



Youth Participation in Early Psychosis

 **Drygen**
The National Centre of Excellence
in Youth Mental Health



EPPIC

Early Psychosis
Prevention and
Intervention
Centre

The EPPIC National Support Program of Orygen, The National Centre of Excellence in Youth Mental Health has produced this document as part of its work to support the scaling up of the EPPIC model within headspace, the National Youth Mental Health Foundation, in Australia.

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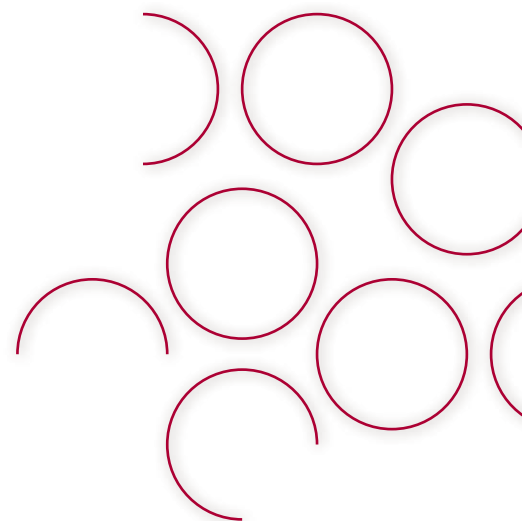


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Introduction

Youth participation is a fundamental right of young people within youth mental health services, as it embeds young people in the decision-making processes of service development and delivery. Providing opportunities for young people to use their experience and skills to actively participate in mental health service design, improvement and delivery has significant benefits for both service providers and young people. In addition, youth participation through a peer support program allows young people to benefit from the support of peers who have been through a first episode of psychosis. By sharing their involvement with an early psychosis service and their recovery, peer support workers help provide hope and optimism to other young people and their families.

The meaningful involvement of young people in services is thought to improve the youth-centredness and youth-friendliness of services and reduce the stigma associated with accessing mental health services. The participation of young people in communication, community development and mental health promotion activities of the service can improve mental health literacy and promote help-seeking among other young people. A dedicated youth participation program is therefore essential to an early psychosis service to promote the best possible service delivery and outcomes.

About this manual

Youth participation in early psychosis is aimed at mental health professionals working with young people with early psychosis, and individuals responsible for early psychosis service development. The content of this manual has been derived from international evidence and more than 20 years of experience of implementing and delivering services to young people with early psychosis and their families at Orygen Youth Health.

This manual has been developed as part of an overall training program delivered by the EPPIC National Support Program (ENSP) that also includes face-to-face training and online learning modules. It should be read in conjunction with the other manuals in this series. The ENSP is assisting with the implementation of the Early Psychosis Prevention and Intervention Centre (EPPIC) Model in early psychosis services. The EPPIC Model has been developed from many years' experience within the clinical program at Orygen Youth Health and has been further informed by the Early Psychosis Feasibility Study Report written and published by the National Advisory Council on Mental Health in 2011 which sought international consensus from early psychosis experts from around the world.¹ It is based on current evidence, the experience of other early psychosis programs internationally and shaped by real world considerations. The EPPIC Model aims to provide early detection and developmentally appropriate, effective, evidence-based care for young people (aged 12–25 years) at risk of or experiencing a first episode of psychosis.

There are a number of core values and principles of practice that inform the EPPIC model of care. Ideally, an early psychosis service should incorporate:²

- easily accessible expert care
- a holistic, biopsychosocial approach to clinical interventions
- a comprehensive and integrated service approach
- evidence-based clinical practice that promotes recovery
- the presence of youth-friendly culture throughout the service (reflected in staff behaviour, clinical skills and attitudes and decor)
- a spirit of hope and optimism that is pervasive throughout the service
- a family-friendly ethos contained in all aspects of the service
- a service culture that facilitates culturally sensitive care to all young people and their families and friends
- a high level of partnerships with local service providers.

Youth participation is a core component of the EPPIC Model, as the experience of a young person in an early psychosis service provides a unique insight into identifying the strengths and weaknesses in service delivery. The National Standards for Mental Health Services state that mental health services should have processes in place to actively involve people who use mental health services, and their families, in service development, planning, delivery, and evaluation and quality programs. Furthermore, the National Mental Health Commission also places a strong emphasis on collaborating with people and their families who have a lived experience of mental health difficulties.

The youth participation activities described in this manual have been developed and implemented via the contribution of young people at Orygen Youth Health. Their contribution has been central to the development of the innovative and successful approach to youth participation and engagement in the EPPIC Program at Orygen Youth Health. The EPPIC Model approach to youth participation aims to improve mental health literacy, promote help-seeking among young people and improve mental health service delivery.

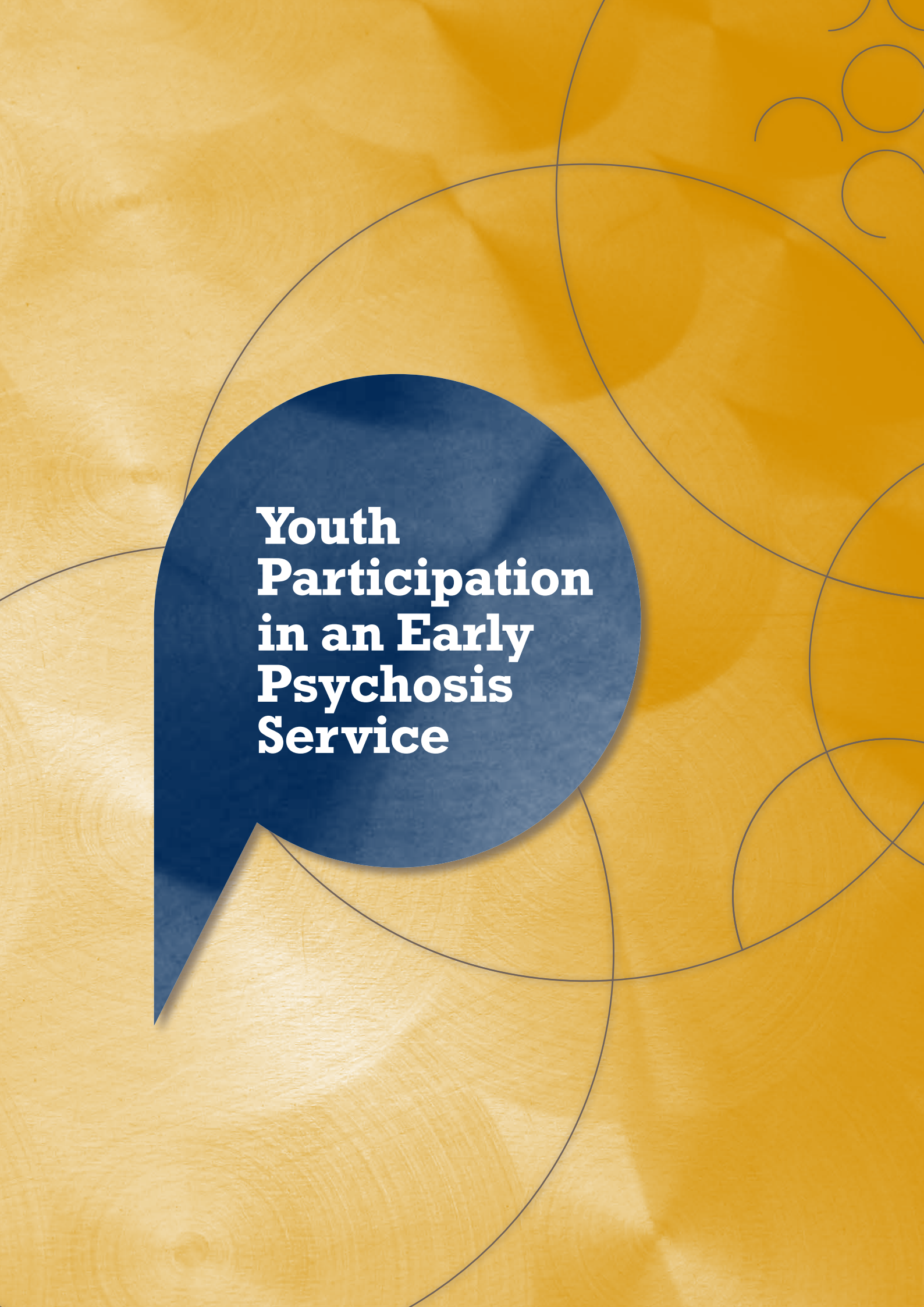
How to use this manual

This manual has five sections. 'Youth participation in an early psychosis service' provides a background and rationale for youth participation in mental health services. 'Establishing a youth participation program' outlines the service culture for successful youth participation in an early psychosis service, provides details on the different youth participation activities and outlines the role of the youth participation coordinator. The section entitled 'Peer support in early psychosis' provides a rationale behind peer support work and focuses on how to provide peer support work in an early psychosis service. While the 'Evaluation and future research' section highlights the importance of evaluating youth participation within a service.

The youth participation program within in an early psychosis service should be managed by a youth participation coordinator who also actively develops a youth participation team. Service provider leaders should read this manual in conjunction with the EPPIC Model and Service Implementation guide for more detail on how to incorporate youth participation into an early psychosis service.

For the purpose of this manual, 'early psychosis' is defined as the early course of a psychotic disorder. It encompasses the period from the emergence of an 'at-risk mental state' through the first episode of full threshold psychosis and the 'critical period' of up to 5 years from entry into treatment for the first psychotic episode. Please note that the term 'family' in this manual refers to a young person's key supports, and may include a range of relationships aside from immediate family, such as other relatives, friends or partners.





**Youth
Participation
in an Early
Psychosis
Service**



Youth participation in early psychosis

Background: the history of consumer participation in mental health services

There have been different models of ‘consumer’* participation in mental health services across the different states and territories of Australia. The Citizens Against Psychiatric Injustices and Coercion (CAPIC), the New South Wales Association of Relatives And Friends of the Mentally Ill (NSW ARAFMI), the Queensland ARAFMI, and the Schizophrenia Fellowship of Victoria were some of the early models of ‘consumer and carer’ participation in mental health in Australia. Adult mental health services in Victoria adopted the model of consumer participation during the process of deinstitutionalisation. The Victorian Mental Illness Awareness Council (VMIAC), a consumer advocacy organisation in Victoria, was active in the development of the Declaration of Rights of People with Psychiatric Illness. VMIAC also produced several pivotal publications regarding consumer participation in mental health such as the Understanding and Involvement (U & I) Project and The Lemon Learning Tree Project. Important recommendations from these publications continue to shape consumer participation in mental health today, including the employment of consumers as staff, the inclusion of consumer participation as a service component rather than an ‘add-on’ and that participation occurs in partnership with service providers.

Current policy and guidelines

Current Australian mental health policy related to the engagement of ‘service users’ suggests that participation involves three different tiers:³

- participation at the individual level, in which individual consumers are engaged as active participants in their own treatment planning
- participation at the service level, in which individual or groups of consumers are engaged as stakeholders and consultants, and
- participation at the systemic level, in which consumers are engaged as advocates, stakeholders and consultants in decision-making regarding policies, funding and services, often for large networks of services or at the state or territory level.

Although there are intersections of these different levels of participation, this manual will predominantly focus on the second level of participation and activities that enhance participation at this level. It is recommended that users of this manual familiarise themselves with their state or territory bodies for system-level participation.

Participation at the service level aims to: uphold the rights of individuals of the service by allowing active participation in the decision-making that directly affects them; increase the likelihood of practitioner commitment to individual involvement in treatment and care; and improve service quality. For the

* Consumer is defined by the National Health and Medical Research Council as a patient or potential patient, carer, organisation representing consumers’ interest or member of the public who are targets of health promotion programs. Please note: in this manual, the terms ‘consumer’ and ‘service-user’ will be used in the text wherever it appears in the published literature; however, the term ‘young people’ or ‘young person’ will be used throughout the manual as an alternative.

BOX 1 THE NATIONAL MENTAL HEALTH STRATEGY CRITERIA FOR CONSUMER AND CARER PARTICIPATION⁵

- Actively involve individuals of the service and carers in planning, service delivery, evaluation and quality programs
- Uphold the rights of individuals and carers when feedback is given on the planning, delivery and evaluation of the service
- Provide training and support to maximise representation and participation
- Individuals have the right to determine who represents their views
- Provide ongoing training and support for involvement in formal advocacy and support roles
- Ensure mentoring program and supervision is provided to employed participants
- Policies and procedures are in place to assist participation in relevant committees, including payments or reimbursement of expenses when participants formally engage in activities

majority of adult mental health services in Victoria, participation involves an employed consultant model, where one or two consumers are appointed, each with tasks defined by the service. The emphasis is on the lived experience of mental ill health and of service use, and how this knowledge can be used to enhance service delivery. These 'consumer consultants' represent their own views and perspectives of the service and undertake tasks such as advocacy, committee membership and peer support.

Consumer participation in mental health services is monitored and audited through the Evaluation and Quality Improvement Program National's National Safety and Quality Health Service Standards. These standards provide performance indicators – for example, creation of a participation plan and the presence of participants on organisation committees for planning and development – against which organisations are accredited. While these standards are a guideline for accreditation, other guidelines include the National Consumer and Carer Forum's *Consumer and Carer Participation Policy: A Framework for the Mental Health Sector*, which is a best-practice guide,⁴ and the National Mental Health Strategy Standards, which state 'Consumers and carers [must be] actively involved in the development, planning, delivery and evaluation of services'.⁵ The criteria for the consumer and carer participation standard of the National Mental Health Strategy⁵ are summarised in Box 1.

While valuable markers of progress, it may be that the achievement of performance indicators is not adequate for participation to be meaningful. Evaluations of how mental health services work to actively engage and consult with consumer representatives have shown that a lack of clear processes and structure to the development of participation, and lack of funding, act as barriers to more strategic and more meaningful participation.⁶ VMIAC suggest that these issues can be addressed through the incorporation of participation activities into the policy and practice directives of the mental health service, and that doing so will enable the contribution of the unique expertise of consumers as authorities in their own life. See also 'Youth participation in mental health: barriers and enablers' on page 11.

What is youth participation?

Youth participation is a range of frameworks used across a range of youth services and education sectors. It involves activities that range from one-off sessions focused on a specific aim or objective, through to more ongoing participation opportunities aimed at skill development and wider social change. Youth participation is often used as a 'tool' or subset of other frameworks such as youth development, civic participation or youth leadership. Youth development supports a positive youth approach by equipping young people with skills that enhance resilience, problem-solving and positive decision-making. Civic participation and youth

‘Participation creates better outcomes for young people and the organisations that are involved in the decision-making process, saving valuable time and energy in the long-term. Youth participation contributes to the developmental needs of youth while benefiting organisations in a unique way.’⁹

leadership support young people to become active and contributing members of their communities. There are some differences in terms of ideologies: for example, a youth development approach is focused on the outcomes for the participating young people, whereas a civic participation approach maintains dual foci on outcomes for participants and the community members who are beneficiaries of the participation. The similarities between frameworks are of great importance to the model of youth participation in mental health. Across all frameworks, youth participation strategies use the existing skills and commitment of young people and assist in the development of new skills. Approaches are normally tailored to suit young people and their development, are universal and aimed at engaging all young people irrespective of their background.

How youth participation is evaluated often depends on the framework through which it is driven and the program’s overall aim. Youth participation may occur as a component of youth development programs and is likely to focus on individual skill acquisition and development, whereas youth participation adopted as part of a democratic participation process may focus on community-level outcomes. For individuals, youth engagement and participation can lead to a range of outcomes ranging from positive development such as resilience⁷ to suicide risk reduction.⁸

Why have youth participation in a mental health service?

Providing opportunities for active youth participation in mental health service design, improvement and delivery has significant benefits for both service providers and young people. Involving young people in services is thought to improve the youth-centredness of the services, increase help-seeking behaviour and reduce stigma.

The requirement for youth participation in the development and implementation of programs under the National Mental Health Strategy and National Suicide Prevention Strategy was identified during the development of the Third National Mental Health Program in Australia.⁹ The Australian Infant, Child, Adolescent and Family Mental Health Association (AICAFMHA) undertook the National Youth Participation Strategy in Mental Health project to plan models of youth participation programs funded under the National Mental Health Strategy and National Suicide Prevention Strategy.⁹ The National Youth Participation Strategy in Mental Health Scoping Project Report states that ‘young people have an internationally recognised right for their views to be heard and taken into account regarding decisions which affect them.’⁹ The National Action Plan for Promotion, Prevention and Early Intervention for Mental Health 2000 identified that consultation with ‘young adults to develop and identify effective promotion, prevention and early intervention programs, settings and messages’ was a priority for all bodies across Australia. The National Youth Participation Strategy in Mental Health Scoping Project Report also states that ‘participation gives young people the opportunity to talk about what is important to them. It leads to better decision making, as they can offer their expertise on a matter and “own” any decisions that will affect them.’⁹

In 2008, the National Youth Participation Strategy in Mental Health Scoping Project Report recommended that youth participation be at the forefront of planning for mental health services that target young people and that models of youth participation are receptive to the needs of young people.⁹

Youth participation in mental health: barriers and enablers

Despite best-practice guidelines and performance indicators, the extent of participation of consumers varies widely between services. The literature suggests that this may be due to clinicians or services interpreting participation at this level as an ideological or 'feel good' intervention rather than one based on evidence.^{6,10-12} Studies in the United Kingdom¹³ and Australia^{14,15} have demonstrated relationships between higher levels of biomedical or scientific orientation of staff and reduced support for consumer involvement in decision-making, including decision-making about their own care and treatment. However, in those areas, consumer participation has a growing evidence base,¹⁶ and the 'need' for consumer participation to improve the consumer-centredness of services has been well established.

