basic details and begin a conversation informed by the guiding principles of youth participation, ensuring that partnerships adhere to these principles from the outset.

Communication: the Youth Engagement and Training Initiative (YETI)

YETI is Orygen's interactive online engagement platform in which young people can safely connect with other young people online, learn about mental health advocacy, and participate in engagement opportunities. YETI allows young people to post, share and like content in a newsfeed environment and is only accessible to young people who have been approved after identity verification. YETI currently engages over 100 young people from across Australia, and offers a range of introductory training modules specific to youth participation.

Role classifications

From the outset of the strategy it was clear that reimbursement was appropriate and necessary. Reasons including that we valued the contribution of young people, that we did not want financial barriers to participation, and that young people could otherwise be working.

Discussion

The above describes an ambitious strategy to facilitate youth participation and engagement across all levels of a national organisation. In an area where research is limited (Monson & Thurley, 2011), descriptions of programs and reflections on their success can help assist other organisations developing or refining their own program.

Having a dedicated Strategy enabled Orygen to embed youth-adult partnerships across the organisation. This process enabled culture change and increased the number of youth partners involved annually from approximately 40 to 200. This growth in demand has been used as an indicator of success by a similar program (Heffernan et al., 2017). However, the number of young people involved cannot be taken as the only marker of quality or success; other factors such as impact on processes, decision-making and outcomes are also important (Chekaway & Richards-Schuster, 2003).

There was likely varying degree of benefit for the young people involved in the programs (Howe et al., 2011; Oliver et al., 2006), yet in order to assess this, full and proper evaluations are needed. This is an evolving initiative that will continue to be refined as it is evaluated, as feedback is received, and as the needs and interests of both young people and the relevant sectors continue to change. Offering a variety of opportunities for young people to get involved in was crucial; this flexibility allowed for various degrees of involvement, aiming for the most appropriate and meaningful approach for each given situation (Kellett, 2011).

Despite creating important opportunities and remaining flexible, a number of challenges remain. These include diversity of partnerships; 'raising the bar' of youth participation; and creating meaningful pathways, which will be discussed below. We anticipate that other organisations embarking on the establishment or expansion of a youth participation program may benefit from focusing on these issues from the outset in order to minimise these challenges.

Although recruiting young people from diverse backgrounds was a priority, stronger focus on diversity is needed. Approaches we have adopted include offering a variety of ways for young people to be involved in the organisation; a comprehensive communication strategy to reach a wide range of young people; recruiting young people based on both key selection and diversity criteria; and removing barriers to

involvement (e.g. financial). We have also fostered existing and developed new relationships with partner organisations connected to communities to include their voices in our work.

Another challenge involves continuing to 'raise the bar' for meaningful youth participation across all levels of the organisation. Despite significant progress, we must increase and strengthen our partnerships with young people through both promoting youth involvement where interest is lower and working with enthusiastic adopters to foster growth. Research is one area of the organisation where varying degrees of experience and enthusiasm were evident (Faithfull et al., 2019). Addressing this requires a multipronged approach, including project- or team-specific solutions and organisation-wide, systemic changes. While the progress we have made (e.g. national youth council, young people included on the ethics committee) demonstrates our commitment to the voice of young people in shaping research (Bell, 2015), we must acknowledge that we are retrofitting youth participation to a well-established research program. Involving young people in priority setting for research (Ghisoni et al., 2017) and increasing the amount of youth-led research will be important.

Creating meaningful pathways has been another challenge. Being involved in the programs enriches young people with valuable experience and skills, and this organisational capacity is lost when young people graduate from the program due to

end of tenure or 'ageing out'. Establishing pre-organised pathways (e.g. youth peer workers may become trainers and/or supervisors) but also remaining flexible to the many and changing interests of each young person is critical.

Overall, the main challenge was the unprecedented growth of the organisation after the Strategy was first implemented, effectively outgrowing the Strategy. The original Strategy resulted in a large increase in the number of young people involved in the organisation. An updated Strategy is now being devised based on the learnings from the original strategy and programs, and to reflect best practice in this rapidly growing field. For example, in line with the increasing professionalisation of the peer workforce (McMahon, 2019), we now consider peer workers to be employees of the organisation, and distinct from the youth participation and engagement program, who are reimbursed volunteers.

