Research Bulletin

Youth partnerships in mental health

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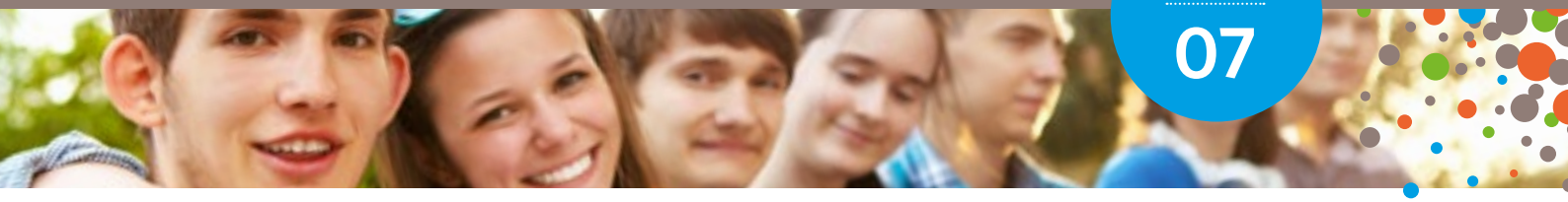

Youth participation models to facilitate partnerships between young people and services have received considerable interest of late. High response rates to such initiatives indicate that young people want to be involved at the process level and organisations and clinicians are generally enthusiastic about incorporating such models into existing services. However, the implementation of youth participation models in the mental health setting can be challenging and often experience high disengagement rates from young people over time. This research bulletin presents some of the lessons learnt from recent evaluations of a number of models implemented across various domains of mental health.

Why invest in youth participation?

Youth participation has been defined as "a process where young people, as active citizens, take part in, express views on, and have decision-making power about issues that affect them" (Farthing, 2012 p.73). The concept of youth participation is one that is protected according to the United Nations Convention on the Rights of the Child (article 12, 1989). It outlines that youth have the right to freely express their views, have them heard and taken into account regarding all matters that affect them. By embedding young people in the decision-making processes that effect change at an operational level, organisations are maximising the resources spent by ensuring services are engaging, accessible and relevant to service users. Meaningful participation can also benefit the young people involved by increasing their sense of citizenship and social inclusion, which can mitigate risk factors for mental ill-health, such as social isolation (Oliver et al., 2006; Victorian Health Promotion Foundation, 2005).

The concept of youth participation has largely been met with enthusiasm from the not-for-profit sector and various governments, and multiple guides on engaging young people have been developed. The Australian Youth Affairs Coalition regularly updates a database of youth participation guides (http://www.ayac.org.au/participationguides.html). To date, they have compiled close to 200 resources that can be browsed by characteristics. While there is a wealth of literature relating to models of youth participation, very little of this is on youth participation in the area of mental health.

A model of youth participation should be flexible to accommodate different levels of participation based on factors such as the young person's capacity, interest, motivation, skill, and importantly preference for level of involvement (AICAFMHA, 2008). This research bulletin presents some key evaluation studies recently published on youth participation in mental health. While not exhaustive, we focus on three domains of participation: 1) in the development of services/ programs; 2) as co-researchers; and 3) in their own treatment. The aim is to give an overview of how young people have been involved in these domains and to provide a guide to stakeholders about how best to engage in youth participation based on the outcomes of these initiatives.

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A practical resource to get you started

Yerp is an online toolkit for young people aged 12 to 25 years who want to get involved in community organisations or create change with their own projects and campaigns, and for the adults who want to support them. A range of useful topics is covered, including 'how to' guides on *"Your rights to privacy and safety"*, *"How meetings work"*, and *"Presenting your findings"*. Yerp was developed by the Youth Affairs Council of Victoria under a steering committee of young people and youth sector representatives and can be accessed online at **yerp.yacvic.org.au**.

Youth participation in mental health services and outreach programs

Young people are "best positioned to judge what is youth-friendly and what is not, whether they feel welcomed by a particular system of care, [and] whether the style and content of education and information works for them" (James, 2007, p.S57). Youth participation is increasingly considered best practice and is seen as an integral ingredient in the development and delivery of youth mental health services (Burns, 2014). While a number of key youth participation programs have been rolled out in Australia (e.g. Ybblue, the youth program of beyondblue; Headroom, providing health promotion and a website; and the Platform Team of Orygen Youth Health), publications on their implementation and evaluation have been limited. The following two studies present preliminary evaluations of two such programs.