Variable degrees of participation may also come about because organisations fear that participation will have an adverse effect on consumers. A systematic review of service user participation in mental health services involving five randomised controlled studies reported that the involvement of service users as employees of mental health services resulted in other service users experiencing greater satisfaction with circumstances and less hospitalisation, and that the involvement of service users in the training of service providers produced a more positive attitude towards service users among staff.¹⁷ Furthermore, the studies reviewed found that employing service users within a mental health service did not have a detrimental effect on symptoms, functioning or quality of life among individuals (as reviewed by Simpson and House¹⁷).

A number of other barriers exist to effective participation strategies for young people within mental health services. Young people are often managing a number of tasks, such as study, work and personal relationships, that may impact on their ability to commit to long-term participation opportunities. At an organisational level, meaningful participation is often time-consuming and is associated with high-program and staffing costs. Frequently, organisations expect to fit participation into existing structures rather than develop new models for participation.⁶ Although not wishing to collude with historic beliefs that consumers cannot participate because they are too unwell, it is important to acknowledge that participation can impact upon wellness, and wellness can impact upon participation. Similarly the skill level of participants can impact on participation.

There is an array of strategies for countering the barriers associated with participation in the published literature. Lloyd and King found that using an array of participatory processes ensured that a wide range of interests were represented and therefore produced better outcomes in terms of consumer centredness.¹⁸ They suggested that organisations should offer a range of 'top down' (e.g. management-led) practices, and embrace a range of 'bottom up' (e.g. grassroots, consumer-led) practices. Where consumer movements have often used models such as Arnstein's ladder of participation¹⁹ to understand the degree of community control, youth participation in mental health assumes that different degrees of delegation, partnership and control are appropriate for different activities and aims.

Models of youth participation programs within mental health services should have clear objectives for participation and work towards accountability among services and the individuals participating in the activities. The objectives of the youth participation program should be clearly communicated across the organisation and integrated into the service. Service managers responsible for youth participation programs will need to ensure that youth participation strategies are adopted throughout the organisation and evaluated in a timely manner to clearly demonstrate the outcomes of the program. Participation programs should be designed in collaboration with young people, or ideally, by young people who participate in them. Engagement of young people into the design of decision-making processes within the organisation will ensure that participation activities are meaningful for young people. The design of the participation program should contain details of the roles and expectations of young people so that the organisation can provide adequate support for young people and that young people understand what they are committing to. Gradually, a range of participation activities reflecting different interests and skills should be developed. In addition to harnessing the existing skills of young people within the youth participation program, the program should also provide formal and informal training opportunities for young people to be mentored to develop new skills.

Youth participation strategies in mental health should ideally embrace ideas from positive youth development models, in addition to incorporating a diverse array of activities such as those used in adult mental health services to enable meaningful participation. Strategies for explicitly discussing the link between skills and participation, and between

wellness and participation, should be developed. Ideally, these strategies should be developed with young people themselves, and should be aimed at providing young people with a high degree of ownership of their own participation and their own hopes for participation.

Models of youth participation in youth mental health services

There are a number of models of youth participation within youth mental health services around the world, some of which are described briefly below.

The Ontario Centre of Excellence for Child and Youth Mental Health (Canada)

The Ontario Centre of Excellence for Child and Youth Mental Health promotes mental health agencies to implement evidence-informed practices, including youth engagement. The centre has supported a number of youth engagement projects and initiatives, such as YouthNet, The Dare to Dream Program and The New Mentality Program. Dare to Dream is a youth-led program that helps young people create project ideas that promote positive mental health and wellbeing. More information is available at <http://www.daretodreamprogram.ca/>. The New Mentality Program is a program that promotes youth engagement in mental health and was developed by Children's Mental Health Ontario. Children's Mental Health Ontario represents and supports child and youth mental health treatment service providers throughout Ontario. The goal of The New Mentality is to develop a provincial network of youth to promote public awareness of mental health issues and advocate for a youth mental health system that meets the needs of children and youth. For more information please see www.thenewmentality.ca.

Children's Mental Health Ontario and the Provincial Centre of Excellence for Child and Youth Mental Health state that 'youth engagement is about empowering all youth as valued partners in addressing and making decisions about issues that affect them personally and/or that they believe to be important'. On a systemic level, the program aims to shape policy and practice, in a positive manner, in order to foster meaningful youth engagement opportunities in youth mental health organisations. The Ontario Centre of Excellence for Child and Youth Mental Health supported the development of a manual called 'Ready...Set...Engage!' that reviewed the evidence and made recommendations on how to build effective youth-adult partnerships for a stronger youth mental health system. The centre also developed a youth

engagement training workshop that aimed to engage in meaningful conversations about youth engagement practice outcomes, best practices for youth engagement in governance and public education, models for understanding youth engagement, transforming services to youth-friendly environments, youth recruitment strategies and participant evaluation.

Youthspace (UK)

Youthspace is a coordinated clinical, research and public health program with a special focus on youth mental health that is an initiative of the Birmingham and Solihull Mental Health Foundation Trust. The program supports a preventative approach to youth mental health and is guided by its 'youth board'. The youth board meets to discuss and give guidance on the development of Youthspace projects and events, including how a youth mental health service will meet the needs of young people, how young people can make a contribution to service development, the design of educational resources and how to improve community awareness and reduce the stigma around mental health. A number of Youthspace projects are discussed throughout this manual. For more information please see www.youthspace.me.

Headstrong: The National Centre for Youth Mental Health (Ireland)

Headstrong is The National Centre for Youth Mental Health that supports youth mental in Ireland. The main aim of Headstrong is to empower young people to develop self-confidence and resilience in order to cope with mental illness by working with communities and services. Headstrong supports youth mental health through service development, advocacy and research. Jigsaw is Headstrong's service development program, which helps to bring community services together to better meet the needs of young people with mental illness. Jigsaw works with, and for, young people in the development of each local project and this gives young people the opportunity to participate in the change process and ensure that these changes are relevant to young people in the community. The core elements of Jigsaw projects include staff availability and premises, comprehensive training, meaningful youth engagement and participation, systematic planning process, management structure and clinical governance processes. Jigsaw has youth advisory panels that are involved in strategy and decision-making at all levels. Youth advisory panels represent Jigsaw in public and are involved in staff recruitment. For more information, please see www.headstrong.ie.

headspace: The National Youth Mental Health Foundation (Australia)

Established by the Commonwealth Government of Australia in 2006, headspace is the National Youth Mental Health Foundation in Australia. The primary focus of headspace is the mental health and wellbeing of young Australians. The headspace model of youth participation is based on the belief that youth participation is fundamental to the delivery of services to young people. It has developed a national youth participation strategy called the headspace Youth National Reference Group (hY NRG), as well as a local youth reference group model that involves a group of young people from local headspace centres that consults on topics such as quality of care, community engagement, health promotion and outreach.

The youth participation roles and activities within the headspace model include interviewing staff, resource development, media work, peer support and skill development, speaking in schools, evaluation of headspace activities, website content, outreach projects, guest speakers, training sessions, focus groups, surveys, feedback forms, interviews and community fundraising events.²⁰ For further information please see: www.headspace.org.au and *Youth Participation and Community Engagement Handbook 2011* by headspace National Youth Mental Health Foundation.

Orygen Youth Health Clinical Program (Australia)

The youth participation program in the Orygen Youth Health Clinical Program (which includes EPPIC) incorporates a number of different activities and opportunities for participation. The rest of this manual will describe the different youth participation activities from the experiences at Orygen Youth Health Clinical Program. The youth participation program at Orygen Youth Health Clinical Program covers a range of initiatives that aim to actively improve the delivery of service to young people, improve mental health literacy, promote help-seeking behaviour among young people and reduce stigma regarding mental illness.²¹ The program provides an opportunity for young people who have either previously or currently used the service to act as consultants or advisors. Additionally, it forges a vital link between young people and service providers, making it possible to identify gaps in the service, to understand feedback from young people and to work together to improve service delivery. Youth participation also has a positive effect on the health and wellbeing of the young person involved. The program supports skill development and provides meaningful spaces for altruism. Youth participation is part of Orygen

Youth Health Clinical Program's commitment to empowering young people to make a contribution to the quality of the service and how it responds to the need of young people. Youth participation activities initiated by Orygen Youth Health Clinical Program include:

- the PLATFORM Team
- staff selection
- committee membership
- media, public speaking and advocacy
- focus groups
- resource development
- research
- mental health promotion
- service improvement
- training and education
- peer support.

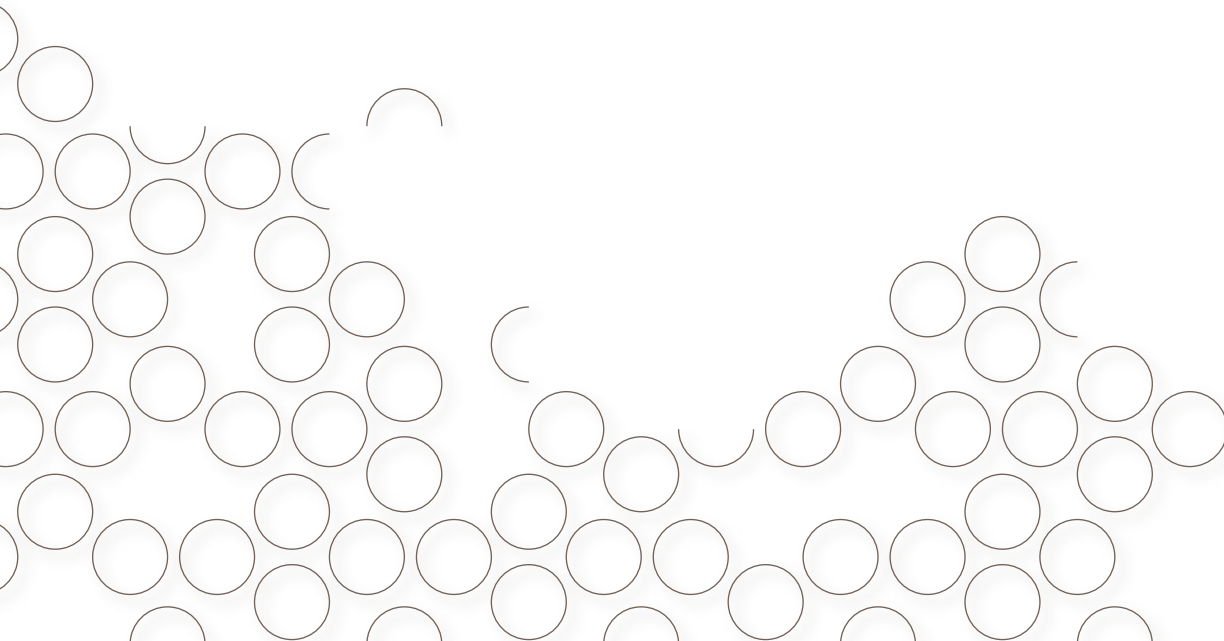
Each activity will be described in other sections of this manual.


The youth participation program at Orygen Youth Health Clinical Program is a part of the Psychosocial Recovery Program, which is also an important part of the EPPIC Model. A youth participation coordinator is employed (0.6 EFT) to coordinate the youth participation activities and liaise with clinical program staff in order to engage young people in activities.²¹ The youth participation coordinator supervises two young people who are employed as project workers on the components of the youth participation program model. The subsequent section will include the youth participation coordinator role based on the model at Orygen Youth Health Clinical Program.

Models of youth participation in mental health services need to be tailored to local context, local resources and locally identified objectives for youth participation. This manual provides very specific examples from experiences at Orygen Youth Health Clinical Program and some examples from other local and international services. Youth mental health services can adopt elements of programs wholesale, but are encouraged to adapt and implement models fit for their population and their context. The box on the next page outlines some essential features of youth participation models.

BOX 2 ESSENTIAL FEATURES OF YOUTH PARTICIPATION MODELS

- Dedicated staffing
- Dedicated budget
- Developed in parallel with the other parts of the program, rather than added on
- Developed with young people themselves rather than designed *for* young people by professionals
- Activities are tailored to be developmentally appropriate to provide opportunities to use existing skills and build new ones
- Activities are tailored to be developmentally appropriate to provide opportunities for meaningful participation in addition to fun and social connectedness
- A range of opportunities that engage a broad cross section of young people, including opportunities which are youth-led and those which are led by others in the organisation





**Establishing
a youth
participation
program**



Youth participation program

Overview

Youth participation is an essential component of the EPPIC Model and early psychosis services. The following section discusses service leadership, culture, participation activities and the role of the youth participation coordinator, which are important factors to consider when setting up a youth participation program in an early psychosis service.

Youth participation leadership and service culture

For a youth participation program to be implemented effectively, it must be accepted and valued by both the young people and the staff within an early psychosis service. It is therefore vital that a service culture is created that supports the meaningful participation of young people in the service's development.

The appointment of a dedicated youth participation coordinator whose responsibility it is to oversee the program and encourage young people to get involved is an essential component of creating this culture. The individual employed as the youth participation coordinator may not necessarily be a health professional, but may come from a community development or youth work background. Ideally, the youth participation coordinator should be part of the psychosocial recovery team. The development of the youth participation coordinator requires supervision by a senior clinician who has a good understanding of, and experience in, youth participation. For more information on the youth participation coordinator role please see the section 'The role of the youth participation coordinator' (page 43).

'It is important to have consistent leadership of the youth participation program, and having a youth participation coordinator who looks after the program means there is consistency. Continuity has been very important in keeping the youth participation program going at the service.'

**Program Manager,
Orygen Youth Health Clinical Program**

One of the main challenges of developing and implementing a youth participation program within an early psychosis service is how the program is received in terms of its purpose and benefits. Many staff members of an early psychosis service may be naïve to why youth participation is important to service delivery. It is important for service leaders to develop a clear mission statement that ensures that the purpose of the program is communicated and understood across the entire service. Education of staff members is also an important part of developing an understanding of the rationale and benefits of the program.

‘It is important that clinical staff are supported to understand youth participation and how young people and the service can both benefit from the program. It can’t be the sole responsibility of the coordinator to drive a culture of youth participation ... it’s a team effort, the entire organisation has to be on board and it should be supported from the top down. The role of the youth participation coordinator isn’t just about supporting young people to be involved [in the youth participation program], it’s also supporting and educating the entire service about the value of the program.’

**Youth Participation Coordinator,
Orygen Youth Health Clinical Program**

‘Having people who lead the service actually taking up youth participation was a key part of getting it going. I’ve heard a few members of PLATFORM comment on the fact that the program manager goes to the PLATFORM meetings. So you need that buy-in from the service leaders.’

**Program Manager,
Orygen Youth Health Clinical Program**

It is important to try a number of different strategies during the initial stages of setting up the youth participation program to ensure that the interface between the clinicians and young people involved in youth participation works. One of the strategies adopted at the Orygen Youth Health Clinical Program is to generate a report every 6 months that outlines the work the PLATFORM team (youth consultation meeting) has been doing. This report is written and circulated to the Executive as a way of communicating and continually building the profile of PLATFORM with senior management of the service. Another strategy is for managers within the service to attend PLATFORM meetings across the year to share information, consult about service initiatives and receive feedback from the youth consultants.

It is equally important to develop policies and procedures for youth participation activities when establishing the youth participation program to ensure consistency in terms of expectations and delivery. The guidelines will help formally define what is expected of the participating young person, the service’s responsibilities and, if a third party has requested youth participation, the responsibilities of that individual or organisation. It is the responsibility of the youth participation coordinator to be clear about what goes into these documents.

‘I think the biggest struggle is actually genuinely setting it up in a way that ensures youth participation in service development occurs efficiently and effectively. I guess one of the dangers is that youth participation can be seen as a bit of an add-on and not integral to service development.’

**Program Manager,
Orygen Youth Health Clinical Program**

The youth participation model that forms part of the overall EPPIC Model is a different model to consumer participation in adult mental health services. Young people are invited to participate for a period of time and are not expected to become ongoing consumer consultants. Workforce development in adult services creates an ongoing consumer workforce by training, supporting and supervising consumers to become consumer consultants. The youth participation program encourages young people to move through the program and be involved where they can, such as media or interview panels, but if they return to school or work, it is considered a positive outcome.

‘When you are setting up a youth participation program, you have to be wary that it is not something that just looks pretty and “ticks a few boxes” but actually does have an impact on the service.’

**Program Manager,
Orygen Youth Health Clinical Program**

Youth participation activities

Youth participation activities are used to encourage young people to participate in the service delivery and are an essential part of the youth participation program. Youth participation activities include media work, staff recruitment, research, focus groups, resource development and training.

The following section describes specific youth participation activities as part of the Youth Participation Program at Orygen Youth Health Clinical Program. However, it is important to note that there are a number of different youth participation activities that are used within youth mental health services across the world, some of which are described in this section, and organisations are encouraged to use activities and models that suit their youth participation program and overall service.

Broadly, youth participation activities at Orygen Youth Health Clinical Program include:

- youth consultant group meetings
- committee membership
- media, public speaking and advocacy
- focus groups
- resource development
- staff selection through involvement in interviews
- research
- community awareness and mental health promotion
- service quality improvement
- involvement in training and education.

