

COVER PAGE

Full Title: Youth Speak: Increasing engagement of young people in mental health research

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Short Title: Increasing youth engagement in research

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ABSTRACT:

Background

Patient and Public Involvement is now an essential part of health related research.

Evidence suggests that research that involves patients and members of the public can enhance methodological rigor and facilitate the implementation of research findings.

Aims

Our paper describes the development of a youth research group (Youth Speak) aimed at increasing youth engagement in mental health research.

Method

We provide a selective review of the literature and outline the challenges and benefits of involving young people in research. Examples of how our group has facilitated involvement and the challenges we have encountered are also discussed.

Results

Meaningful involvement of young people in mental health research is poorly documented or significantly lacking given the dearth of published literature. This may reflect the difficulty of obtaining sustained funding which is required to facilitate non-tokenistic involvement or a perception that young people are unable to provide meaningful contributions in this area.

Conclusions

By establishing groups such as Youth Speak, which focus on the long-term involvement and development of young people in all stages of the research process, we hope to empower young people so that they can reshape youth mental health services.

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Keywords: Youth; Engagement; Involvement;

Main Text

In the United Kingdom, Patient and Public Involvement (PPI) is now recognised as essential for health service development and research. For example, one of the key objectives for the National Institute for Health Research (NIHR) has been to increase the involvement of patients and their families in research, beyond being participants (Ennis & Wykes, 2013). Outside of the U.K., other national research bodies have placed varying degrees of emphasis on user involvement. For example, the National Health and Medical Research Council (NHMRC) in Australia has worked in partnership with consumers and researchers to develop the Statement on Consumer and Community Participation in Health and Medical Research (Consumers Health Forum of Australia, 2012). However user involvement within the National Institute of Health (NIH, U.S.A) reflects a participatory approach merely upon taking part in clinical trials.

Evidence suggests that research involving patients and members of the public is more robust, likely to increase participation, and facilitates translation of research findings into practice (Staley, 2009; Ennis & Wykes, 2013). In recognition of these important outcomes many funding bodies encourage patients and the public to be actively involved, and in several instances mental health service users have been involved in defining research priorities (Rose et al., 2008; Thornicroft et al., 2002). For example, service users have contributed to decisions on outcome measures that should be collected for clinical trials (Crawford et al., 2011), and demonstrated that patient–researchers can elicit different types of information and outcomes to more traditional academic researchers (Rose et al 2011). Studies have also shown personal benefits for patients such as improved social inclusion, and a sense of purpose and personal well-being (e.g. Tait & Lester, 2005; Minogue, Boness & Brown, 2005).

Despite these benefits, a review of studies engaging patient and public involvement in health and social care found few studies relating to youth mental health (Boote, 2011). For example in Australia, Byas and colleagues (2002) worked in collaboration with young people as co-researchers in designing, conducting and writing a project on client experiences of therapy. In North America, Jivanjee et al., (2009) established an advisory board of young people who provided assistance in all stages of a study focusing upon mental health and life transitions. Finally in Canada, Poland, Tupker and Breland (2002) hired six street-involved youth to conduct research among their peers to develop drug and harm reduction materials.

Despite these publications it appears that young people have been particularly excluded from the process of shaping mental health research, with their perspectives in many cases being ignored or filtered through the interpretations of adult researchers or their carers. This is apparent in three other youth mental health studies identified in this review (c.f., Mulvaney-Day et al., 2006; Stein et al., 2002; Pullmann, 2009), which involved carers and teachers rather than young people. Indeed it could be argued that knowledge creation about young people that does not involve young people could be perceived as incomplete or lack real world validity (Jones, 2004).

Involving and listening to the views of young people within society has been promoted by the United Nations Convention on the Rights of the Child, which requires that children should be informed, involved and consulted about all decisions that affect their lives (UNICEF, 1989). Successive U.K. governments have sought to ensure the importance and development of these rights within the domain of health service improvement (Children and Young People's Health Outcomes Strategy, 2012). However, such rights and emphasis does not always equate to meaningful involvement in research which often appears tokenistic and poorly conceptualised (Kellett, 2010). Indeed, young

people with mental health difficulties are rarely consulted or actively involved in research, possibly due to a perception that they find it more difficult to articulate experiences or due to a perceived inability to accurately recall experiences (Schimmelmann & Schultze-Lutter, 2012; Booth & Booth, 1996).