Ramey, H. L., & Rose-Krasnor, L. (2015). **The new mentality: Youth-adult partnerships in community mental health promotion.** Children and Youth Services Review, 50, 28-37.

The New Mentality was a youth-adult partnership in mental health promotion in Canada that engaged young people (aged 13 to 25 years) to raise community awareness of child and youth mental health concerns, reduce stigma, and advocate for a system of care that was more responsive to their needs. The program first established a network

of young people and adults ("adult allies") who had an interest in mental health issues. Additional young people were recruited from each site to participate in program activities, which included events (e.g. mental health workshops for young people) and development of tools for information sharing (e.g. mental health magazines). Evaluation was based on program documents as well as semi-structured interviews and focus groups with 19 youth participants and 21 adult allies and stakeholders. Youth participants were also invited to be co-researchers in the evaluation of the program.

Results An early challenge that emerged was the need for program structure and a clear vision. Young people identified that having a work plan from the outset that included explicit and modifiable goals and milestones would help sustain the program over the longer term. Despite the experience adult allies and organisations had in working with young people, some found it challenging to engage with youth participants outside their usual role of "client". In addition, all adult allies reported finding it difficult to achieve a balance between leading the young people and leaving them to coordinate projects independently. While youth participants wanted to be treated as leaders, they also appreciated the availability of support and found active adult participation helpful. In fact, they desired more opportunities to be mentored, particularly when youth co-leaders were unavailable. It was crucial that adult allies had the resources and time to expend on youth engagement, as partnerships suffered when participants were not able to access the allies when needed. Another essential relationship that emerged was that between youth co-leaders. Having more than one youth leader at each site prevented isolation and was suggested as good standard practice for future partnership programs.

Many young people felt that they were having a positive impact on the mental health system and some also experienced personal benefits such as increased self-efficacy and improvements in their mental health. Youth co-researchers appreciated having hands-on experience with the research, such as engaging in analysis of raw data, but reported that they would have preferred to be involved in the evaluation earlier in the program development to have more meaningful engagement with the research process.

Limitations This preliminary study was intended as an examination of the process of setting up a youth-adult partnership and future research should investigate whether involving young people in the development and delivery of mental health promotion activities improve service outcomes such as the youth-friendliness and acceptability of the activities. The authors noted that many young people's involvement with The New Mentality was transient, and it will be worthwhile to examine young people's motivations for, and barriers towards maintaining engagement in these programs.

Take home messages The relationships in youth-adult partnerships are crucial to the success of these initiatives and cultural shifts at the organizational level are needed to allow for some level of equality between service providers and youth. Engaging with a young person beyond their traditional role as a service recipient and finding a balance between allowing youth participants autonomy while still providing direction can be challenging, even for adults experienced in working with young people. Youth participants want to take on leadership roles in a supported environment and this can be facilitated through dedicating sufficient resources to ensure active adult input is available when needed. Having a consensual understanding of the model being used and developing a clear but flexible work plan can provide structure to guide participants and may reduce rates of disengagement over time by maintaining momentum. Young people involved as co-researchers valued hands-on experience beyond the role of a consultant and wanted to be involved in the research process from the conception phase.

Coates, D., & Howe, D. (2016). **Integrating a youth participation model in a youth mental health service: Challenges and lessons learned.** Child & Youth Services, 37(3), 287-300.

The Youth Alliance (YA) was a youth participation initiative at headspace Gosford that recruited young people ("consultants") aged 15 to 25 years to support the delivery of quality services for young people with mild to moderate mental health problems. Participation in the YA included a range of activities such as membership in working parties to contribute a youth perspective when planning aspects of the service, involvement in focus groups and consultations to influence the development and design of youth mental health services in the community, and playing a key role in community awareness campaigns. A full-time YA coordinator

> Allowing young people to pursue projects that ultimately are not realistic causes frustration and disillusionment

was employed to provide supervision and support to the consultants and was responsible for fostering relationships in the workplace and the local community. Young people were motivated to join the YA to help overcome barriers to help-seeking and to ensure young people get the support they need, and to build their confidence, social skills and make new friends (Coates & Howe, 2014).