‘Having youth participation projects where it’s clear what the outcomes are creates a culture where people are willing to think about how young people can contribute and help in a range of different ways.’

**Program Manager,
Orygen Youth Health Clinical Program**

Youth consultant group meetings

The youth consultant group at Orygen Youth Health Clinical Program is called ‘PLATFORM’ (please see the boxes on page 21–22 for examples of youth consultant group meetings from other youth mental health services, including Youthboard, from Youthspace, and hY NRG, from headspace). Young people who are either currently using or have previously used Orygen Youth Health Clinical Program’s services and are interested in contributing their expertise, ideas and feedback can participate in regular PLATFORM meetings.

The purpose of the youth consultant group meetings is to provide a space for young people to come together to:

- provide feedback to staff within the service about service-led development and improvement initiatives
- obtain feedback from staff within the service about other initiatives and opportunities for participation
- discuss possible projects for youth-led activities, particularly regarding service improvement
- review the progress of current team projects and perform project tasks
- receive briefings and register interest for upcoming consultation opportunities
- review resources developed by the service (e.g. design and content of factsheets, brochures)
- hear reports from team members who participate in other working groups and committees
- hear about, and celebrate, participation activities occurring since the last meeting, or outcomes of previous participation activities.

The length, format, content and frequency of youth consultant group meetings are important aspects to consider in terms of young people being able to contribute meaningfully and to see projects through. Meetings should run for a pre-determined period of time (no less than 1 hour and no longer than 2 hours). At Orygen Youth Health Clinical Program, the frequency of meetings is reviewed annually and is changed depending on participant preferences, though is never less than monthly. A young person should chair the meetings and another young person should take the meeting minutes. Wherever possible, the agenda should

be generated by the participants. Meeting members are able to contribute items for discussion, via the youth participation coordinator, during the weeks leading up to the meeting. The youth participation coordinator may make efforts to incorporate a mix of activities in the meeting in consultation with the young person who is chairing the meeting; this supports young people to contribute in different ways. For example, there may be opportunities for small group work on tasks, providing both written and verbal feedback. At the beginning of each meeting, the meeting guidelines and privacy policy should be discussed to ensure that existing and new participants are aware of these guidelines. Following each meeting, minutes are compiled and distributed to members via email or post.

The following resources are required to run youth consultant group meetings:

- a suitable meeting area that is comfortable, private and informal
- a computer – used for minute taking, reviewing online documents/resources and carrying out project tasks
- staff member for support of the meeting
- promotional materials (e.g. posters advertising the next meeting time)
- documents for participants such as agenda and other resources
- food and beverages catering for all dietary requirements of group members.

To participate in youth consultant group meetings at Orygen Youth Health Clinical Program, a young person should meet the specific membership eligibility criteria listed in the box below.

BOX 3 ELIGIBILITY CRITERIA FOR MEMBERSHIP OF PLATFORM

- Under the age of 28 years
- Either currently receiving treatment and care from Orygen Youth Health Clinical Program or discharged within the preceding 3 years
- Be willing to participate in setting goals at the beginning of membership and at 3-monthly time periods thereafter to identify areas of interest and set goals for participation and skill development
- Be willing to develop and maintain a wellness plan with the youth participation coordinator
- Be willing and able to adhere to the rules of participation, including meeting guidelines, privacy and confidentiality statements

‘Recruiting to PLATFORM can be difficult. Young people are often overwhelmed with information from the service and it’s challenging to reach them in a timely and effective manner. We use promotional posters and brochures that are co-designed with young people to advertise PLATFORM and rely heavily on case managers and other staff members to refer young people to the program. We’ve mostly relied on members to tell other young people and endorse PLATFORM. It’s really great when this happens because it reaffirms that young people enjoy being involved.’

**Youth Participation Coordinator,
Orygen Youth Health Clinical Program**

Recruitment to youth consultant group meetings is via self-referral or referral by a case manager. There is no application, assessment or interview process and young people are encouraged to ‘show up’ at meetings and participate. This approach is used to minimise barriers to participation and allow young people the opportunity to ‘try out’ the group meetings. It is important for participation to be as flexible as possible, to take into account varying degrees of recovery, different skill sets and other personal commitments and competing priorities. There is no compulsory training for young people to be able to participate in youth consultant group meetings. Wherever possible, young people should be supported with professional or personal development opportunities that assist with skill development aligned with their personal goals for participation, such as facilitating group discussion, chairing meetings or developing Word documents or PowerPoint presentations. Young people have the opportunity to develop and practise a range of skills including advocacy, decision-making, participation in group discussions, planning, time management, problem-solving and peer-to-peer support.

‘PLATFORM is harder to get advertising for than peer support because with peer support, people see us on the inpatient ward all the time and they say “I want to do what you do when I get out of here”. The guys know what we’re doing, whereas the work done with PLATFORM is slightly more behind-the-scenes.’

PLATFORM member

'I think there's a general respect for the work that PLATFORM does. The clinical staff can see that youth participation makes a difference and they're proud of the way that PLATFORM is involved in the program.'

Program Manager,
Orygen Youth Health Clinical Program

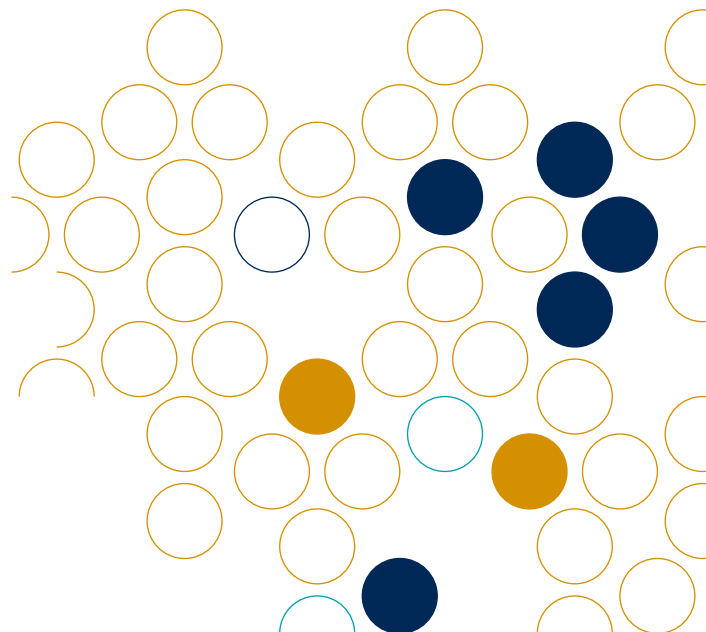
'I'm always surprised by how disconnected we can be from the perspectives of young people. Using PLATFORM to inform research, organisational change, projects and other service work adds a depth and value that you can't get elsewhere. We don't know what really works for young people unless we ask them. We can't think we know what it's like to be a young person who has experienced a first episode of psychosis – we can understand their perspectives but we'll never see it the way they do.'

Clinical Specialist,
Orygen, The National Centre of Excellence
in Youth Mental Health

BOX 4 THE YOUTH ACTION COMMITTEE (YAC) — THE NEW MENTALITY COMMITTEE FROM ONTARIO

The Youth Action Committee (YAC) is the Children's Mental Health Ontario's (CMHO) New Mentality Committee. The New Mentality is a program that engages youth to improve mental health services for children and youth.

The YAC currently consist of eight young people from across the Ontario province that has co-chairs, several young people and a CMHO board member. YAC develops and implements action plans that reflect the interests of young people each year, and responds to recommendations that are presented by youth who attend CMHO conferences and events. YAC aims to act as an advisory group to the CMHO's board of directors to ensure that there are youth-friendly policies incorporated into the organisation's overall policies. Additionally, YAC works on annual projects that aim to reduce stigma through raising child and youth mental health awareness. YAC developed a youth mental health toolkit in its inaugural year to inspire young people to talk about mental health issues and reduce stigma.



BOX 5 YOUTHBOARD – YOUTHSPEACE

The Youthboard directly guides Birmingham Youthspace, a coordinated clinical, research and public health program that focuses on youth mental health. The Youthboard consists of young people and staff members from Birmingham Youthspace and Fairbridge West Midlands and meets monthly to discuss the provide guidance on the design and development of Youthspace projects and events. The Youthboard discusses:

- how a new clinical service can best serve its young people
- how its website can best inform young people of mental health issues relevant to them
- how young people can make a contribution to new service development and design of educational materials
- how Youthspace can raise awareness and reduce stigma surrounding mental health to a general public audience.

Youthboard has its own written rules and regulations, which have been agreed to by the membership, and has an elected chair and several members with key roles. The Youthboard regularly provides the Youthspace program with feedback and guidance on service or public health development tasks. Initially Youthboard will discuss ideas in small workshops and regroup to inform the program with suggestions and guidance. Examples of the projects undertaken by Youthboard include the development of the youthspace.me website, design of the Youthspace logo, the creation of ID cards, support for educational events, and the creation of training materials and campaign posters. Regular attendees of the Youthboard are also involved other groups, such as the film media group and health mapping group.

BOX 6 HY NRG – HEADSPACE NATIONAL

The headspace hY NRG model uses existing young people from local headspace centre youth advisory groups for consultation on a variety of topics and projects. The hY NRG is supported by four youth advisors who are previous members of hY NRG who want to continue to share their experiences with the service.²⁰ hY NRG define youth participation as young people:

- contributing to acts within society to improve, expand or aid projects, goals or ideas
- participating in the community with a view to improve current and future services
- being meaningfully engaged in decisions that affect them and the community
- being supported in providing input at local and national level in the governance, planning and delivery of services that will have a positive impact on future governance.

Committee membership

Most organisations have a number of committees or steering groups. The work of these committees is typically reported back to senior management and others within the organisation. Where a youth consultant group such as PLATFORM exists, the work of these committees and groups should also be reported back to the youth consultant group.

From time to time, a young person may be asked to be a member of a committee as part of the service's youth participation program. If a young person is to represent 'all' young people on a committee, it is expected that they report back to the youth consultant group in the same way that a clinical representative is expected to report back to their team.

The time of day and the place where committee meetings occur are practical considerations for involvement of young people in committees. Young people may have difficulties attending meetings early in the morning and some may experience initial challenges from participating in overly formal meeting structures and spaces.

Recruitment to committees can occur either through an interest-based or a competitive model. At Orygen Youth Health Clinical Program, the terms of reference for a committee are shared with PLATFORM and the chair of the committee attends a PLATFORM meeting to discuss their expectations of participation. Young people can then express interest either directly to the youth participation coordinator or to the committee chair.

While committee membership of a clinician who has a current clinical role with the young person should not exclude the young person from participating, the involvement of the clinician should be discussed with the young person, and the involvement of the young person should be discussed with the clinician. The chair can offer to provide support to both the young person and the clinician to ensure that participation does not interfere with their clinical relationship.

The young person is expected to participate equally with other committee members in meetings, and the chair will need to work to make this possible. This will include supporting other committee members to reduce the use of jargon, to explain topics that rely heavily on inferred knowledge or training in a health discipline and to reduce reference to specific clinical incidents. The young person may require support from the chair in the form of specifically seeking their input and ensuring

that they verbally participate to the extent that other members do. Possible challenges to active participation include not having access to particular documents or not having regular email access. These challenges should be solved collaboratively.

Media, public speaking and advocacy

Young people may be motivated to share their stories to help the general public understand mental ill health and to reduce stigma, to help politicians and bureaucrats to understand resource shortfalls or opportunities and to promote help-seeking among young people. Service providers can work with young people to enrich any public speaking or media engagement opportunity.

Young people should be offered training for public speaking or media involvement. This training should cover general public speaking skills and some speaking skills specific to circumstance. Generic skills include planning, audience engagement and body language, and more specific skills include using one's own story to highlight key messages. At Orygen Youth Health Clinical Program, training incorporates supporting young people to identify boundaries around their stories in terms of what they will and won't share. As these boundaries may change over time, attention is also given to consent, particularly regarding media engagement and understanding how media products might be used. At Orygen Youth Health Clinical Program, the youth participation coordinator works in close partnership with the media and advocacy officer to deliver thorough training.

Young people should be reimbursed for participation in media and public speaking at a higher rate, in acknowledgement of the greater degree of skill required, and the vulnerability this type of participation poses. The Health Issues Centre has developed a position statement on paying and reimbursing for participation and nominates a payment schedule that outlines payments for specific roles of participation.²² For more information please see *Interim Position Statement: Paying and Reimbursing Consumers, Carers and Community Members to Participate* by the Health Issues Centre.

At Orygen Youth Health Clinical Program, requests for public speaking or media engagement go to the youth participation coordinator (see the 'Receiving requests for youth participation' section of this manual). The youth participation coordinator works closely with the young person and the individual making the request to 'brief' and prepare for the

opportunity. This might include supporting the young person to think more specifically about the parts of their story that they share and what they would like their key message to be. The youth participation coordinator may offer the young person an opportunity to rehearse, to ensure that the timing is manageable. Rehearsing is particularly important for a young person undertaking this activity for the first time, as it provides an opportunity to see how a young person will react and cope when asked certain questions. Following the media or speaking activity, the youth participation coordinator works with the young person to reflect on their experience and to identify what they would do differently in future opportunities. A follow-up face-to-face debrief with the young person a few days later is crucial, as the young person may not have sufficient time to process immediately following the activity and start to feel overwhelmed days after the activity. It is then the shared responsibility of the coordinator and the young person to make use of these reflections in future media and public-speaking opportunities. The youth participation coordinator also uses this opportunity to support the young person to make use of their wellness plan if required.

Giving consent

Young people will normally be very eager to participate in public speaking or media activities, especially during early recovery, as they are starting to feel better; however, they often don't fully understand the ramifications of giving consent for third-party organisations to interview or record them and use their photos or videos. The early psychosis service must explain to the young person that once they give consent for external organisations to use their images or recordings, these organisations can use the photo or footage whenever they need it and may use it for a variety of purposes, for a number of years. The youth participation coordinator should explain to the young person that in, say, 10 years time they may no longer want images of themselves out in the public domain or used in the context

of 'mental illness' any more, because they have moved on from that period of their lives. It is equally important that young people understand that the material produced may be seen by third parties such as content producers, printers and designers when they produce and publish these items.

It is strongly recommended that the service explains that whether or not a young person participates in an activity it will not affect their clinical care, and that they do not have to participate if they don't want to. The early psychosis service needs to carefully explain to the young person that if they do give consent, they may not be able to withdraw consent later on if they change their mind.

The early psychosis service should be aware of the timing of the participation and pay particular attention to where the young person is in their recovery and consider this when explaining the impact of giving consent and the potential positive or negative attention associated with it. For example, it should be explained that the young person's story might be skewed or misused by third parties and that this could be quite stressful and distressing. It is important for the service to be well prepared for how third-party interviews and recordings of young people take place. They should work with the young person to anticipate the questions that might be asked and to work out with the young person before an interview what subjects or experiences they don't want to talk about.

When families are asked to speak about their experiences, early psychosis services should encourage families to obtain consent from the young person before they consider being involved in a media or public speaking event. Box 7 highlights several crucial considerations when working with a young person with early psychosis in a media or public speaking event.

‘When I’m working with a young person who wants to share their experience of early psychosis via a media or public speaking activity, I make sure I spend a lot of time talking about boundaries for disclosure. We explore parts of their story that may be powerful, helpful and important to share, and we also explore parts of their story that may be too personal or may leave the young person feeling exposed or regretful for sharing.’

**– Youth Participation Coordinator,
Orygen Youth Health Clinical Program**

BOX 7 CRUCIAL CONSIDERATIONS WHEN A YOUNG PERSON WITH EARLY PSYCHOSIS IS INVOLVED IN MEDIA AND PUBLIC SPEAKING

- It is important to think about whether the skills required for the media or speaking event match the strengths and skills of the young person participating in the activity – public speaking and media events may be a stressful experience and often sit outside the limits of most of people’s comfort zones
- The youth participation coordinator must always allow sufficient time to brief and support the young person – this should be carefully planned to ensure that the young person understands their role
- The young person must always be supported to establish boundaries for their participation. There should be clear boundaries about what the young person wants to share with the audience, and the youth participation coordinator should carefully explain to the young person the potential ramifications of disclosure of their experience
- Develop clear strategies with the young person in the event that they become overwhelmed during a public speaking/media event
- Carefully revise the wellness plan (see page 46) before the young person is planning on participating in a media or public speaking event and go over their early warning signs as they can change or shift
- It is essential to allow sufficient time for a face-to-face debrief with the young person after the event and follow up with them again a few days later, as the young person may not have sufficient time to process immediately after the event
- It is very important to support the young person days following the activity

Focus groups

Focus groups are a type of qualitative data collection used in research and often used in areas such as market research. Focus groups provide opportunities to access a range of stakeholder opinions but also to access to information as it emerges more organically within the group dynamic. They may be a resource-efficient way to access a variety of opinions, to reach consensus on a topic or to attempt to understand quantitative data.

Focus groups within the youth participation program might be developed for a range of issues, including the initial development of a research question, solving service development issues or beginning to develop a resource. It may be the role of the youth participation coordinator to assist the individual requesting a focus group to consider how a focus group can be most effectively used. For example, adjunct data-gathering such as in-depth individual interviews and pen and paper questionnaires may assist a broader cross section of young people to participate. The incorporation of a range of activities into the focus group session itself may assist young people to meaningfully contribute. Activities that have been used at Orygen Youth Health Clinical Program include:

- turn-taking, Talking Stick or group round, to provide all participants with the opportunity to express their opinion
- using Post-It notes for individuals, to list ideas before whole-group discussion
- using card-sort activities to identify priorities
- using sticky dots to identify priorities or preferences.