Attempts to increase and promote research involvement in the National Health Service in the U.K. has been facilitated by organisations such as INVOLVE (a national advisory group funded by the NIHR). Several other organisations and charities have also been interested in promoting children's rights and involvement in health research (e.g. the National Children's Bureau, the Medicines for Children Research Network). Outside of the UK, organizations such as ReachOut in Australia and the Transformational Research in Adolescent Mental Health (TRAM) in Canada have been established to build both research and practice in youth mental health emphasizing youth involvement.

Varying levels of involving young people and the public in research have been outlined to date. One of the most commonly used models is described by Hayes et al., (2012) whereby engagement increases from a purely consultation approach, to collaboration and then to user control. Consultation within the research process (e.g. which topic to investigate, how to recruit to a study etc.) is loosely defined as asking people for their views to inform decision making. Collaboration is the middle stage of this model, which implies a degree of on-going involvement with the power to affect decisions (e.g. designing the research study; McLaughlin, 2006). Finally, user control refers to research where power resides with users and members of the public themselves who are responsible for the initiative and subsequent decision making. Hart's ladder of participation (Hart, 2008) is an expansion of the model outlined above and is specifically devised for youth participation with eight stages of increasing involvement. However, these hierarchical models have been criticised as failing to reflect the complexity of PPI especially in relation

to the processes by which ideas are exchanged and decisions shared. Therefore alternative models have been proposed (see Stewart & Liabo, 2012).

Regardless of the level of involvement that is adopted by a study, it is important to note that involving young people in research does not always lead to improved research design and outcomes. Studies that are inadequately planned and resourced, in terms of funding, training and time, are likely to result in tokenistic and methodologically poor research (McLaughlin, 2006). Tarpey (2011) identified in a report on research ethics applications that although 62% of applications indicated a plan for involving patients, 69% of these plans were not confirmed by further supporting information. One interpretation of this is that PPI is considered by many as a 'tick box exercise' with minimal plans regarding offering opportunities for meaningful involvement.

In light of the dearth of information relating to the involvement of young people in mental health research and the potential for tokenistic approaches, this paper outlines an example of enhanced patient and public involvement through the establishment of a youth mental health research group.

The establishment of Youth Speak

Youth Speak on Mental Health Research (shortened to Youth Speak) was established in 2013 and comprises young people aged 14-24 years who have experienced mental health problems themselves or been a carer/sibling of someone with mental health problems or have had no personal experience of mental health issues. Members of Youth Speak meet on a monthly basis to discuss research priorities, feedback information from local and national conferences, and collaborate with academics and clinicians. All activities are co-ordinated by academic (adult) researchers with contact between meetings occurring via email and social media.

At the time of writing Youth Speak membership is approximately 20 young people with meetings regularly attended by six to eight members. The proportion of members with or without mental health difficulties is unknown as we do not require young people to state the presence or nature of any mental health difficulties upon joining the group (unless this information has to be discussed from a safeguarding perspective). Recruitment to the group initially focused on reaching young people through local mental health charities (YoundMinds, Mind) and youth related services. More recently, membership has grown steadily as current members recruit using snowballing based approaches within other daily life settings. A particular difficulty has been engaging both male and ethnic minority members although this appears to be a national problem in relation to PPI in mental health research (Patterson et al., 2014).

The principle of developing a youth culture that promotes inclusiveness (Hamilton et al., 2004) has driven our approach to developing Youth Speak. In promoting a youth culture, meetings are held outside of school and college hours in public buildings (town halls or university buildings) that are non-stigmatising and are highly accessible by public transport. At each meeting we provide food, refreshments and icebreaker activities, while the young members set the agenda, determine priorities and run the meeting. The inclusion of young people with and without mental health experience has also been a strategic inclusive approach aiming to reduce stigma and ensure that research is focussed on resilience and wellbeing rather than solely on a psychiatric disorder.