While the original YA received considerable interest from young people, it was based on a formal participation model that required a high level of commitment from the young people involved and suffered from significant disengagement over time (Howe, Batchelor, & Bochynska, 2011). The YA was redeveloped based on lessons learned and a literature review, which highlighted the importance of flexibility in order to adapt to the strengths, capacity, and interest of the young people involved to attract a diverse group of participants. A tiered, "continuum of participation model" was implemented in the redeveloped YA where consultants' level of commitment could vary depending on the projects and their availability or interest level. Tier 1 of the model involved casual paid employment; tier 2 was flexible engagement depending on personal circumstances, with remuneration in the form of vouchers; and tier 3 was ad hoc engagement as part of a pool of potential participants. This article presents findings from an evaluation of tier 2 of the redeveloped YA based on focus groups with 12 consultants.

It was also recognised that for a youth participation model to be successfully integrated into an existing structure, existing staff need to be actively engaged in the process. Consultations were conducted with clinical staff and management to identify potential barriers and the main concerns expressed are summarized in Table 1.

Table 1. Concerns clinical staff had about implementation of the YA in their existing service and the steps taken to address these

Concerns raised by clinical staff	Action steps taken in the new YA
Consultants exposed to private information of peers and may not understand confidentiality issues	Appropriate training and supervision of consultants to manage risk of confidentiality breeches
Other young people being deterred from accessing the service due to fears of being recognised by peers in the YA	Consultants only involved in activities and projects with no direct client contact
Mental health of consultants and risk of secondary traumatic stress for those with history of mental health issues	Consultants complete a "wellness plan" prior to involvement and consent to YA coordinator liaising with mental health teams about their mental health as required
Consultants overhearing and misinterpreting clinicians' conversations	Staff reminded that client discussions should demonstrate respect and uphold the dignity of young people with mental health issues, regardless of whether consultants are present

Results In addition to the practical challenges of implementing the tiered approach at the organisational level, consultants expressed reservations about having different levels of engagement. All young people involved stated that they preferred to be employees rather than volunteers, as they believed it would facilitate integration of the YA into the service and they "would be taken more seriously". Remuneration with vouchers was also viewed as tokenistic as it took away from their ability to volunteer in the truest sense and its value was questioned due to the restrictions on its use. Eight months into the YA, only half the consultants were still engaged and some speculated that dropout was in part due to the lack of clarity and consistency of the tiered model.

Consultants appreciated the autonomy they were afforded in the YA to drive independent project based on their interests but some expressed a desire for this to be balanced with group activities as well. They also stressed the importance of role clarity so that the boundaries associated with operating within an organisation were clear. It was noted that allowing young people to pursue projects that ultimately are not realistic causes frustration and disillusionment, and that it was the role of the coordinator to manage expectations accordingly. Consultants also appreciated regular feedback that was appropriate and supportive as it provided them with direction, validated their efforts and helped maintain their motivation to engage. Finally, they highlighted the value of skill development through training that would challenge them, such as in effective communication and conflict resolution.

Limitations The evaluations of both the original and new YA models did not collect specific outcome measures of how the young people influenced service development, policy, and organizational change. While staff were consulted prior to the implementation of the model, clinicians were not involved in the evaluation of the YA. It would be beneficial to examine whether the steps taken to minimise some of the potential barriers raised (see Table 1) were adequate and acceptable to clinicians, consultants, and other young people who attend the service. It is worth noting that headspace Gosford is co-located with a tertiary mental health service for young people with moderate to severe mental health problems. Some of the challenges faced might therefore not be generalizable to other settings.

Take home messages While not without its challenges, the YA demonstrates that it is possible to integrate a youth participation model not just into a primary mental health service, but one that is co-located with an acute mental health service. Young people across diverse backgrounds want to be involved at the organisational level and further investigation needs to be undertaken into how to sustain their engagement over time. Increasing flexibility through a tiered participation model did not address the issue with dropout rates and was not well received by young people in this study, possibly because the increase in flexibility was at the expense of model clarity. Young people value consistency in a youth participation model and appreciate clearly defined roles, particularly when navigating the boundaries of working within a bureaucracy. They wanted opportunities for skill development and training, and prefer being employed by the service as they believe it will provide them with more credibility. Young people raised the need to form better relationships with clinical staff and it is paramount that existing staff members are actively engaged throughout the process and efforts need to be made to identify and address their concerns to facilitate integration. Finally, autonomy given to young people in the form of freedom to pursue individual projects should be balanced with the opportunity for group projects and activities as well, especially considering how the social benefits of being involved is a key reason young people joined the YA in the first place.