‘Initially we ran focus groups with PLATFORM to inform several aspects of the design or development of the sites of our model of moderated online social therapy (MOST) interventions, and slowly we got to a process where every single new thing is checked by them. Although the innovation is through us because it is not fair to ask young people to innovate on your behalf, whenever we come up with something new we’ll run it by them and they give us ideas and new things that we can do. But certainly MOST was triggered by them. We never thought about integrating all these components in this way; we took it to the next level, but the original idea was theirs. It’s funny; people say “How did you think of MOST?” And I say “I actually didn’t.” We thought about it after we talked to PLATFORM and young people – they sort of gave us everything we needed to know for us to come up with it. Young people, once again, inspired us.’

Head, Online Interventions and Innovation,
Orygen

Resource development

Young people are constantly exposed to information and resources about mental health, wellbeing and services; these resources communicate important information including psychoeducation, available services, rights and treatment options. Where young people are the 'end-users' of resources developed, they have a key role in ensuring the relevance and useability of resource materials. Resource development might be youth-led, that is, young people identify the need for a new resource to support their own work, or that they would have benefited from. More commonly, perhaps, resource development is service-led, that is, representatives from the organisation meet with young people having already identified a need and with some ideas about how to meet that need.

Whether youth-led or service-led, a resource will be enhanced through the involvement of young people in:

- assessing the need for the identified resource
- identifying budget and other resources available for its development
- identifying the medium for content delivery (e.g. interactive website, factsheet, video)
- identifying relevant content
- reviewing language used to ensure youth-friendliness
- reviewing design to ensure the resource is engaging
- developing an implementation plan to ensure that the resource is used.

Awareness of available budget, media and time constraints from the outset ensures that young people's engagement can be meaningful, as they will understand the limitations of what is able to

be developed. It is also necessary to budget time for the youth participation coordinator to seek and collate young people's input; at Orygen Youth Health Clinical Program, this is done through PLATFORM meetings.

For service-driven consultations, the person or people developing the resource will attend a PLATFORM meeting, ideally at the very early stage of its development. This enables significant input as outlined above. The content developer, for example, a clinician, may attend several meetings to ensure that they have included relevant content in appropriate language. The resource developer, for example, a graphic designer of a factsheet, may also attend several meetings to consult regarding display and imagery. The youth participation coordinator works with the consulting professionals to ensure that feedback from young people is acknowledged and, where not all feedback has been adopted, to provide clear feedback to young people as to why.

The development of an assessment checklist might assist young people in providing the type of feedback that organisations are seeking. Additionally, young people may have a key role to play in implementing these resources; for example, peer support workers and other young people may ensure that resources are available across the different Orygen Youth Health Clinical Program sites, and may be involved in promoting the use of different resources by young people and training staff to use the specific resources. Two examples of resources developed in collaboration with young people for use by young people at Orygen Youth Health Clinical Program are presented in the following boxes. An example from Youthspace is presented over the page.

BOX 8 'WHAT'S NEXT?' GUIDE TO DISCHARGE FROM ORYGEN YOUTH HEALTH

The Orygen Youth Health Discharge Guide 'What's Next?' is a booklet developed by PLATFORM, young people and staff members to provide young people being discharged from the service with information about the discharge process. 'What's Next?' also provides young people with information about linking in with other services and stories from young people about moving on from the service. Young people identified the need to develop a guide via feedback in the 2010 and 2011 Satisfaction Surveys for young people to use when they were being discharged from Orygen Youth Health Clinical Program.

PLATFORM and staff members worked together to decide what kind of information would be helpful for young people nearing the end of their time with the service. PLATFORM helped write and design the discharge guide.

BOX 9 ORYGEN YOUTH HEALTH ONLINE 'CLIENT HUB'

The 'Client Hub' component of the Orygen Youth Health website was developed because young people expressed the need for electronically available information and resources about a range of service topics. These service-related topics include care teams at Orygen Youth Health Clinical Program, inpatient and outpatient care, what service programs are available for young people, information about accessing peer support and youth participation and resources such as complaints/feedback form, the discharge guide and psychoeducation factsheets. While these had previously been made available to young people as hardcopy information booklets, young people described a need to have flexible and timely access to this information 'on demand'.

Over a number of months, young people worked with professionals from across the service to identify the content they needed and to write the content in a youth-friendly manner. A web designer worked closely with the group to ensure engaging design and clear pathways to information. A youth representative continues to hold a position on the Website Working Group.

'The discharge guide is a great example of a project with tiered participation. Some young people only wanted to contribute to the design of the guide by choosing colours, fonts, layout and pictures, while others took part in focus groups to decide on the topics covered in the guide. Young people were also involved in writing and reviewing the content for the guide. Everyone had an opportunity to contribute their skills, experience and preferences, no matter how well or unwell they were at the time.'

Youth Participation Coordinator,
Orygen Youth Health Clinical Program

BOX 10 YOUTHSPEACE WEBSITE: YOUTHSPEACE.ME

The Youthspace website, youthspace.me, is a youth-led health promotion program supported by the Birmingham and Solihull Mental Health Trust. It is a forum for young people to learn and share some of the things they may not know how to talk about. youthspace.me was developed by the Youthboard, which guides Birmingham Youthspace in the development and design of resources for young people. The website has a blog section, a help and advice section that consists of factsheets and booklets and a video gallery for young people to access. The website provides young people with up-to-date information about mental health from clinicians and real-life experiences of mental health and emotional wellbeing in a comfortable, youth-friendly interface. For more information, please see www.youthspace.me

Interviews

At Orygen Youth Health Clinical Program, young people are able to participate in the staff selection process specifically through participation in job interviews. Involving young people in the selection of staff acknowledges that young people who have used the service have valuable experience and knowledge that can aid decisions about who is considered suitable to work at Orygen Youth Health. The inclusion of young people in staff selection aims to:

- communicate a clear message to potential employees that young people are partners in decision-making at Orygen Youth Health and that youth participation is a part of all levels of service development and delivery
- build a service that is responsive to the needs of young people, as young people have a key role in selecting the workforce at Orygen Youth Health
- acknowledge that young people have valuable experience, knowledge and skills and that Orygen Youth Health will provide opportunities for these to be used.

It is part of the Orygen Youth Health policy that young people who are involved in interviews will be valued as equal members of the panel and will be reimbursed for their participation in the interview process. An example of a poster advertising participation on an interview panel to young people at Orygen Youth Health can be found in Appendix 1. The process for involving a young person in the interview process is outlined in the table below.

It is important that young people who participate in the staff selection process are provided with adequate training and skill development. Training young people to participate in the process of interviewing and staff selection ensures that young people are well prepared for their role during the process. This training also ensures that young people are valued by other members of the panel in the process, as they are seen as skilled, experienced and bringing a valuable perspective to the process. The half-day training package is a mixture of interactive learning via role plays and theory. Topics covered during the training include:

- the purpose and process of the job interview
- preparing for your role on the interview panel
- understanding behavioural and hypothetical questions
- identifying what matters to you as a young person
- developing your own interview questions
- how to conduct yourself in an interview
- managing challenging situations in interviews
- matching applicants' answers against selection criteria
- making joint decisions with the panel about applicants' suitability
- privacy and confidentiality
- equal opportunity and discrimination legislation.

TABLE 1. PROCEDURE FOR INVOLVING A YOUNG PERSON IN AN INTERVIEW

1. Notify youth participation coordinator for a request of a young person for an interview panel when a position is advertised.
2. Youth participation coordinator selects a young person from a pool of trained young people who have previously received treatment from the service.
3. Young person is provided with the position description, selection criteria and resumes of applicants.
4. The chair of the interview panel meets with the young person to discuss the interview format and the role of the young person during the interview. During this time, the interview template is discussed and the young person formulates their own questions with the chair.
5. The young person is introduced to the interview panel before the interview.
6. Following the interview, the interview panel provides feedback to the youth participation coordinator about the young person's participation during the interview. The youth participation coordinator also seeks feedback from the young person about the interview experience.
7. The chair of the interview panel advises the young person of the outcome of the interviews (i.e. who they selected and why).

Training should be offered on a regular basis, allowing new team members the opportunity to be trained to participate. Whenever possible, previously trained young people who have participated in interview panels should guest facilitate training sessions to share their experience and perspectives on the interview process. Staff who have involved young people in staff selection or staff who have been interviewed by a young person should be encouraged to share their experiences within the organisation in order to promote the value of young people's involvement in staff selection.

The training schedule should be regularly reviewed by the youth participation coordinator and a human resources representative, with input from previous trainees, to ensure best practice in training young people to participate in staff selection. It is important to incorporate feedback and suggestions from previously trained young people in regards to how to improve training, as well as to align with changes to policies.

Young people who participate in staff selection may require support to participate meaningfully. It is the youth participation coordinator's role to:

- ensure that the young person has a current wellness plan (see page 46)
- ask the young person about additional support they may require to participate
- introduce the panel chair and the young person
- ensure that panel members have assigned adequate time to meet the young person prior to the interviews
- ensure that the young person has received all the resources and information they require (e.g. position description, resume and cover letters from shortlisted applicants)
- meet with the young person after the interview to seek feedback about their experience
- ensure that the young person is reimbursed for participation.

Additionally, young people that participate on interview panels will require support from the chair of the interview panel. It is the chair's role to:

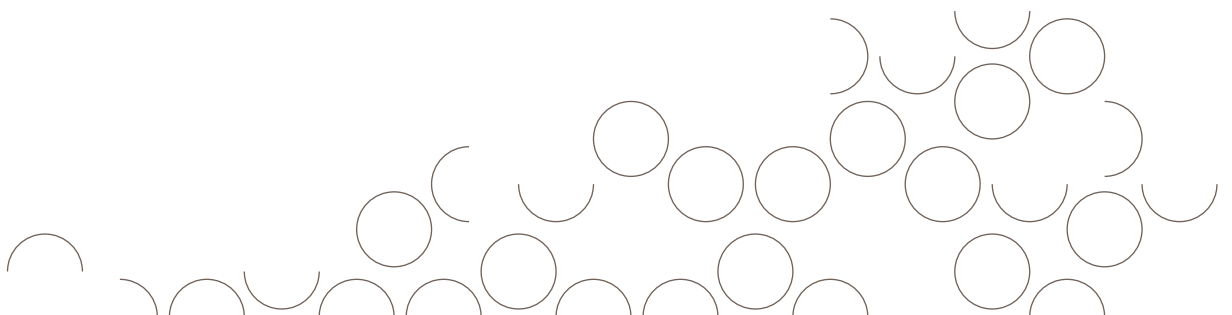
- meet with the young person before the interview to discuss plans and questions
- communicate details of the interview, such as date, time and location
- provide relevant resources (e.g. position description, resumes, interview templates etc.)
- ensure that the young person has an allocated part of the interview to ask their questions of the applicant
- ensure the young person feels included in the interview process
- include the young person in discussions about selection
- advise the young person of the outcome of the interviews.

Participation on an interview panel at Orygen Youth Health Clinical Program is limited to young people who have previously received treatment from the service who:

- have undergone interview panel training
- have no personal or professional relationship with the person being interviewed
- have an up-to-date wellness plan
- sign a NorthWestern Mental Health Confidentiality and Non-Disclosure Agreement.

Young people who are currently receiving treatment from the service are excluded from participation in order to avoid a situation where a job applicant becomes involved in the treatment and care of a young person who has interviewed them. Young people must be able to commit to:

- attending all interviews for the advertised position
- reading the position description, resumes and applications
- developing suitable questions from a young person's perspective
- advising of any conflict of interest
- having a current wellness plan.



‘We had a young person sit in on an interview panel while recruiting a case manager. This was a great experience, as the young person was able to bring a focus that otherwise was not a top priority for other panellists involved in the interview. The young person asked appropriate questions and contributed to the discussion about candidates in a mature and helpful way. The interview panel valued their input and would recommend involving a young person in future recruitment interviews.’

**Senior Project Manager,
Orygen Youth Health Clinical Program**

‘Involving a young person in the interview process can also be a helpful way to see how an applicant engages with a young person. It can say a lot about how a possible future clinician responds and speaks to a young person. I remember one interview where the applicant did not look at or speak to the young person at all; this seemed to be a tell-tale sign of how they viewed and treated young people.’

**Former Manager of YAT,
Orygen Youth Health Clinical Program**

Youth participation in research

Since 2002, the National Health and Medical Research Council (NHMRC) of Australia has had a clear statement prioritising the active participation of consumers, defined as patients or potential patients, carers or members of the public who are targets of health promotion programs, in healthcare research.²³ The Statement on Consumer and Community Participation in Health and Medical Research was developed with a vision of ‘consumers and researchers working in partnership based on understanding, respect and shared commitment to research that will improve the health of humankind’. The Statement on Participation recognises ‘the contribution that consumers can make to health and medical research and their right to do so.’ The majority of consumer participation in health and medical research

occurs in health services research, clinical research and multidisciplinary research. The main aims that guide consumer participation in research, as stated by the NHMRC, are collaboration, partnerships, role of the partnerships, information and resources for participation in research. Each of these aims is described briefly in Table 2. A model framework for consumer and community participation in health and medical research was developed in 2005 by the NHMRC based on the objectives of the statement of consumer and community participation. For details on the *Model Framework for Consumer and Community Participation in Health and Medical Research*,²⁴ please see www.nhmrc.gov.au.



TABLE 2. OBJECTIVES TO GUIDE CONSUMER PARTICIPATION IN RESEARCH²³

COLLABORATION
The community is better informed, recognises the value of research and has a greater understanding of the strategies of research
Individuals and communities have influence in research questions so that research remains relevant to the needs of the communities and contributes meaningfully to the improvement of health outcomes
PARTNERSHIPS
Partnerships should be sensitive to the purpose, personalities, expertise and environment in which they function
Partners have responsibilities and accountability to each other, to the organisation and the researcher's funding bodies
ROLE OF THE PARTNERSHIP
Partnerships will shape the research priorities, questions and design of research projects in a way that recognises the rights of everyone involved
The roles of research partnerships depend on level and type of research
Participatory processes recognise contributions from different view points
INFORMATION ABOUT RESEARCH
Partnerships will support the rights of research participants to their own results, be accountable for the research results, and encourage and facilitate dissemination of balanced information about the research results to the community
Partnerships should consider ways of making research results more accessible to the community other than solely publication in a scientific journal
RESOURCES FOR PARTICIPATION
Partnerships will advocate for the resources required for effective participation in health and medical research
Funding should cover the evaluation of the positive social and medical change as a result of participation

At Orygen Youth Health, young people's participation in research design and implementation is typically through the PLATFORM meetings. Participation ranges from consultative (e.g. checking the face validity or perceived importance of a particular research question) through to joint planning (e.g. developing the methodology for pursuing a particular research question).

The involvement of young people in healthcare research is seen to lead to research findings that are more relevant to young people's own interests and needs and to the development of interventions that are more acceptable to consumers. There is a belief that young people and researchers have much to gain through collaboration based on the expertise of researchers and the life experience of young people. The benefits of involving consumers in research include:²⁵

- an inclusive approach to design, conduct and interpretation of research and, consequently, relevant results
- an invaluable contribution to research questions and methodologies
- engagement that is different to traditional relationships
- increased credibility of researchers in the eyes of the population or community
- opportunities to increase recruitment of participants into research projects and reduce the number of study drop-outs.

There are a number of models of how young people can be involved in research, which vary in the extent to which they are youth or organisation-led. Young people can be involved in research in number of ways, including: a consulting capacity

(e.g. asking a group of young people about the perceived relevance of a given research question), advising capacity (e.g. seeking guidance from young people regarding their priorities), joint planning (e.g. developing an appropriate protocol for a research question), and a delegated role (e.g. joint analysis of data).

The potential benefits and challenges provided by youth participation in research are listed below (see Table 3).

TABLE 3. **BENEFITS AND CHALLENGES OF YOUTH PARTICIPATION IN RESEARCH**

BENEFITS
Improved feasibility and acceptability of research design
Improved recruitment of research participants
Increased consumer-friendliness of interventions and measures
Increased stakeholder commitment to research translation
CHALLENGES
Lack of interest from consumers
No shared understanding of 'purpose' of involvement
Youth participation may be time and resource intensive
Competing demands (on both researchers and consumers)

Three important aspects to consider when involving young people in research design:

- The role of young people in the development and implementation of research should be defined as early as possible in the research process.
- Training should be made available to support young people to fulfil the defined role and for researchers to support consumers in their role.
- Clear questions should guide young people's involvement at each stage of the research. For example, locally, the Young and Well CRC Brains Trust have a series of questions to guide their review of initial research grant applications.

'I have consulted with the PLATFORM team on at least three occasions and each time I have found the group to be an invaluable resource for the research projects in question. PLATFORM members provide unique and thoughtful perspectives that I could not have obtained elsewhere. The members of PLATFORM critiqued resources and concepts in a very practical way and were able to use their experiences in their feedback. Consulting a youth reference group is a critical step in research to ensure the successful implementation of the project. In some instances, unexpected feedback was received and it was fantastic to be able to tweak the protocol before the study had begun. For me, consulting with the PLATFORM team has been an essential part of designing and conducting research and I would highly recommend it.'