Involving young people in all functions of youth mental health organisations is essential. This paper detailed an ambitious and evolving strategy for a national organisation. By providing practical examples of the successes and challenges, this work seeks to provide 'real-world' information about how other organisations can approach similar initiatives. International collaboration between both youth participation staff and, the young people involved in these programs, is needed to refine and share best-practice approaches, methodologies, and evaluation strategies.

Collaboration, ongoing evaluation and the development of new and ambitious approaches will ensure the field progresses and continues to make a positive impact on the lives of young people and the organisations that support them.

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Conflict of interest statement

None of the authors have a conflict of interest to declare.

Data availability statement

Data sharing is not applicable to this article as no new data were created or analysed in this study.

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Box 1. Ten guiding principles of youth engagement and participation.

1. Have clear expectations
<i>Have clear expectations about what can and can't happen from the outset, and acknowledge when processes and outcomes may change.</i>
2. Be flexible
<i>Be flexible about when and how young people can engage. Offer a range of ways young people can participate (e.g. varying commitment levels) to maximise youth participation.</i>
3. Value experience
<i>Including qualifications, lived experience and unique perspectives. Recognise individual skills and interests and try to draw on and build on them.</i>
4. Involve more than one young person
<i>Involve more than one person where possible and appropriate. Also aim for diverse representation so that partnerships can reach their full potential.</i>
5. Mutual benefit
<i>Make sure the young person is benefiting too (e.g. learning new skills).</i>
6. Reimburse appropriately
<i>Depending on the nature and duration of the commitment.</i>
7. Support involvement
<i>Different young people will require different support. Involve young people because they are the right people, not because of convenience.</i>
8. Avoid tokenism

Don't develop something and then get young people to provide input when it is too late to make meaningful changes.

9. Provide resources

Plan for youth involvement and make sure both you and the young people have what you need to enjoy a successful partnership.

10. Provide feedback

Let the young people know what changed as a result of their involvement and what you were able to achieve together.

Box 2. Inclusion of young people on a Human Ethics Advisory Group.

Orygen directs a Faculty Centre at The University of Melbourne (the Centre for Youth Mental Health) and has a Human Ethics Advisory Group, the Orygen Research and Review Committee (RRC), where all projects being undertaken at Orygen or by Orygen researchers need to submit an expression of interest (EOI) form and then a full ethics application for approval. Although plans to include young people on the RRC have long been discussed, bureaucratic and practical barriers have prevented this from happening. Two unplanned initiatives not included in the Strategy occurred in collaboration with the inaugural YRC. These included: 1) working through the barriers to involving young people as members of the RRC and adding two additional youth-specific RRC membership roles to be filled by current YRC members, meaning that all discussions involve two young people trained and supported to sit on an ethics committee; and 2) an additional field was added to the EOI form whereby applicants are now required to detail the ways in which researchers are partnering with young people to undertake the research. As an extension of this, the RRC is now moving towards implementing a requirement that all projects need to have at least one 'youth sponsor' on the research project whose responsibility it is to either be a partner within the research project and/or oversee youth partnerships for the duration of the study from inception to dissemination (and translation if appropriate).

Box 3. The Youth Educators Program: an example of the challenges that can be faced when developing new youth participation and engagement programs

One of the projects I worked on during my time at Orygen was the Youth Educator Program. With a personal interest and background in workforce development I loved being involved in this project. I gained valuable skills in learning how to write up a project proposal and manage multiple stakeholders. The other young people working on this project and I had the opportunity to present our ideas to a group of Orygen executives and staff members and work through issues and challenges as they arose. Despite there being some challenges in these meetings, they were extremely beneficial to my own professional development as I was able to learn the skills needed to negotiate with multiple stakeholders and other young people. Specifically, the challenges that arose surrounded differing ideas of what the actual objective of the program was and when it should be implemented. It was sometimes challenging to make sure my voice was being heard while balancing the needs of what young people want and what is achievable for the organisation. Keeping communication open was also problematic at times, with often information around timeframes and workplans for different Orygen program areas not being made clear to us. It was especially difficult to have all the information when I was based interstate and had limited face-to-face time with staff members. Due to delays in being provided Orygen workplans the program was not able to be implemented before my time on the Youth Advisory Council finished and so there was a risk that knowledge and skills would be lost in the handover to the new council. A recommendation for other organisations is to have a clear handover plan in place

early on, when youth councils have limited terms, because even when the intention is to finish projects before new young people start often things don't always go to plan.