Young people as co-researchers in mental health research

Evidence from the adult mental health literature suggests that involving service users and members of the public as co-researchers have a number of potential benefits. These include increased likelihood of achieving recruitment targets through increased participation (Ennis & Wykes, 2013), increased research methodological strength through the generation of novel, more complex and comprehensive data and analyses (Gillard et al., 2010), and personal benefits for service users such as increased mental health literacy and improved social inclusion (Tait & Lester, 2005). The National Health and Medical Research Council's (NHMRC) Statement on Consumer and Community Participation in Health and Medical Research outlines that "consumer and community involvement is about research being carried out

with or by consumers and community members rather than to, about or for them" (NHMRC, 2016). In addition, NHMRC encourages researchers to consider the benefits of actively engaging consumers in proposed research projects when applying for funding. However, it is important to note that simply involving young people in research may not necessarily lead to improved research design and outcomes if studies are inadequately planned and resourced. Meaningful involvement of young people in mental health research is not well documented and the following two studies offer some insight into the process of engaging young people as co-researchers.

Mawn, L., Welsh, P., Kirkpatrick, L., Webster, L. A., & Stain, H. J. (2015). **Getting it right! Enhancing youth involvement in mental health research.** Health Expectations, 19(4), 908-919.

This qualitative study recruited an opportunistic sample of young people (aged 14 to 24 years) from mental health organisations to explore their perspectives about being involved in mental health research. Semi-structured interviews were conducted with eight participants and identified themes were subsequently discussed in a focus group to ensure that findings reflected young people's perspective and not the interpretation of the adult researchers.

Results Six key themes emerged reflecting young people's desire to actively contribute to every stage of the research process. The importance of being involved as early as feasibly possible was highlighted and was linked with enhancing motivation and interest, and with young people taking more ownership over the project if their ideas contributed to its formation. While data analysis was generally viewed as boring and difficult, participants also considered it a good opportunity to develop their skills if supported with training. Participants felt that involving young people in data analysis could enhance the analysis process as they may offer a different perspective of the same data to that of adult researchers. They also felt that involving young people in the dissemination stage of research serves as an opportunity to challenge stigma and publically advocate for youth participation in research.

Young people valued the opportunity to contribute to helping others and to instigate change through their involvement in research, and it was important to them to receive updates from researchers as the project progressed. While payment or gift vouchers were viewed as appropriate forms of reimbursement, they were not always perceived as essential. Instead, meaningful involvement could be facilitated through providing personal development opportunities and reimbursement in the form of travel expenses and refreshments.

Barriers to engagement as co-researchers Some participants held a number of preconceptions about research involvement in the mental health context that generated feelings of anxiety. These included the idea that research involved medication trials and that participants needed to be highly intelligent to contribute. Young people also had concerns about not being supported and of others taking credit for their contributions. Finally, stigma, demands of daily life, and the formality of some meetings were also identified as barriers to engaging in research.

Suggestions to facilitate youth engagement in mental health research Participants suggested generating interest through having a presence at youth events and festivals. Recruitment efforts should be facilitated by other young people who are currently involved, or who have had prior experience in research and should include example research tasks to demonstrate to young people what their participation might involve. A final theme involved the use of technology to supplement face-to-face communication. This flexible approach where participants can choose to present their ideas at meetings or online at a later time through dedicated forums or social media maximises the contributions from a range of young people, not just those who are socially confident with expressing their views at meetings.

Limitations Participants in this study were predominantly female and consisted of potentially highly motivated and engaged young people. Future research should examine whether involving young people enhances the robustness of research. For example, whether young people offer novel interpretations of the data, as suggested by the participants in this study.