**Research Fellow,
Orygen**

“Youth participation has been one of the key elements of the moderated online social therapy (MOST) projects, which use information and communication technology in the treatment of mental health conditions. From when we first started thinking about developing online interventions for young people with early psychosis we were told to follow participatory design principles. So about five years ago, we started running focus groups with PLATFORM and other young people; the feedback from these focus groups informed many of the projects we are running at the moment.

Part of the feedback was that young people did not consider Facebook to be a good place to get support for emotional disorders, but that they still wanted to capitalise on social networking. They also wanted something more positive and optimistic that did not only focus on symptoms and negatively on their conditions. Over time, we ran more focus groups and came up with the MOST model. MOST is a new model of providing online interventions for first episode psychosis built by a multidisciplinary team of clinical psychologists, computer programmers, health informatics experts, web designers, graphic designers, artists and professional writers. The MOST model combines fully integrated online social networking with evidence-based interventions and external moderation. After two years running the project, we decided to have peer moderators with the online systems. We did a study with young people and 90 per cent of them said that they wanted to become peer support workers in the online platform. Following this, we developed a training program in collaboration with the PLATFORM team and the youth participation clinical experts in Orygen Youth Health Clinical Program and now we have eight young people as peer support workers and this has been the key in engaging young people online. ”

Head, Online Interventions and Innovation Research,
Orygen

Mental health promotion

Young people are important stakeholders in mental health promotion program design as the end-users of programs. Mental health promotion strategy programs may be enriched through the involvement of young people in their delivery. Mental health promotion has a wide range of objectives and at Orygen Youth Health Clinical Program young people are frequently consulted about the content and designs of specific programs. This type of consultation is mostly done with PLATFORM but, depending on the intended audience for the program, may involve other groups of young people, such as student representative councils in schools, youth consultants in migrant services or informal groups of young people such as drop-in services.

Involving young people in the design of mental health promotion programs should include:

- seeking their endorsement of a particular objective
- seeking their input into the design of a program to meet that objective, including the who, what, where and how
- seeking their thoughts about the roles for young people in the delivery of the program.

Where young people are directly involved in the delivery of mental health promotion programs, clear objectives should similarly be outlined and an evidence-based approach applied to their attainment. For example, it is understood that hearing about an individual's lived experience can reduce the stigmatising attitudes that people have towards individuals with a mental illness.^{26,27}

Avenues for young people's involvement in the delivery of mental health promotion programs should ideally be developed in consultation with young people themselves during the design stage. Young people are briefed about the overall objectives of the program, and as activities of the program are designed, young people are able to describe which roles should be held by young people. For example, at Orygen Youth Health, although young people identified that a school-based depression awareness and help-seeking promotion program, 'HeadSmart', should be provided by a mental health clinician, they also identified that students would benefit from hearing from 'lived experiences'. As a result, young people now dedicate time to being filmed talking about their experiences of mental illness so that students can hear a story of lived-experience that contextualises the information the clinician imparts.

Strategies for training and recruiting young people to a mental health promotion program largely depend on the strategy itself. Some of the specific mental health promotion strategies in which young people are engaged in at Orygen Youth Health can be found in the 'Media and public speaking' and the 'Peer support work' section of this manual. Training and support strategies should be developed in collaboration with young people to support young people involved in health promotion strategies. Another example of a youth-led health promotion program is the Youthspace website supported by the Birmingham and Solihull Mental Health Trust which is described briefly below. Youth Net is another youth-led health promotion described over the page.

BOX 11 YOUTHSPEACE/YOUTHBOARD PROJECT: THE MISUNDERSTANDING PROJECT

The Misunderstanding project was a collaborative project between Youthboard and BRAP, a local human rights charity (funded by Time to Change) that looked at the language used in the media and elsewhere to describe mental health. The project used film and tasks developed by members of Youthboard and other young people with little or no knowledge of mental health to increase the understanding of the language used in mental health. Youthboard and BRAP produced a film that explored the perceptions and opinions of people with limited knowledge of mental illness; this involved interviewing members of the public and finding out their attitudes towards mental health and interviewing people who had experienced mental health problems. Resources were developed that accompanied the film, and these were delivered to schools, youth groups and adult groups across Birmingham to encourage discussion around mental health and the experiences of young people. The film and resources are being used by Youthboard and BRAP to challenge the stigma and misunderstanding around mental health.

BOX 12 YOUTH NET/RÉSEAU ADO

Youth Net/Réseau ADO is a bilingual youth mental health promotion program by youth of the Mental Health Patient Service Unit at the Children's Hospital of Eastern Ontario. The program offers alternative support services for young people and aims to reduce the stigma associated with mental illness through prevention/intervention activities, education, research and advocacy. Youth Net/Réseau ADO has a strong emphasis on youth involvement and runs groups and youth initiatives throughout the year that allow young people to talk about mental health and offer ways of coping with stress through social interaction and creative expression.

Service quality improvement

Service providers often continue to operate in particular ways because that is how they always have done, and may not give much thought to improving the quality of the service. Young people who are using or who have used services are ideally positioned to help them understand where and how service provision may be improved. This may involve initial participation in service design when services are established or ongoing opportunities for young people to contribute to the service's continued improvement. The latter is perhaps most thorough when it occurs through multiple avenues, as it does at Orygen Youth Health.

These avenues are, in no order of priority:

- service-led consultations regarding new policy directives or new opportunities, occurring mainly through PLATFORM.

- youth-led consultations occurring as a result of concerns identified by PLATFORM members or through peer support work
- quarterly review of all formal feedback provided to the organisation
- annual implementation of a Consumer Experience of Care survey and follow-up of findings.

While the first two opportunities predominantly use the lived experience of PLATFORM, the latter two are ways that PLATFORM aims to ensure that they represent the experiences, views and values of the larger population of young people accessing the service. These two are described in more detail in the boxes below and the opposite page. The Youthboard project is also described on page 38.

BOX 13 FEEDBACK FROM YOUNG PEOPLE ACCESSING THE SERVICE

All mental health services are required to have formal mechanisms for users of the service to provide feedback and for that feedback to be responded to in an appropriate manner. Over a number of years, PLATFORM has been involved in the development of Orygen Youth Health's 'Speak Out' feedback system. This allows users to fill out either a hard copy or online feedback form, which is responded to by staff within a given timeframe. PLATFORM are working with the Orygen Youth Health Service Improvement Coordinator to develop quarterly reporting to PLATFORM, and PLATFORM supports the organisation to report back to all young people. PLATFORM members also identify common areas of feedback and aim to ensure that these areas become a part of their work.

BOX 14 EXPERIENCE OF CARE SURVEY

Many organisations are expected to regularly conduct an Experience of Care Survey. At Orygen Youth Health Clinical Program, this initiative is led by PLATFORM, which worked with coordinators of programs to identify areas in which feedback was sought and developed a comprehensive survey for young people. This survey is administered annually over a 2-week period. Surveys are made available in waiting rooms and interview rooms, and trained PLATFORM members and peer support workers can work with young people face-to-face or via the telephone to complete surveys; clinicians can also offer surveys directly to young people. Survey data is collated and reported back to the entire organisation. Specific program managers and staff may have ideas about how to respond and may do so independently or in consultation with PLATFORM. Furthermore, each year a day of planning that involves representatives from each team within the organisation is conducted to discuss the priorities highlighted in the survey with the PLATFORM members. This planning day aims to explore three priority areas in detail and to identify strategies to improve service quality in these areas. These strategies then form a part of the work plans for individuals and PLATFORM for the subsequent year. While feedback can be sought regarding a particular service improvement initiative, the contribution of youth participation towards improved service quality can be monitored through the Experience of Care Survey and trends in particular areas in which PLATFORM has been focusing their work.

Although PLATFORM is the typical site for service improvement consultations and work at Orygen Youth Health Clinical Program, there may be opportunities for particular individuals with interest and skills in an area to become involved as consultants to specific projects. If this type of participation is to be meaningful, project workers will want to consider:

- a clear position description outlining the skills sought and the skill development opportunity offered
- competitive recruitment
- skills training in particular areas
- a model of project work that embraces the youth consultant as a formal part of the project team
- accountability mechanisms that report back to PLATFORM and the larger body of young people using the service, and seek the input of these groups.

‘When I was doing an evaluation of the work done by YAT [Youth Access Team] as the manager, I found it helpful to talk to the young people from PLATFORM about their experiences with YAT services and get their suggestions on how we could improve our service. This led me to think about the different issues that needed addressing that I hadn’t thought about, like how clinicians answered the phone and how we could improve that.’

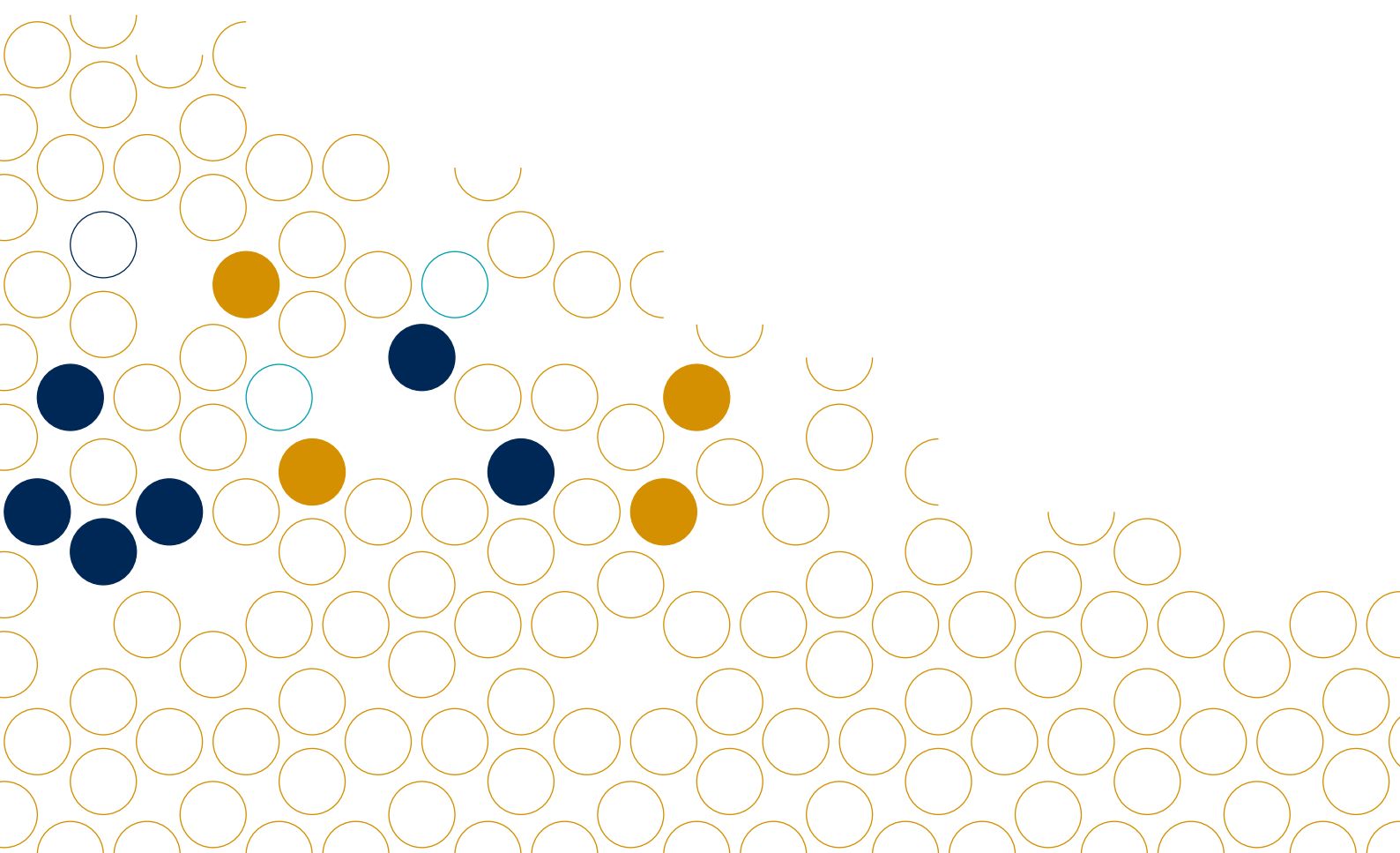
**Former manager of YAT,
Orygen Youth Health Clinical Program**

BOX 15 YOUTHBOARD PROJECT: JAPONICA WARD PROJECT

Youthboard was asked to be involved in the development of a new Birmingham and Solihull Mental Health NHS Foundation Trust inpatient ward for 16–17-year-old females. Youthboard was directly involved in the development of the recruitment program that would ensure that staff members underwent a thorough interview process and were able to relate well to young people. During the recruitment program, Youthboard organised a recruitment morning where members had an opportunity to talk to candidates in an informal setting. The recruitment morning also involved a collaborative care planning activity task with the candidate and a member from Youthboard in order to gauge how well the candidate worked with a young person. Interviews for clinical psychologist roles required candidates to complete a role play exercise that were observed by the interview panel that included a Youthboard member.

Youthboard was then asked to develop a 2-day training/induction program to introduce new staff members to Youthboard and promote youth participation in delivering services. During the induction program, Youthboard showcased their projects and worked with the staff members to design their ward welcomes board in addition to other tasks and activities that looked to help young people.

A digital tour of the new inpatient ward was then created by Youthboard which included a summary of different roles of staff member. Youthboard scripted, filmed and edited the tour of the ward and was presented by a young person who guides the viewer through the ward introducing the ward staff. A patient information booklet for the new ward was also created by Youthboard.



Training and education

Young people who have previously received treatment from Orygen Youth Health Clinical Program are invited to help develop and deliver the organisation's training and education to internal and external staff members. As with other participation activities, the degree to which this is youth-led or service-led varies, and participation can range from consultation regarding proposed training session topics and titles, through to content and the engagement of young people as guest speakers and co-trainers.

Blackhall and colleagues state that service users are considered to be experts in their own care and in this manner should be allowed to have input in service delivery, and that their influence in healthcare education can have a positive impact on attitudes towards mental ill health.²⁸ Research demonstrates that involvement of individuals receiving care from mental health services in the design, development and delivery of training for mental health professionals has a positive impact on work practices.²⁸⁻³¹

A preliminary study investigating service user involvement in mental health nurse education in the United Kingdom (UK) reported that this had a positive impact on attitude and empathy towards people with mental illness.²⁸ Another study from the UK evaluated the education development program for staff working within a mental health inpatient environment that had input from service users;³¹ service users were closely involved in the design, implementation, analysis and the education intervention element of the program. Authors of this study reported that the involvement of service users contributed to the overall success of the education program of the study, in particular, teaching sessions where service users gave personal examples of approaches used by healthcare staff were important as they highlighted the significance of being treated in a respectful manner and the impact this has on recovery.³¹

The overall objectives of involving young people in the development of content training are to:

- help trainees improve their understanding of the challenges faced by young people when accessing, navigating and engaging with services
- help trainees improve their knowledge of recovery-orientated practices by hearing from young people about what they find useful
- help trainees develop a better understanding of how to relate to, respect and value young people of the service as individuals
- challenge stigma around working with young people with a mental illness, especially in regards to particular diagnoses (e.g. borderline personality disorder or self-harming behaviours)
- deliver content that includes topics that are considered important by young people.

At Orygen Youth Health Clinical Program, staff members involved in training regularly attend the youth consultant team meetings to discuss upcoming training. The general outline of the topics, target audience, training content, session formats and proposed learning outcomes are discussed. Young people will be consulted regarding possible changes to training content and are provided with the opportunity to further develop the training content via feedback. Feedback regarding young people's own experiences may be sought through one-to-one meetings or by scheduling a focus group. The training team also outlines any opportunities for young people to attend training sessions as a guest speaker in order to contribute their perspectives as service users. Young people may also advocate for opportunities for their contributions to be made to workshops where trainers had not previously considered young people's involvement.

An example of the involvement of young people in the development and delivery of training at Orygen Youth Health is represented in Figure 1. The Youthspace e-learning project, as an example of involving young people in training, is described in Box 16 on page 43.

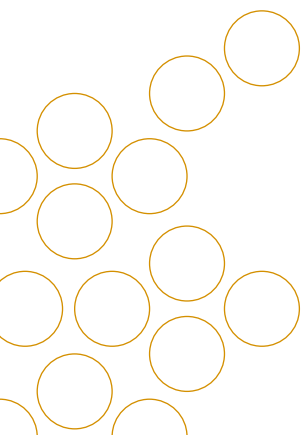


FIGURE 1. THE INVOLVEMENT OF YOUNG PEOPLE IN TRAINING AND EDUCATION AT ORYGEN YOUTH HEALTH



Young people who are interested in participating as guest speakers in training workshops are required to undertake public speaking and media training. Please see the 'Media, public speaking and advocacy' section of this manual for further information.

Young people participating as guest speakers at training workshops require support from the youth participation coordinator, the training team and training facilitators. The youth participation coordinator can help support young people by:

- maintaining strong relationships with the training team to support the engagement of young people in training workshops
- supporting young people to develop participation goals as guest speakers and at media and public speaking training
- ensuring that wellness plans are up-to-date
- assigning time to meet with young people who have participated as guest speakers to review their participation goals
- supporting further personal and professional development through identifying skill development opportunities for individuals or the whole team.