Mary Brushe, inaugural Orygen Youth Advisory Council member

Box 4. Youth involvement in major projects: A new home for Orygen

In early 2016, Orygen commenced the final phases of planning for the development of a new \$78 million youth mental health facility. Youth participation was incorporated throughout the building design process. The overarching design principles ensured that the needs and wishes of young people were a priority, and that the facility supported a collaborative and engaging approach to work. A range of participatory approaches were used to engage over 140 young people, which included our YAC and YRC, members of our headspace YAG's, the OYHCP Platform Team, and young people from the wider community. Young people provided comprehensive input into the overall design of the space, including the decision to create youth traineeships for a concierge function in place of a reception. Other input included provisions for dedicated consulting areas; the use of both small 'cave-like' rooms and larger, open designs; a design that uses passive security rather than barriers and locked doors; and a building that has the atmosphere closer to a university campus than a hospital. Inclusivity was of particular importance, with young people's strong advocacy resulting in the implementation of gender neutral toilets across the facility. Young people have also been engaged in all groups throughout the project, working alongside staff to decide on room layouts, room furnishings, selection of finishes, furniture selection and colours. Through our procurement processes, Orygen asked the builders to consider how they might work with us to create jobs for young people. To date we have secured employment for a young person on the Building Project Team. This overall approach was a major shift

for the Project Team, who reported that they are seeking to take a participatory approach forward in other projects.

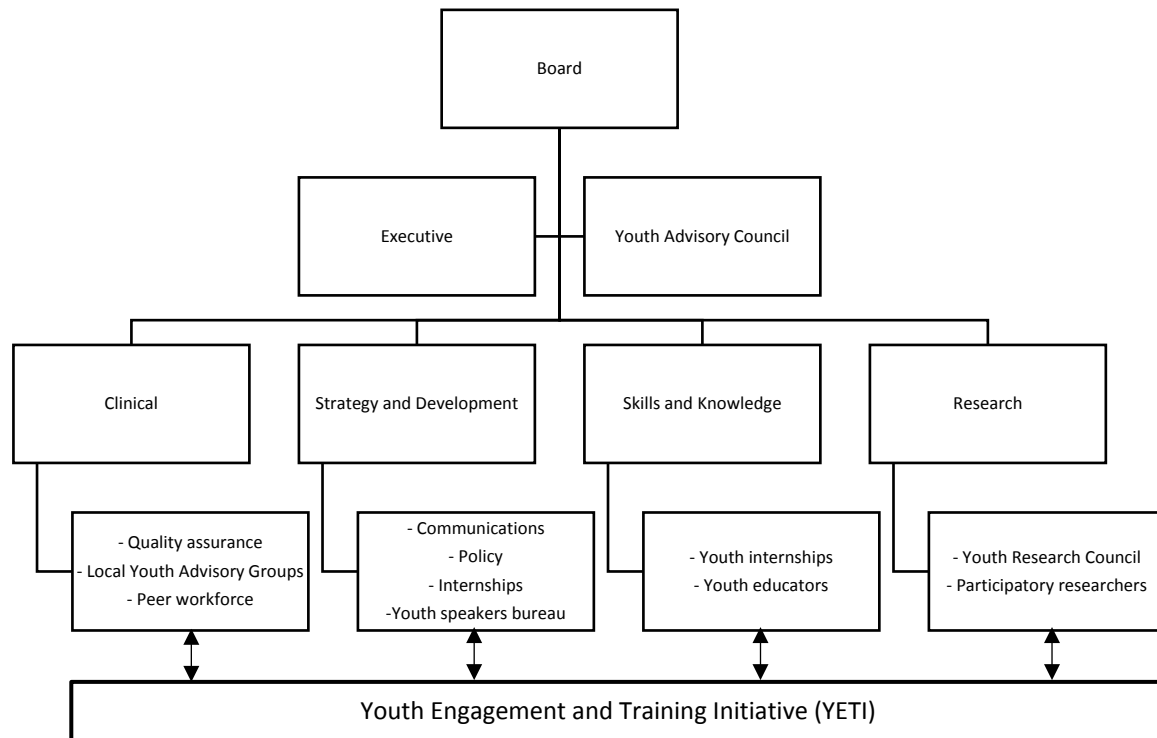


Figure 1. Overview of the original Youth Participation and Engagement Strategy activities in relation to the Orygen Board, Executive and organisational areas (2015-2018).