Take home messages Young people with a pre-existing interest in mental health wish to contribute to mental health research in spite of possible stigma or competing life commitments. They are particularly motivated if projects offer personal development opportunities and a sense of impact by making a difference to others. These incentives outweigh that of reimbursements through cash or gift vouchers, and highlight the importance of researchers providing participants with research updates in order to reinforce the value of their

contribution to the project. Young people want to be involved in all stages of research, including idea generation, recruitment, data analysis, and dissemination of findings. This not only enhances their sense of ownership of the project but also contributes to the creation of a "research cycle", such as when existing co-researchers publically advocate for youth participation in research during the recruitment process, which in turn makes other young people more likely to get involved.

Coser, L. R., Tozer, K., Van Borek, N., Tzemis, D., Taylor, D., Saewyc, E., & Buxton, J. A. (2014). **Finding a Voice Participatory Research With Street-Involved Youth in the Youth Injection Prevention Project.** Health promotion practice, 1524839914527294.

This study presents an evaluation of the process of recruiting young people with personal experience with street involvement and/or illicit drug use as co-researchers in a drug prevention project. Ten young people (aged 17 to 24 years) from diverse backgrounds were employed part-time as co-researchers and most had not completed high school. Evaluation was based on semi-structured interviews conducted with youth co-researchers, researchers' field notes and minutes from team meetings and debriefing sessions.

Results The initial plan was for youth co-researchers to only be involved in focus group moderation, note taking and validating research findings. However, youth co-researchers wanted to be involved in data analysis and took the initiative to request training in qualitative analysis methodology. In addition, they asked to co-present their research findings at conferences and successfully organised fundraising activities in order to attend these (Funk et al., 2012). Not all youth wanted to participate at the same level and flexibility was allowed so that youth could determine their own level of involvement based on their ability and interest. While these provisions helped with engaging youth co-researchers whose quality of participation declined when they faced difficulties in their personal lives, it was at the expense of adhering to project timelines and budget.

Academic researchers realised early in the project that they needed to provide youth co-researchers with more than just basis skills training, but also with support in the research process and their personal lives. A youth counsellor was recruited from a partner organisation but this service was not frequently utilised and youth co-researchers instead raised personal issues and queries about the project with the academic researchers they were working with. While this commitment created extra responsibilities for the academic researchers (for example, meeting young people outside work hours), the support youth co-researchers received from academic researchers and each other was unique to their lives and was essential to their engagement with the project.

> “simply involving young people in research may not necessarily lead to improved research design and outcomes if studies are inadequately planned and resourced

Limitations An academic researcher who was closely involved with the project conducted the evaluation and interviews took place while youth were still employed in the project, raising the potential for response bias. It would have been helpful to include feedback from participants at the conclusion of the project so that responses reflect participants' entire experience of the process. The authors were upfront about the unanticipated additional resources that this project required in order to be successful and future research should further investigate the benefits and costs of involving youth in participatory research. This should not only include the outcomes for academic researchers and youth co-researchers, but also for research participants and on research outcomes.

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Take home messages It is feasible to meaningfully engage at-risk young people from groups that are traditionally marginalised and stigmatised, and who have not completed secondary education, and to employ them as co-researchers. Youth co-researchers experienced increased self- and social awareness over the course of the project and became empowered to advocate for their own needs and wishes over time. Many felt strongly about not wanting to just be involved in a tokenistic manner and took the initiative to increase their level of participation at various phases of the research. Successful engagement of young people as co-researchers required extra resources (e.g. time and training) beyond initial expectations and this needs to be accounted for in the planning stages of similar projects. Youth co-researchers benefited from support not just with the research process but also with personal matters, and they preferred to receive this from adults involved in the project rather than from an external youth counsellor.

Youth participation in their own mental health treatment

Shared Decision-Making (SDM) is a semi-structured, collaborative process between a clinician and client that promotes the selection of a treatment choice that is based on relevant evidence and consideration of the preferences and values of the client (Hoffmann et al., 2014). While SDM is seen as a hallmark of good clinical practice and is a model endorsed by mental health clinicians (Simmons et al., 2013) and young people and caregivers (Simmons et al., 2011), clinical application is hampered by a lack of available tools to support this process.

Simmons, M. B., Elmes, A., McKenzie, J. E., Trevena, L., & Hetrick, S. E. (2016). **Right choice, right time: Evaluation of an online decision aid for youth depression.** Health Expectations.