The training team and training facilitators can support young people by:

- attending meetings to brief young people about training plans and opportunities for involvement

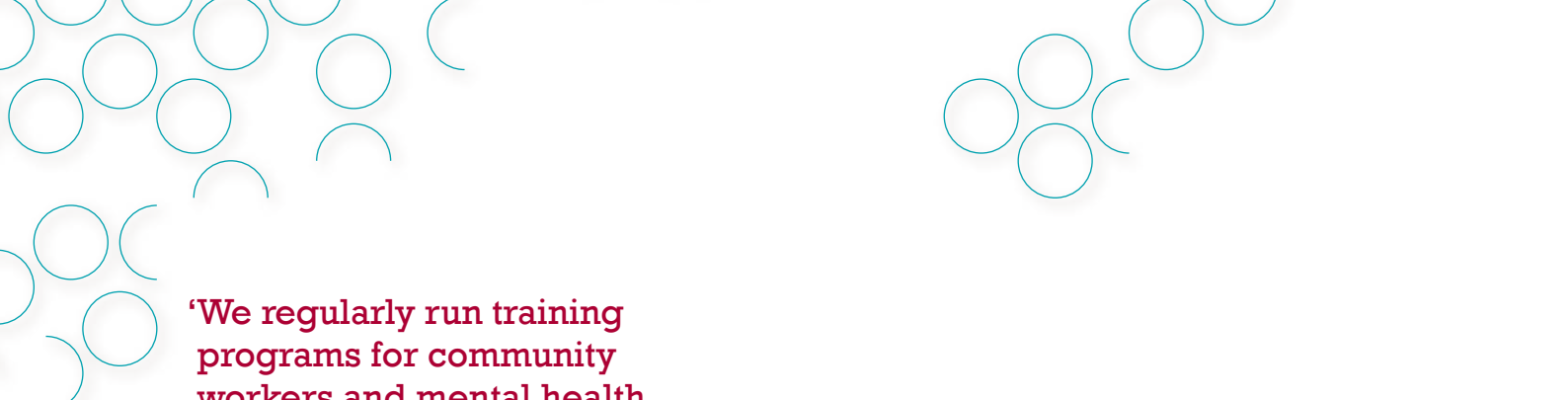
- providing clear briefs to young people about how they can contribute to the design, development and delivery of training
- assigning time for planning sessions with guest speakers prior to training
- seeking feedback from guest speakers about boundaries of disclosure
- providing support during guest speaking activity
- providing time for a debrief session after the guest speaking activity
- providing feedback to the guest speaker and the youth participation coordinator.

The lived experience of the young person wishing to participate as a guest speaker in a training workshop must fit the overall aim of the workshop. Young people will also need to:

- attend media and public speaking training
- commit to developing key messages, a narrative of their experience, and boundaries of disclosure; these should be discussed with the youth participation coordinator and/or training facilitator
- commit to attending training planning sessions
- have an up-to-date wellness plan
- meet the selection criteria for the training (e.g. someone who had been in an inpatient setting).

'It was pretty good to be involved in the training. It was a bit nerve-wracking, but I think it's really important to have someone with a lived experience to be there and have a say and put a face to the textbook accounts of what you should and shouldn't do [with young people] and the clinicians seemed to respond really well to that. I think a lot of health professionals already have that technical training but they may not have the experience or skills of just dealing with someone who is going through these sorts of things. I think there's a lot of empathy that can be gained from hearing someone's real-life story.'

PLATFORM member



'We regularly run training programs for community workers and mental health clinicians, and we involve young people who have previously used the service in all of these, in person, or on video if the training is held interstate. Having young people talk about their experiences, the challenges they faced, how they feel, and the stigma associated with a mental illness and the discrimination they have experienced is always highlighted by the participants as an important aspect of the training. We constantly have people say that hearing directly from young people allowed them to connect with the individual who has the disorder better than any amount of talking about it. We try to involve more than one young person so that participants can hear how experiences vary and get a better sense that all sorts of individuals experience mental illness.'

Senior Project Manager,
Orygen

'I remember one of the first trainings I attended in youth mental health many years ago was about the experience of psychosis. It was presented by early psychosis clinicians and young people who had a lived experience of early psychosis. I remember being blown away by the young people's ability to talk about their experiences and share what it was like for them. It brought to life the impact of early psychosis on a young person and emphasised the importance of maintaining hope when working towards recovery with a young person.'

Clinical specialist,
Orygen

BOX 16 YOUTHSPEACE E-LEARNING

The Youthspace e-learning project was supported by the Birmingham and Solihull Trust and involved young people from the Youthspace youth board working with mental health clinicians to develop e-learning modules that would give a basic introduction to youth mental health via the Youthspace website. The modules were developed around three core themes:

Awareness

This is a general overview of common mental health issues to assist individuals working young people to identify the early warning signs of an emerging mental health problem.

Engagement

This module was developed to help services improve their engagement of young people by focusing on the first experience or appointment with the service.

Assessment

This is aimed at mental health professionals to help with the mental health assessment.

Young people from youth board involved in the project were given the opportunity to develop skills in film production, leadership, team work, presentation and interview.

The role of the youth participation coordinator

Please note: this section is based on the role of the youth participation coordinator at Orygen Youth Health Clinical Program in Melbourne, Australia, which draws on the experience of working with young people with a history of mental health difficulties. This section details specific processes of the youth participation model at Orygen Youth Health Clinical Program.

Description of the youth participation coordinator role

The youth participation coordinator is responsible for the implementation and ongoing development of the youth participation program within the service. The role involves recruitment of young people, development of avenues for participation, development of supports for participation, and advocacy within the organisation for participation. The overall aim of the role is to involve young people in a respectful and meaningful way as partners in service development and improvement.

Young people experiencing a first episode of psychosis may require a high level of support to meaningfully engage in youth participation activities and it is important that a dedicated staff member be available to provide this support. The role

covers a broad portfolio, with many stakeholders within the organisation, spanning clinical services, research, training and communications, community development and senior management.

When establishing the youth participation coordinator role in an early psychosis service, it is important that the sole purpose of the role is the coordination of youth participation activities and not to provide clinical services in any capacity. Having a clinical service staff member act as a youth participation coordinator may deter the involvement and feedback of young people, as they may fear that expressing negative feedback will adversely impact their treatment and care.

When recruiting the youth participation coordinator, it is recommended that essential criteria include:

- a relevant tertiary qualification within the youth, social work or community sector
- experience in coordinating or working on youth/peer/consumer participation projects
- understanding of mental health issues and/or previous experience working with adolescents/young people with mental illness
- understanding of the barriers of participation faced by young people who use mental health services

- the ability to effectively engage young people to participate in a range of activities and consider their individual barriers, competencies and limitations.

Other criteria to be considered are:

- demonstrated experience planning and facilitating engagement activities using a range of modalities
- excellent interpersonal and communication skills (written and verbal)
- commitment to working collaboratively with an ability to work autonomously
- understanding of project development and management, including program planning and evaluation processes
- basic computer skills in terms of the use of a variety of software packages including Word, Excel, PowerPoint
- ability to independently develop and maintain record-keeping for accountability and evaluation.

It is essential that the youth participation coordinator undergoes orientation to the models of care provided in the service. It is important that the youth participation coordinator has a solid understanding of what early psychosis is, the treatment approach associated with early psychosis and the unique issues young people face when experiencing a first episode of psychosis. This knowledge provides insight into the experiences of young people, enabling the youth participation coordinator to better support their participation. It is recommended that the youth participation coordinator become a member of their State or Territory Youth Affairs Council.

Responsibilities of the youth participation coordinator

The key responsibilities of the youth participation coordinator are described here in detail. Briefly, they cover:

- running youth consultant group meetings
- managing requests for youth participation
- seeking opportunities for youth participation
- managing young people's wellness plans and participation goals
- selecting, training and supporting young people for youth participation.

Youth consultant group meetings

The youth participation coordinator plans and coordinates regular youth consultant team meetings in collaboration with young people and others in the service (see 'Youth consultant group meetings' on page 18 for more detail about the scope of these meetings). Although chaired and minuted by young people, it is an important aspect of the youth participation coordinator's role to ensure that the young people involved feel that they are able to freely express ideas and concerns and give feedback. The role should also facilitate young people's engagement and skill development, for example, by verbally contributing, taking the lead in a project, or liaising with other parts of the service. The youth participation coordinator also supports young people to work together as a team through the collaborative development of guidelines for participation in meetings, such as respecting each others' contributions, boundaries and privacy. The youth participation coordinator is responsible for facilitating the flow of information from young consultants to others in the organisation and from other parts of the organisation to the young consultants.

'PLATFORM meetings are held during business hours, so it can be difficult for young people to attend if they have work, school or other commitments. It's really important to be flexible and think about other ways to engage young people and provide alternatives for them to contribute. I often catch up with people one-on-one, or invite them to contribute feedback or ideas via email. Participants always receive meeting minutes and have opportunities to add items to the meeting agenda regardless of whether they are able to attend or not.'

Youth Participation Coordinator,
Orygen Youth Health Clinical Program

Managing requests for youth participation

The youth participation coordinator manages and responds to requests to engage the knowledge and experience of young people of the youth participation program both from within the organisation and from external parties.

The youth participation coordinator ensures that the participation of young people in consultations is meaningful, purposeful and respectful by working closely with individuals or organisations requesting the participation. To avoid tokenistic participation, it is the youth participation coordinator's responsibility to ask those making a request for youth participation to provide detailed information about what they expect or require. This includes:

- their reasons for wanting to involve young people – how they envisage young people's contributions will benefit or shape the project or initiative
- clear instructions about what the participation will involve – how will the young person participate? What is required of them?
- selection or exclusion criteria – does the project call for young people with specific skills or experience?
- support – what support will be offered to participants? This includes reimbursements and gratuities such as travel expenses and food

- feedback and results – when and how can the participants expect to hear about how their feedback or contributions impacted or shaped the project or initiative?

The youth participation coordinator also works closely with the individuals or organisation requesting youth participation to ensure that the 'pitch' to young people is appropriate. This may include the youth participation coordinator presenting the information/opportunity to young people on behalf of the requesting organisation, or supporting the requesters to attend youth consultant team meetings to talk to young people. This often requires the translation of technically-worded requests into youth-friendly information that motivates participation. The subsequent actions are described in more detail later in the section 'Recruiting young people for youth participation'.

Seeking opportunities for youth participation

The youth participation coordinator plays an important role in educating other staff about youth participation in order to create a culture where young people are included as partners in service change and development. For this reason, it is important for the youth participation coordinator to remain informed of service initiatives so they can advocate for young people to have a role in decision-making processes. Examples of ways to seek opportunities for youth consultation are listed in the box below.

BOX 17 EXAMPLES OF SEEKING OPPORTUNITIES FOR YOUTH PARTICIPATION

- Find out about any resources being developed for the service and request that young people review the content and design
- Ask that young people be asked for input into any changes to the design or decoration of the service, such as waiting rooms and interview rooms
- Request senior management to consider any roles for young people to be involved in helping to identify important items for inclusion in strategic planning
- Speak to researchers about involving young people in reviewing their research designs, for example, reviewing or collaborating in the development of recruitment strategies, measures, or consent forms to ensure youth-friendliness

Recruiting young people for youth participation

Young people are recruited to youth participation programs in a variety of ways. They may have been advised of their rights to participate by a clinician or a peer support worker, they may have sought advice about how to volunteer for the service, or they may have heard about a specific participation opportunity that reflects their interests. In addition to word of mouth, information about participation is available to all young people on advertising posters and brochures in waiting rooms, toilet door campaigns, the 'Client Hub' of the Orygen Youth Health website and in the 'Client Guide' made available to all young people using the service.

The youth participation coordinator at Orygen Youth Health Clinical Program takes primary responsibility for the recruitment of young people to participation activities. As staff referral to the youth participation program accounts for a large proportion of membership, the youth participation coordinator regularly informs clinical staff of current projects and opportunities for participation. Case managers can refer young people to discuss opportunities, or young people can contact the coordinator independently via phone or email.

The youth participation coordinator may make appointments with young people to discuss participation in terms of their hopes, interests and goals for participation, which also allows the youth participation coordinator to respond to any queries or concerns that they might have and provide them with details of specific opportunities. Reimbursement is also discussed at this point; while reimbursement is not intended as an incentive for participation, it is aimed at minimising potential barriers to participation.

Once 'general' recruitment has occurred, that is, a young person has expressed an interest in participating, they are typically engaged in PLATFORM youth consultant team meetings and then their recruitment to specific activities occurs through this forum, text message, email and phone call. Recruitment is based on interests outlined in the young person's participation goals (see below). The guidelines for selecting and supporting young people for involvement in a particular youth participation activity at Orygen Youth Health Clinical Program are presented on page 49.

Youth participation goals

When a young person expresses interest in taking part in the youth participation program, the youth participation coordinator will meet with them to discuss the ways in which they can become involved. During this time, in addition to developing a wellness plan (see below), participation goals are discussed and outlined. The participation goals form (Appendix 3) is used to ensure that the program is aware of the young person's training and mentoring needs so that they are supported to participate in the ways that they hope to. Participation goals forms are reviewed and updated every 6 months or earlier, depending on the young person. The revision of participation goals encourages the young person and the youth participation coordinator to think further about personal and professional development opportunities.

Managing wellness plans

Wellness plans are documents created by young people in collaboration with the youth participation coordinator to support their engagement in the youth participation program at Orygen Youth Health Clinical Program. Wellness plans are developed to acknowledge and manage the ways in which participation in the program might positively and negatively affect young people's wellness. These documents are used as a reference to support young people during their engagement in youth participation activities.

A young person's wellness plan is developed during a one-to-one discussion between the young person and the youth participation coordinator, with the aim of establishing a shared understanding of the young person's mental health, what the potential stressors are from participation, early warning signs of deterioration, self-help coping strategies and the young person's personal or professional supports. The wellness plan is complemented by the young person's participation goals – what they might hope to achieve from participation in the program. Wellness plans outline the following information:

- the young person's emergency contact details
- the individuals or services they are currently engaged with for support/care
- self-care strategies

- signs and symptoms that may indicate that the young person is unwell or becoming unwell
- an outline of any activities that the young person does not wish to engage in
- additional support the young person requires in order to participate.

Wellness plans are referred to by the young person and the youth participation coordinator prior to the young person engaging in any youth participation activities to familiarise themselves

with support strategies, signs that may indicate the young person is distressed or their wellness has fluctuated and any consultation guidelines or boundaries. Wellness plans are stored both electronically and as hard copies, with the same protocol that would be used for clinical information and Human Resources information. They are updated every 6 months by the young person and the youth participation coordinator. A sample of a wellness plan used at Orygen Youth Health Clinical Program can be found in Appendix 2.

‘Wellness plans aren’t just a tool to help me provide support to a young person. They’re like a guidebook on how we navigate participation together.’

**Youth Participation Coordinator,
Orygen Youth Health Clinical Program**

‘Wellness plans are an incredibly useful tool. They outline early warning signs and symptoms that I need to look out for and provide me with support strategies that the young person finds helpful. We also add extra information to the wellness plans over time as we further develop our relationship and work together. For example, I might make notes for myself if I notice that a young person responds well to a particular approach to supporting them during an activity or consultation. One young person and I have a “secret code” whereby if she feels overwhelmed during a consultation she takes a phone call and then excuses herself. I know this means she’s had enough and I will follow up with her and provide support. It’s a discreet way of her asserting her limitations and activating a support response from me without having to awkwardly pull me aside in a consultation and feel embarrassed. We try to include many different support approaches into wellness plans for young people.’

**Youth Participation Coordinator,
Orygen Youth Health Clinical Program**

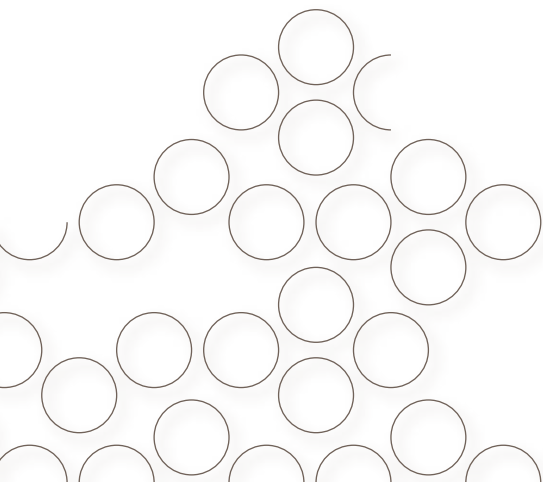
Training young people for youth participation

Young people are offered training for specific areas of participation to support both positive development and meaningful participation. Training supports skill acquisition among young people to enable meaningful participation alongside adult service providers and can enhance the credibility of the program of youth participation. It can also equip young people with skills that are transferable into other settings.

The youth participation coordinator is responsible for the development and delivery of training packages related to the specific activities of youth participation in the service. Training packages may be developed and delivered in collaboration with other internal or external staff to ensure the most relevant training content and delivery. Young people who are skilled in a particular area should also be engaged in the development and delivering of training. All training packages should be regularly reviewed when feedback from young people is received and participation opportunities change. Details of training packages associated with specific participation activities are outlined in the 'Training peer support workers' section on page 56.

'When young people participate in any kind of activity where they reflect upon and describe their experience of early psychosis, it's very important to provide adequate support before, during and after the consultation. In preparation for these kinds of activities, we spend time setting boundaries for disclosure, identifying key messages and talk about how it feels to revisit those experiences. During the consultation, I support young people to maintain their disclosure boundaries because it's easy to get caught up in the storytelling. I also help them to stay on topic and get their key messages across. I'm also look out for any indicators that they feel uncomfortable, confronted or have reached their limit for participating. After the consultation, I always commend young people on their contributions, describe what I thought they did really well, ask for feedback on how they think it went and provide support. I also tell them to go and do something indulgent or relaxing for themselves to reinforce the importance of self-care.'

Youth Participation Coordinator,
Orygen Youth Health Clinical Program



Guidelines for selecting and supporting young people in a youth participation activity

This section briefly describes some of the processes and guidelines at Orygen Youth Health Clinical Program for involving young people in a specific youth participation activity.

Recruiting and engaging young people in a youth participation activity

All consultation requests are made to the youth participation coordinator using the youth participation request form (Appendix 4) to capture details of the consultation such as date and time, type of activity and reimbursement. Young people who are members of PLATFORM and other young people who have expressed interest in a particular type of participation activity via their participation goals (Appendix 3) may be contacted to assess their interest. Details of the activity provided by the person making the request are required to allow young people to make informed decisions about whether they would like to participate. Specific participation selection criteria will be clearly outlined at this stage.

Selecting young people for a youth participation activity

A shortlist of young people interested in participation, based on the selection criteria should be created. At this stage the youth participation coordinator will ensure that each young person listed on the shortlist has undergone any training relevant for participation in the specific activity. It is also at this stage that the youth participation coordinator ensures that participants have a wellness plan in order to participate.

Wellness plans and support

The youth participation coordinator will meet individually with young people to revisit or create a wellness plan (Appendix 2) before the youth consultation or activity. This stage is an opportunity for young people to remind themselves of agreed-upon support strategies and boundaries that they hope to maintain for themselves. Emergency contact details may need to be updated. During this time, the youth participation coordinator may talk with the young person about informing their case manager about the activity. The young person may discuss the activity with their case manager, and the impact that it may have on their recovery. If at this time the young person decides that they are unable to participate, the youth participation coordinator should work with them to ensure that they feel adequately supported and skilled to participate in future activities.

Briefing the organiser seeking youth participation

The following administration tasks should be carried out before the activity:

- Confirm the length of the activity with the organiser
- Confirm the reimbursement rate with the organiser
- Provide the organiser with details of:
 - Name and contact details of participating young people
 - Relevant background information on participating young people
 - Boundary information regarding topics young people do not wish to talk about or information they do not wish to share
 - Emergency contact numbers for support

Ensure that the young person is still comfortable participating in the activity immediately before the activity. The details of the activity are discussed again, to ensure that the young person is clear about what is required of them. The details of travel plans, meeting times, venues, organiser contact numbers are also discussed before the youth participation activity. The youth participation coordinator (or another staff member accompanying the young person in the event that the youth participation coordinator is unable to) will take a copy of the wellness plan of the young person, along with any notes about participation goals and boundaries.

Support during the youth participation activity

Introduce the young people to the organisers of the activity and any staff or individuals taking part in the activity. Young people may benefit from advocacy to reduce barriers to participation and to enhance the likelihood of participation being a positive experience. For example, supporting staff may wish to intervene if topics or questioning breach the boundaries identified by the young people beforehand. Breaks can also be used to check-in with the young people to ensure that they are comfortable with the activity, and to identify any changes to support required. Information from wellness plans can be used to support young people to self-care.

Post-participation debriefing

It is important to meet with young people immediately after the youth participation activity for young people to discuss their experience of the participation activity, to provide feedback in terms of improvement and changes for activities, and to determine how the activity may have impacted upon their wellness. The youth participation coordinator can enquire about the self-care strategies that young people may use following the activity/consultation and remind them to refer to their individual wellness plans. If a young person is distressed by a participation activity, this should lead to a review of participation goals and may lead to changes in both goals and the wellness plan.

Responding to an incident

If a young person appears to be experiencing distress during a youth participation activity the situation should be assessed and the appropriate response or support should be provided.

- a. No emergency response required: action wellness plan


The young person should be provided with a confidential space to talk about what is happening to them. The young person's wellness plan should be referred to and the young person supported to use identified coping strategies. If something has happened to upset the young person during the consultation/activity, ensure that a resolution is reached or followed up as soon as possible and the outcome communicated to the young person. If the young person is no longer receiving care from the service encourage them to contact their care provider or ask permission to give their nominated care provider a call in order to organise an appointment. Ensure that the young person is able to get home safely and enquire about their self-care strategies and support networks or resources once they are at home.

- b. Emergency response required

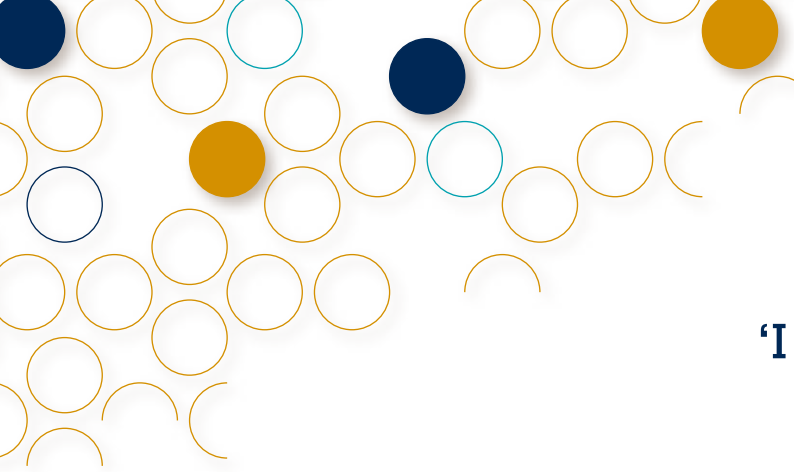
If the young person is very distressed or if you, the young person and other staff members are at risk of harm, the youth participation coordinator may action an emergency response per the organisation's protocol. While the youth participation coordinator is not in a clinical role, and while emergency response is extremely uncommon, it is important for the youth participation coordinator to be aware of the clinical response to feel confident should an emergency arise.

Record keeping

It is important to keep records of young people participating in activities or consultations. The type of participation, reimbursements and how young people are involved form an important component of the evaluation of the youth participation program.

The background is a solid yellow color with a subtle, organic texture. Scattered across the top and right sides are several thin, dark grey circles of varying sizes. A large, dark blue speech bubble shape is positioned in the lower-left quadrant, containing the title text.

**Peer Support
in Early
Psychosis**



‘I remember how scared and alone I felt when I was unwell, so I know that providing some peer support as one young person to another does make a difference.’

Peer support worker,
Orygen Youth Health
Clinical Program

Peer support in early psychosis

Overview

Peer support is considered an important part of youth participation. Communicating the lived experience of a young person who has had a first episode of psychosis helps other young people and families receiving treatment and care from a youth mental health service by providing a validated and unique level of understanding. A peer support program allows young people to use their experience of treatment, care, diagnosis, common challenges and recovery to provide a message of hope to other young people and their families.

What is peer support?

Peer support is defined by Mead (2003) as ‘a system of giving and receiving help founded on key principles of respect, shared responsibility, and mutual agreement of what is helpful’.³² Peer support workers are young people who have previously received care from the Orygen Youth Health Clinical Program service and provide support to young people who are currently using the service. The peer support program is a valuable component of Orygen Youth Health Clinical Program and is run by young people who have been specifically trained. The program is offered alongside clinical care to enrich young people’s experience of using the service. The main objectives of the program are to:

- support young people to be hopeful about recovery
- support young people’s engagement in treatment and recovery
- support young people to understand their rights as service users
- provide young people with the opportunity for supportive, positive, recovery-focused social interaction with a peer
- provide access to psychoeducation and information and resources on wellbeing.

At Orygen Youth Health Clinical Program, peer support services are offered to young people in both inpatient/acute and outpatient/recovery programs.

Why provide peer support?

Peer support recognises that individuals with a lived experience of ill mental health can provide valuable support to those trying to deal with similar issues. In 2011, Victoria’s Centre of Excellence in Peer Support launched its ‘Charter of Peer Support’, which was developed in collaboration with seven state-wide specialised peer support organisations of Victoria, Australia, collectively known as the Mutual Support and Self Help Consortium.³³ The core value of the charter is that ‘peer support is intrinsic to mental health and total wellbeing’.³³

A summary of the charter's statements are presented in the box below. For further information on the charter, please see the Centre of Excellence in Peer Support at: www.peersupportvic.org.

BOX 18 CHARTER OF PEER SUPPORT STATEMENTS³³

The Centre of Excellence in Peer Support's 'Charter of Peer Support' states that 'every person living with or experiencing a mental health issue has the right to access avenues to share their lived experience in a confidential, safe environment, where they are heard, respected, honoured and understood.'

Peer support provides each person with:

- opportunities to benefit from collective wisdom
- opportunities to understand and destigmatise mental health issues
- a renewed sense of self respect, understanding and belonging by being part of a caring community
- opportunities for people to rediscover and activate their personal resources
- opportunities to receive hope, inspiration and empowerment for recovery
- opportunities to give help to others, as equal-to-equal
- a pathway to help that is non-threatening, affordable, either complementary to existing clinical services or stand alone and open to freedom of participation without waiting lists or limitations on visits.

The peer support program at Orygen Youth Health Clinical Program was developed in response to feedback from young people at the service that said they found value in speaking to each other about their experiences and how this made them feel hopeful about recovery.

Research has demonstrated that people who have access to peer support experience:

- increased awareness of the service³⁴
- increased likelihood of linking to services they require³⁵
- increased independent and empowerment³⁶
- reduced stigma³⁷
- improved functioning.³⁷⁻³⁹

A review of peer support in professionally-led mental health services concluded that peer support workers promote hope and belief in recovery, increase self-esteem, self-efficacy and self-management of difficulties, and improve social inclusion, empowerment, engagement and social networks more successfully when compared with professional qualified staff.⁴⁰

'I didn't believe I could get better. I felt like I had no chance. After I met a peer support worker who went through the same stuff as me and got better, I started to believe that maybe it was possible for me too.'

Young person talking about peer support, Orygen Youth Health Clinical Program

'A peer support worker literally saved my life. I wanted to die and she got me to change my mind by reminding me that there are people to help me, and that she'd felt this way too but you can get through it.'

Young person talking about peer support, Orygen

How to provide peer support in an early psychosis service

The peer support program at Orygen Youth Health Clinical Program now offers a number of peer support services, including:

- regular peer support at the inpatient facility
- referral-based one-to-one peer support between a young person and a peer support worker, either face-to-face or via the telephone
- group information sessions such as orientation and discharge from the service led by peer support workers.

These services are described in more detail in Box 19.

Young people access the peer support program for a number of reasons, usually because they wish to connect with a peer they can relate to in terms of mental health issues and recovery. Topics frequently discussed are:

- medication and other treatments
- friendships and relationships
- coping strategies
- discharge from the service
- family relationships
- alcohol and other drugs
- returning to, or maintaining, work or study
- activities outside the service
- youth participation program
- complaints/feedback process.

‘I feel very fulfilled when I leave my peer support shifts. I feel like I have made a difference to people who are going through a very difficult time.’

Peer Support Worker,
Orygen Youth Health Clinical Program

‘I think the peer support program has really helped show clinicians the value of youth participation. It’s pretty clear to a clinician that having a young person on the inpatient unit who has been through the service and is doing well come to talk to young people who are coming into the inpatient unit for the first time is valuable. It’s obvious that it’s an enormous support, and people understand its impact on the service.’

Program Manager,
Orygen Youth Health Clinical Program

BOX 19 PEER SUPPORT SERVICES**Inpatient peer support**

- Peer support workers provide opportunities for social connection and informal support to young people during their admission to the service
 - Engage in activities such as board games, sports, crafts, music and cooking with young people
- Peer support workers work closely with the allied health team at the inpatient unit to engage and support young people
 - Reduce boredom, disorientation and trauma sometimes experienced by young people admitted to inpatient care
 - Help with transition from inpatient to outpatient care through introduction to the outpatient facility

One-to-one peer support

- Young people, case managers or doctors on their behalf, are able to book one-to-one appointments with a peer support worker to talk about a range of topics
- Peer support workers and young people with similar experiences are matched to ensure they can relate to each other
- The session is organised at a time that is convenient for both the young person and the peer support worker; young people are able to arrange follow-up sessions if they would like further support from a peer support worker

Peer support group information sessions

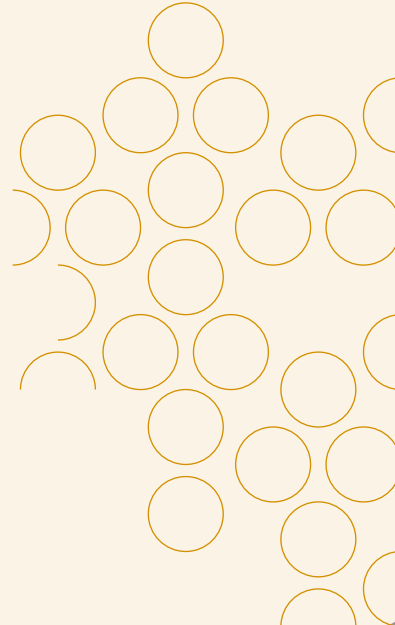
- Peer support workers regularly lead open group discussions that are open to all young people currently receiving treatment from the service
- Two sessions are offered:
 - Orientation to Orygen Youth Health
 - For young people new to the service or young people who may benefit from hearing more about what is on offer
 - Session provides information about case managers and doctors, crisis teams, inpatient units, group program, youth participation and a tour of the service
 - What's Next — Discharge from Orygen Youth Health Clinical Program
 - For young people who are nearing the end of their time with the service
 - Session provides information on the discharge process, community group options, follow-up services, self care, continued recovery, vocational and educational options, and youth participation

BOX 20 BASIC SKILLS AND KNOWLEDGE COVERED IN PEER SUPPORT TRAINING

- The theory behind peer support
- Peer support in the context of the organisation
- Exploring recovery
- Using your story and experience
- Interpersonal skills for providing peer support
- Symptoms of mental disorders
- Confidentiality and duty of care
- Boundaries
- Advocacy
- Self-care
- Support and incident management

Additional Training Topics

- Understanding the purpose of inpatient care
- Engaging with acutely unwell young people
- Understanding the use of intensive care areas
- Hospital emergency procedures



Training peer support workers

Young people who wish to become peer support workers undergo a comprehensive training program to equip them with the appropriate skills and knowledge to understand the principles behind peer support work. The training package at Orygen Youth Health Clinical Program has been developed over 6 years in collaboration with staff, young people and peer support workers and is facilitated by the youth participation coordinator, a supervising clinician from the service and an experienced peer support worker. The package incorporates PowerPoint presentations and workbook tasks, didactic content, experiential learning (e.g. games, role plays), individual reflection and group discussion.

Peer support training encompasses a range of skills and knowledge, presented in the box above.

Peer support training focuses heavily on equipping peer support workers with skills to provide recovery-orientated support. Peer support trainees are encouraged to consider how their experiences can contribute to a young person's sense of hope for recovery, recovery goals and recovery tools; self-care is also strongly emphasised during training. The training package highlights the importance of developing self-care strategies and support networks, recognising early warning signs and taking time out from providing peer support during periods of fluctuations in wellness. Training is offered twice a year and dates are scheduled in advance.

‘The training we provide our peer support workers not only provides them with the skills and knowledge to provide support to others but also helps them think about how they’re going to continue to care for themselves. The peer support workers learn a range of practical skills while exploring their own recovery journey.

It’s really great to watch young people transform from being attached to the service into taking on a role where they’re providing support to other young people and feeling incredibly empowered. My favourite part of training is taking the new peer support workers back to the hospital for orientation and watching them hold heads up as if to say, “Look at me now, see how far I’ve come”.’

**Youth Participation Coordinator,
Orygen Youth Health Clinical Program**

Supporting peer support workers

An important aspect of peer support program is providing support to peer support workers. All peer support workers are required to attend monthly group supervision. This supervision is provided by an outpatient clinician, who works closely with the peer support team and the youth participation program, and an allied health staff member from the inpatient unit who supervises the peer support workers during their visits. It is important that supervisors are not only skilled clinicians but also people who value and understand peer support. Supervision is an opportunity for peer support workers to reflect on their role, discuss how the team functions, debrief, discuss difficulties and share strategies. This is also an opportunity to explore the interface between peer support and

other programs at Orygen Youth Health Clinical Program, discuss the direction of the peer support program and identify training needs. Peer support workers are encouraged to contact specifically nominated staff members from the youth participation program at both the inpatient and outpatient facilities. Access to formal debriefing from specialised clinical staff members as a result of a critical incident is also available to peer support workers. All peer support workers are required to develop and maintain a wellness plan with the youth participation coordinator.

Resources

The peer support program is significantly resourced by paid staff members. The youth participation coordinator and peer support program officer are primarily responsible for the daily operation of the program. In addition, two clinical staff members provide supervision to the peer support workers, one of whom also facilitates the training of the peer support team, and other staff members volunteer their time for peer support worker interviews. Staff members nominated at both the inpatient and outpatient facilities are required to provide *ad hoc* support to the peer support program by assisting with the interviews of the peer support applicants and are available for emergency support in absence of program staff.