This uncontrolled cohort study examined the use of an online decision aid to facilitate shared decision making in the treatment of youth depression. The "youth depression decision aid" website developed by the authors included five sections (see Table

2) and was presented to participants on tablet computers. The study recruited young people (aged 12 to 25 years) with mild, mild-moderate or moderate-severe depression who attended an enhanced primary care service (headspace) and were facing a decision about treatment for depression. Clients were given a baseline assessment before using the decision aid and both client and clinician participants were given a post-decision assessment directly after the appointment where the decision aid was used and again 6 to 8 weeks following that.

Table 2. Brief description of the content of the online decision aid

Sections of the online decision aid
1. Mood questionnaire (completed in waiting room)
2. "What Matters to You?" (to elicit personal needs, preferences and values around treatment options)
3. "Treatment Options" 3a. Mild depression: "Should I make lifestyle changes or use guided self-help?" 3b. Mild-moderate depression: "Should I undertake cognitive behavioural therapy or not?" 3c. Moderate-severe depression: "Should I take antidepressant medication in addition to cognitive behavioural therapy?"
4. "Your Decision" (known causes of decisional conflict were listed for discussion)
5. "Information" (about depression and treatment)

Results Of the 57 clients who participated in the study and used the decision aid, 48 clients completed the follow-up assessment. Client participants' baseline scores on the PHQ-9 suggested that 18% had mild depression, 26% had mild-moderate depression and 56% had moderate-severe depression.

After using the decision aid, clients felt significantly less conflicted about which treatment option to choose, were more able to make a decision about treatment and were more likely to make a decision that was consistent with clinical practice guidelines, compared to before using the decision aid. Clients reported feeling involved in the decision making process and of those who were able to make a decision after using the decision aid (97%), all felt that their chosen treatment was the one they most preferred and matched their personal needs and values. Client and clinician participants reported a high level of satisfaction with the decision that had been made after using the decision aid and this rating was maintained at the follow-up assessment. Approximately 8 weeks after making the decision, clients had significantly reduced depression scores compared to baseline and more than 80% had continued to engage in their chosen treatment.

Limitations The lack of a control group in this study limits the conclusions that can be made about the role the decision aid had in the observed improvements in depression symptoms and high engagement rates. It is also unclear whether the change made during the appointment from an initial treatment choice that was non-guideline concordant to one that was guideline-concordant would have occurred even without use of the decision aid. Further research examining the effectiveness of the decision aid in a randomized control trial is needed to compare its effects with treatment as usual. While clinicians were provided with instructions on using the decision aid, there was no formal assessment of fidelity.

Take home messages Decision aids facilitate shared decision making in a formalised way and may improve concordance with clinical practice guidelines. It is possible to facilitate client-centred care in the treatment of mild to severe youth depression through use of an online decision aid. The majority of the study population endorsed symptoms consistent with moderate to severe depression and the decision aid supported communication of the evidence around potential risk of treatment for this group. Using this tool, young people were able to make decisions about their care that were not only in line with treatment guidelines but also with their personal preferences and values. Young people's satisfaction with, and adherence to their treatment choice following use of the decision aid remained high 8 weeks after making the decision.

Where to from here?

Conclusions

The evaluation of youth participation is still in its early stages, with most examining the *process* using qualitative, uncontrolled designs with small numbers of young people and stakeholders. The evidence to date suggest that youth participation models can be implemented even in challenging contexts such as within a tertiary mental health service, with young people from disadvantaged backgrounds, young people who have not completed secondary education, and young people with moderate-severe depression. Young people want to be meaningfully involved in various aspects of mental health care from community outreach to research, to their own treatment. Young people care about this and they consistently request to increase the level of their participation and to be involved as early as possible in the process. There are clear personal benefits for young people involved in these initiatives, including skill acquisition and increased self-efficacy. The quality of relationships with adult partners is crucial to the success of youth participation models and adequate resources and commitment from the organisation need to be provided from the planning stages to ensure the sustainability and responsible implementation of these valuable initiatives. A number of studies have noted the significant investment required to support youth participation in the long term and further examination of the outcomes of these models may help establish their cost-effectiveness to support their continued funding. While it can be argued that youth participation is a right and therefore does not need to justify its value, there is still a need for monitoring and evaluation as part of a learning culture to ensure the sustainability and quality of youth participation programs.