Along with training as described above, marketing materials used to recruit young people to the peer support program are also required. Templates for the collection of evaluation data as well as rosters for peer support shifts, attendance records and reimbursement records are also required to monitor and evaluate – and therefore resource – the peer support program.

Eligibility

To apply to become a peer support worker at Orygen Youth Health Clinical Program, young people are required to meet the following eligibility criteria:

- Applicants must be discharged from the service for a minimum of 4 weeks and maximum of 4 years at the time of interviewing for the role.
- Applicants are required to submit an application and eligibility criteria form to be considered for an interview.
- Applicants must attend an interview in order to assess their suitability to the role.
- Successful applicants are required to complete the full training package in order to commence in a peer support role.

- Applicants must:
 - consider their current state of wellness and anticipate that joining the peer support program will not adversely affect their own wellness at this stage of their recovery
 - agree to act as a role model for other young people accessing the service, and uphold the recovery and wellbeing principles of the program
 - be reliable to attend the peer support sessions they have nominated/are rostered on to complete and must agree to follow the process for advising staff and colleagues if they cannot attend.
- Applicants should understand that:
 - peer support workers are recruited as reimbursed volunteers, and should understand that they are not employed by the organisation
 - peer support shifts are not regular or guaranteed
 - the peer support program is not a social group or an avenue to seek support
 - if a peer support worker becomes less well they must request time out from the program, and/or they will be instructed to take time out from the program
 - if a peer support worker becomes unwell during their time in the role and wishes to return to peer support, they are required to take a 3 month break from re-joining the program in order to focus on their own recovery; re-entry into the program is at the youth participation coordinator and clinical supervisor's discretion
 - peer support workers are required to hold/apply for a Working With Children check
 - peer support workers must also agree to develop and maintain a wellness plan with the youth participation coordinator.

Recruitment

The recruitment of young people to become peer support workers at Orygen Youth Health involves a marketing campaign that takes place twice a year. The campaign targets young people who are nearing discharge from the service. The peer support program recruits, interviews and trains potential peer support workers in February and September; however, applications are open all year in order to build a pool of potential candidates. The recruitment campaigns include advertising

materials uploaded to the website and placed in waiting rooms or areas frequently used by young people of the service. An example of a poster used for the peer support program at Orygen Youth Health Clinical Program is included in Appendix 5.

Case managers are encouraged to advise young people interested in becoming peer support workers of the interview and training dates during the recruitment campaign and throughout the year. Current peer support workers encourage other young people interested to apply or work towards becoming a peer support worker by meeting with young people to discuss the peer support role. The youth participation coordinator and the peer support project officer contact young people who have expressed interest in the peer support program.

'I remember how scared and alone I felt when I was unwell, so I know that providing some peer support as one young person to another does make a difference.'

**Peer support worker,
Orygen Youth Health Clinical Program**

Application and interview process

The application process involves young people filling out an application and eligibility form, and submitting the form to the youth participation coordinator to review. The interview process involves a panel format with three staff members: the youth participation coordinator, the peer support project officer and a case manager/clinical staff member. Peer support worker candidates are asked a range of questions in order to assess their suitability, understanding of the role and ability to manage their own wellness while supporting young people. A case manager or clinical staff member is there to observe the candidate's current state of wellness. There is a high turnover of peer support workers due to the nature of the work and competing demands of young people's lives, therefore there is no restriction on the number of successful candidates progressing through from interviews to training.

Peer support program evaluation

The peer support program collects evaluation data about the peer support services at Orygen Youth Health Clinical Program. The data collected about the peer support program identifies how the peer support services are being used and helps the service identify opportunities for improvement and expansion of the program. Additionally, the data helps identify training opportunities for peer support workers. Evaluation data collected from peer support workers after they have completed a session with a young person provides information about:

- how many young people have engaged with the peer support worker
- how many first contacts they have made (i.e. with young people new to the peer support program)

- the primary focus of the support, such as sharing personal experiences, provide advocacy, provide resources, fun activities
- the primary reason for the support, such as emotional support, reduce stigma, support discharge etc.
- where the support took place (e.g. inpatient or outpatient settings).

Considering the strong emphasis on using technology to support the health and wellbeing of young people, we anticipate that there will be a growing demand for online peer support services in the future. At the time of writing this manual, a pilot of online peer support is underway.

Peer support in an early psychosis service can support young people and facilitate a message of optimism for recovery. It does this by allowing young people to access peers with lived experience not only of service use but also of psychosis and the common challenges it presents.

The background is a textured, light grey surface. A large, dark blue speech bubble shape is positioned on the left side, containing the text. To the right of the speech bubble, there are several orange-outlined circles of varying sizes, some overlapping. The overall design is clean and modern.

Evaluation and Future Research



Evaluating youth participation

Youth participation programs, like many complex programs in healthcare, are challenging to evaluate rigorously. Evaluation at the local level is dependent on the overall identified objectives of the youth participation program. In other words, a youth participation approach that focuses on youth development principles may assess how individual young people experienced benefits through their own participation, whereas a youth participation program that focuses on quality improvement may examine the extent of service quality improvement in particular areas.

Formative and process evaluation may be two useful forms of evaluation to assess the success of youth participation activities of a youth participation program in an early psychosis service. Formative evaluation incorporates needs assessment and response planning, and may be a useful way to help design a youth participation program. This form of evaluation aims to identify appropriate elements of a program to meet the overall objectives of the participation program. Formative evaluation approaches are engaging, accessible and can be meaningfully used with young people. 'Problem and solution trees' or 'fishbone analysis' are examples of formative evaluation.

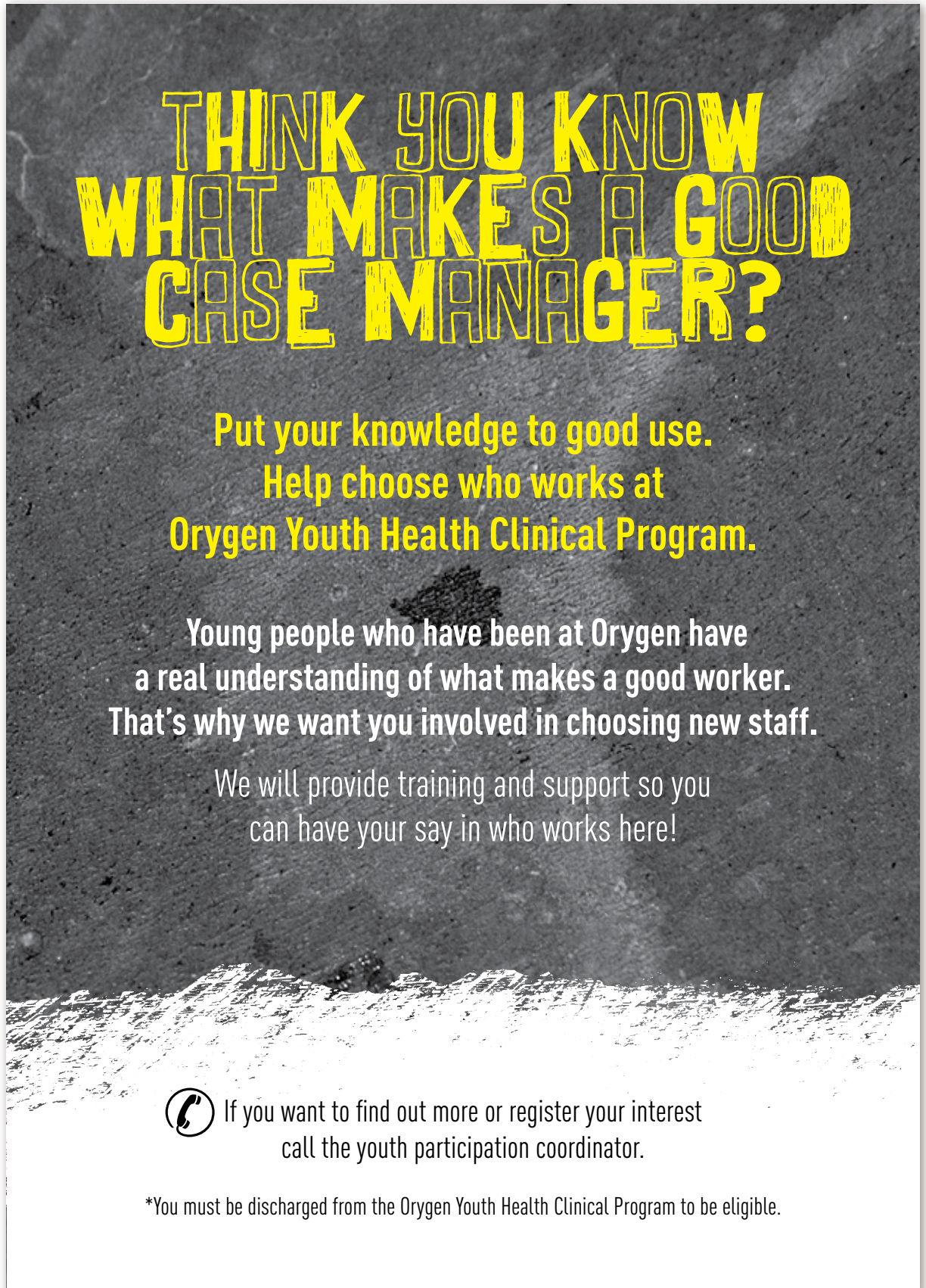
Process evaluation examines the fidelity of a program to its model and determines whether a program is being implemented with a high or low level of fidelity. Examples of process evaluation are key performance indicators and service quality indicators. The use of indicators assumes that the attainment of the indicator will lead to a good outcome. Indicators are often a feasible approach to evaluation but often fail to take into account the complexity of the system that it is evaluating and do not offer suggestions for enhancing service quality.

Another type of evaluation is outcome evaluation, which investigates whether a particular program is meeting its identified objectives. Common outcome evaluation approaches include quasi-experimental pre-post quantitative methods, stakeholder consultation qualitative method and monitoring. The youth participation program at Orygen Youth Health Clinical Program monitors the degree of satisfaction across a range of identified domains to continually assess the outcomes of participation of the program. Youth participation programs can often become too multidimensional to effectively evaluate as a whole. A more practical approach to outcome evaluation may be examining youth participation activity and their objectives individually. Examples include: examining the difference in experiences of young people who had contact with a peer support worker on the inpatient unit, and those who did not; comparing schools who had a young person co-deliver a mental health promotion program with those who did not; or evaluating the degree to which staff are aware of the organisation's commitment to youth participation and are committed themselves to young people's participation in their own care, dependent on the involvement (or not) of a young person on their initial interview panel.

Irrespective of the evaluation approach chosen, young people themselves should be involved in the development of intervention approaches, may be involved directly in data collection and are crucially involved in data analysis. Youth participation approaches will continue to broaden their focus and to improve in their quality if we systematically evaluate them, and systematically engage young people as evaluators.



Appendices


Appendix 1: A poster advertising youth participation in staff interviews

**THINK YOU KNOW
WHAT MAKES A GOOD
CASE MANAGER?**

**Put your knowledge to good use.
Help choose who works at
Orygen Youth Health Clinical Program.**

Young people who have been at Orygen have
a real understanding of what makes a good worker.
That's why we want you involved in choosing new staff.

We will provide training and support so you
can have your say in who works here!

 If you want to find out more or register your interest
call the youth participation coordinator.

*You must be discharged from the Orygen Youth Health Clinical Program to be eligible.



Appendix 2: A sample of a wellness plan

I'm joining the youth participation team as a (please tick one):

Platform team member Peer support worker

I'm a (please tick one):

Current young person of Orygen Youth Health Clinical Program A past young person of Orygen Youth Health Clinical Program and I was discharged

PERSONAL DETAILS

Name: _____

Address: _____

Contact phone numbers: _____

Email address: _____

EMERGENCY CONTACT DETAILS

Who should we contact in case of an emergency?

Name: _____

Relationship to you: _____

Phone numbers: _____

YOUR SUPPORTS

We may need to contact your Orygen Youth Health case manager or doctor when we are very worried about you. We will always ask your permission before we contact them. If you are not a young person currently receiving care from Orygen Youth Health, we will not contact your care provider but will use the information listed below to prompt you to speak to them.

Name of Orygen case manager: _____

Name of doctor: _____

Name of other healthcare provider: _____

Other services you are currently accessing: _____

Who would you contact if you need some support? _____

LOOKING AFTER YOURSELF

List the activities, tools or resources you use to help you to relax and distress.
For example, yoga, hobbies, socialising, dancing or playing sports.

List things you have done in the past that have helped when you weren't feeling well or were in a crisis.
For example, talking to a friend or family members, using a helpline or using strategies suggested by your case manager or doctor.

HOW WE CAN SUPPORT YOU

What are the signs and symptoms you, or someone else, would notice when you are becoming unwell?

Can you think of any activities that may make you uncomfortable, stressed or may trigger your symptoms of becoming unwell? For example, talking about self-harm or visiting the inpatient unit.

Do you require addition support to assist you to participate in the PLATFORM or peer support team?

The youth participation workers are here to support you to be part of the PLATFORM or peer support team. It is important that you remember to look yourself as your wellness is our number one priority and should be your number one priority.

A person's wellness can impact their ability to participate the PLATFORM or peer support team. This may mean that sometimes you may need to ask to take a break from participating or the youth participation workers may ask you to take a break if you're experiencing signs or symptoms of being unwell. This is unlikely to occur but it is important that everyone understands the situation if this does happen. The youth participation workers need to ensure that they uphold the integrity of the PLATFORM and peer support teams but, more importantly, need to ensure that you are supported to maintain your wellness. You, as a member of the PLATFORM or peer support team, have a responsibility to take breaks when you feel it would be in the best interests of everyone involved.

For peer support workers

If you are admitted to an inpatient unit or become unwell while you are an active peer support worker, you will be required to take a 3-month-break from participating from the time of discharge or the episode of being unwell. The 3-month break ensures that you have sufficient time to focus on getting well, and so that the young people you are providing peer support to can see you setting a good example of self-care and recovery. The youth participation workers will help you to return to the role following your 3-month break.

For PLATFORM team members

If you are admitted to an inpatient unit or you become unwell while you are an active PLATFORM team member, you will be required to take a 4-week break from some PLATFORM activities such as public speaking and media engagements. You are welcome to attend PLATFORM meetings and the youth participation workers will support you to participate once you are well again.

Team member name:

Team member signature:

Youth participation worker:

Youth participation worker signature

Date:

6 month review date:



Appendix 3: A sample of a participation goals form

PERSONAL DETAILS

Team member name: _____

Mobile number: _____

Email address: _____

TELL US A BIT ABOUT YOURSELF

Do you work? Y / N If so, where do you work? _____

Do you study? Y / N If so, where do study? _____

Do you have any hobbies? Y / N If so, please list your hobbies. _____

Do you play sports? Y / N If so, please list the sports you play.

**Do you have any other interests that you would like us to know about you? Y / N
If so, please list your interests.**

What would you like to achieve by joining the PLATFORM team?

Which of the following activities would you like to participate in?

- Staff interviews Resource development Media engagement events
 Research projects Public speaking Committee member

Appendix 4: A sample of a youth participation request form

Please complete and return to the youth participation coordinator via email.

YOUR DETAILS

Request date: _____ **Person making request:** _____

Contact phone number: _____

Email address: _____

Organisation/Department: _____

REQUEST DETAILS

Date required: _____ **Number of young people required** (minimum 2): _____

Location: _____

Time/hours (minimum 1 hour): _____

CONSULTATION DETAILS

Please note: A minimum of 2 young people are required to participate in all requests.

Please tick which activity you would like young people to participate in:

- PLATFORM meeting discussion:** 15 minute discussion with the PLATFORM team at a meeting (for Orygen Youth Health and Orygen Youth Health Clinical Program staff only)
- Speaking engagement:** a conference, forum, meeting or training workshop where youth representatives share their personal experiences
- Media engagement:** a television, print or internet
- Staff interview panels:** for staff recruitment and selection
- Focus group or discussion:** for feedback, ideas or opinions from young people to help shape your project
- Orygen Youth Health participation program presentation:** youth representatives talking about the youth participation program
- Resource development:** help creating a youth-friendly document
- Service development feedback:** young people can provide valuable feedback as service users based on their experience
- Research project consultation:** for feedback and guidance from young people about developing research projects
- Committees:** getting young people involved in your committee or steering group

Other: (please specify)

CONSULTATION BRIEF

Tell us about your project or consultation that you would like youth representatives involved in. For workshop, media and conference engagements, please provide details of your audience.

PARTICIPATION CRITERIA

Are there participation criteria for your activity? Do you require young people who had have a particular experience or from a particular age group?

PARTICIPATION DETAILS

How would you like young people to participate? How will the participation activity be structured? What do you expect the young people to do?

WHY INVOLVE YOUNG PEOPLE?

Why do you feel youth involvement in your participation activity would be beneficial?

FEEDBACK AND END RESULTS

Meaning participation involves informing young people on how their feedback, ideas and contributions have made a difference in your project etc.

When do you anticipate you can provide feedback on the youth representative's participation?

BILLING AND REIMBURSEMENT

Youth participation incurs a fee that is used to reimburse participants for their time and contribution.

Please see a separate document for details of participation fees.

Organisation/program/person to be billed:

Billing address or email for invoice:

Other billing information:

Billing contact person

Cost centre authorisation:

Email:

Phone number:

For more information about the youth participation program, please contact the youth participation coordinator.

Appendix 5: An example of a peer support worker recruitment poster



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