What does this mean for practice?

Suggestions for how to increase youth participation

- Have a presence at youth events and festivals to generate interest in the organisation.
- Activate young people with current or past experience with youth participation models to be involved in recruitment activities.
- Consult existing staff throughout the process of implementing youth participation models. Staff members are generally enthusiastic about these initiatives but also have valid concerns about the process that should be addressed.
- Adults involved – even those with experience in youth mental health - may need support and training to be effective in adult-youth partnerships.
- Allocate sufficient funds to allow for flexibility with timelines and budget to accommodate for periods of lowered engagement when young people go through personal difficulties.
- If possible, hire youth participants as employees.

Practical considerations when implementing a youth participation model

- Provide young people with the opportunity to be meaningfully involved across all stages of the project. In particular, their involvement in the early staging of planning can increase their sense of ownership of the project and reduce disengagement over time.
- From the outset, have a clear work plan with explicit but modifiable milestones to guide youth participants and also maintain their focus and momentum.
- Balance support with allowing independence by ensuring an adult support person is consistently available for consultation when needed.
- The adult support person needs to manage the expectations of young people from the start so they can anticipate potential challenges with participation and can make informed decisions about what is best for their mental health. This will also avoid young people investing time and effort into project ideas that may not be feasible at the organisation level.
- Allow young people to take on leadership roles in a supported manner by having at least two youth co-leaders on projects.
- Skill development is a major incentive for participation and relevant training opportunities should be provided.
- Social interactions are another incentive for participation and group activities should be incorporated to increase group cohesion.
- Utilise technology to provide young people who might not be comfortable with contributing in face to face meetings an opportunity to express their ideas through online modalities.
- Youth participants should be supported not just with the project they are involved in but also with their personal issues, as far as possible.
- Young people should be provided with regular feedback on their input and on the progress of the project.
- Young people have a right to be involved in decisions that impact them and appropriate resources and tools (e.g decision aids) should be utilised to promote inclusion of young people in making decisions about their own care.

Future research opportunities

- Develop and evaluate a youth participation model that is flexible (e.g. to accommodate different levels of participation) while still being structured enough to provide model consistency and clarity. A tiered approach (Coates & Howe, 2016; described above) was not well received by young people.
- Explore ways to maintain engagement over time. Most studies were able to generate interest and recruit young people, but subsequently experienced significant dropout.
- Move beyond process evaluation to further evaluate the outcomes of youth participation models for: (1) youth participants (e.g. mental health); (2) the service (e.g. perceived youth friendliness, cultural shifts at organisation level); (3) other young people who use the service (e.g. stigma, acceptability of the service); and (4) existing staff (e.g. level of involvement)
- Research on youth co-researchers should investigate the impact on the research process and research findings (e.g. are these more robust with the involvement of young people?)
- Develop and evaluate decision aids to support shared decision making in youth mental health treatment. The decision aid discussed above focused on a single treatment decision and further research is needed to investigate how SDM can be appropriately implemented across a wider range of treatment decisions made in services.

References

Australian Infant, Child, Adolescent and Family Mental Health Association. (2008) 'National Youth Participation Strategy Scoping Project Report'. Stepney: Australian Infant, Child, Adolescent and Family Mental Health Association.

Coates, D., & Howe, D. (2014). The importance and benefits of youth participation in mental health settings from the perspective of the headspace Gosford Youth Alliance in Australia. *Children and Youth Services Review, 46,* 294-299.

Ennis, L., & Wykes, T. (2013). Impact of patient involvement in mental health research: longitudinal study. *The British Journal of Psychiatry*, *203*(5), 381-386.

Funk, A., Van Borek, N., Taylor, D., Grewal, P., Tzemis, D., & Buxton, J. A. (2012). Climbing the "ladder of participation": engaging experiential youth in a participatory research project. *Canadian Journal of Public Health*, *103*(4), e228-92.

Hagen, P, Collin, P, Metcalf, A, Nicholas, M, Rahilly, K, & Swainston, N 2012, Participatory Design of evidence-based online youth mental health promotion, prevention, early intervention and treatment. Young and Well Cooperative Research Centre, Melbourne.

Hart, R. (1992) Children's Participation: From Tokenism to Citizenship, Florence: Unicef Innocenti.

Hoffmann, T. C., Légaré, F., Simmons, M. B., McNamara, K., McCaffery, K., Trevena, L. J., ... & Del Mar, C. B. (2014). Shared decision making: what do clinicians need to know and why should they bother. *Medical Journal of Australia*, *201*(1), 35-9.

Howe, D., Batchelor, S., & Bochynska, K. (2011). Finding our way: Youth participation in the development and promotion of youth mental health services on the NSW Central Coast. *Advances in Mental Health, 10*(1), 20-28.

James, A. M. (2007). Principles of youth participation in mental health services. *Medical Journal of Australia, 187*(7), 57-9.

National Health and Medical Research Council (2016). Statement on Consumer and Community involvement in Health and Medical Research, Consumers Health Forum of Australia.

Oliver, K. G., Collin, P., Burns, J., & Nicholas, J. (2006). Building resilience in young people through meaningful participation. *Australian e-Journal for the Advancement of Mental Health*, *5*(1), 34-40.

Simmons, M. B., Hetrick, S. E., & Jorm, A. F. (2011). Experiences of treatment decision making for young people diagnosed with depressive disorders: a qualitative study in primary care and specialist mental health settings. *BMC psychiatry, 11*(1), 1.

Simmons, M. B., Hetrick, S. E., & Jorm, A. F. (2013). Making decisions about treatment for young people diagnosed with depressive disorders: a qualitative study of clinicians' experiences. *BMC psychiatry, 13*(1), 1.

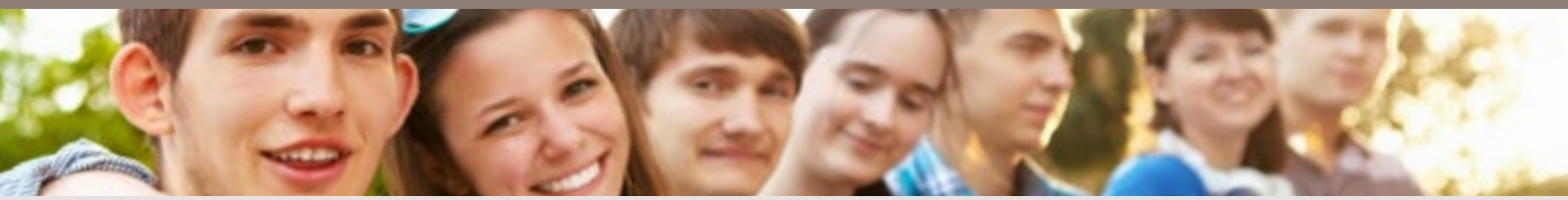
Stewart, R., & Liabo, K. (2012). Involvement in research without compromising research quality. *Journal of health services research & policy*, *17*(4), 248-251.

Strachan, R. (2009) Youth Voice and Participation on the National Youth Summit Advisory Board and Beyond. *Focal Point: research, policy, & practice in children's mental health, 23*(2), 20-24.

Tait, L., & Lester, H. (2005). Encouraging user involvement in mental health services. *Advances in psychiatric treatment*, *11*(3), 168-175.

United Nations (1989). Convention on the Rights of the Child. Available from: https://www.humanrights.gov.au/convention-rights-child. Accessed 21 January 2017.

Victorian Health Promotion Foundation. *Social Inclusion as a Determinant of Mental Health and Wellbeing*. Carlton, Victoria, Australia: Victorian Health Promotion Foundation; 2005. Available from: https://www.vichealth.vic.gov.au/media-and-resources/publications/social-inclusion-as-a-determinant-of-mental-health-and-wellbeing. Accessed January 15, 2017.



Research Bulletin Writers

Dr Stefanie De Silva
Alan Bailey
Dr Alexandra Parker

Research Bulletin Consultant

Dr Magenta Simmons

Research bulletins are designed to so that clinicians and researchers can access an overview of recent research on a specific topic without having to source the primary articles. The implications of the research for clinical practice and opportunities for future research to advance knowledge in the particular topic area are also canvassed.

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35 Poplar Road
Parkville VIC 3052
1300 679 436
orygen.org.au

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