A collaborative or adult initiated yet shared decisions approach with youth is the model of engagement for Youth Speak (Hart, 2008). Group members have led the development of the name, objectives and logo for Youth Speak as well as devising and implementing strategies to recruit new members from the local community. The core aims developed by members are; (i) giving young people a voice and skills in mental health

research; (ii) reducing mental health stigma for young people through research and action; and (iii) shaping research to influence mental health services for young people. Despite this current collaborative approach we aim to develop the group so that with the provision of training and support, members will be able to lead future research projects if desired.

In striving to achieve these aims, we are facilitating a regular dialogue between academics, clinicians and young people on key mental health research priorities. For example, Youth Speak acts as a critical resource for local researchers by ascertaining characteristics likely to transform research to appeal to young people and enhance youth participation. Group members determine the projects that will be supported by Youth Speak and the level of support to be offered. Voting takes place on such matters with group co-ordinators informing researchers with the outcome of these decisions. Within any research dialogue, young people are encouraged not only to support, but to develop and challenge ideas and priorities. We aim to foster personal development opportunities to ensure members have the necessary skills to become co-applicants and steering group members on local and national research projects and grants. Youth Speak members are offered mentoring and in-house training at Durham University in areas such as questionnaire design, facilitating focus groups, poster and presentation skills as well as opportunities to attend and present at internal and external conferences. All research involvement and development opportunities undertaken by members are documented at monthly meetings, although further evaluative data needs to be gathered regarding young people's experiences of group membership.

Within a national and international context, we believe our approach to youth engagement in mental health research is unique by placing a strong emphasis on the personal development of our members as well as the inclusive nature of our membership criteria. Although organisations such as Orygen Youth Health (Melbourne, Australia),

Headstrong (Ireland) Youthspace (Birmingham, UK) and Youth Net (Canada) adopt many of the principles previously identified as facilitating meaningful involvement, their remit has primarily focussed on service development and improvement within clinical settings. For these organisations, research engagement is only a secondary rather than a primary focus. The most comparative approach we have identified in facilitating youth involvement in mental health research in the U.K. has been the establishment of a national Young Person's Mental Health Advisory group (facilitated by the Mental Health Research Network) which was formed in early 2014 (Megan Rees, Personal Correspondence, April 2014; NIHR CRN, 2014).

[INSERT TABLE ONE HERE]

Research collaboration with Youth Speak

Youth Speak members have been central to a number of research projects and events, including the writing of this paper. Youth Speak member and co-author PW selected examples of the group's key research collaborations (below), summarised the group's composition and was mentored during this process. Another member has worked as a co-applicant on a Research for Patient Benefit (RfPB) grant application linked to the screening of depression in primary care. The young person was involved in preparing the application, assisted the team in re-focusing the research question and provided advice on appropriate study methods. For example, the original research question focussed on the validation of two short screening measures of depression. However, input from the Youth Speak member refocused the research toward understanding young people's experiences, emphasising that it is important to understand why young people may not disclose information as a preface to developing a screening tool. This reshaping of the research

question and the proposed methodology demonstrate the collaborative, joint decision making approach of Youth Speak.

Another member of Youth Speak is part of our research team for a study funded by the NIHR Mental Health Research Network. The aim of this small qualitative study is to investigate strategies that facilitate the involvement of young people in mental health research. During the project this young person has supported the design of information booklets, consent forms and ensuring the study application meets ethical requirements. Indeed, recruitment to this project has been enhanced as potential participants are given the opportunity to discuss the project in confidence with this peer researcher prior to committing to this study.

Finally, all members of Youth Speak were invited to deliver a workshop on ‘Engaging young people in mental health research’ to clinicians and researchers at the Tees, Esk and Wear Valleys NHS Foundation Trust Research Conference. This workshop was indeed an example of a user led approach, whereby Youth Speak co-coordinators organised practice facilities and workshop materials whilst members designed and led the workshop using exercises challenging prejudices around young people.

Challenges of youth PPI

Whilst Ennis & Wykes (2013) state that patient involvement is taking place in some difficult contexts, it is also appropriate to classify youth mental health as one of these difficult areas. A primary concern and threat to the sustainability of Youth Speak is the procurement of funding. This difficulty is compounded by the lack of specific funding initiatives targeting enhanced and sustained PPI. While research funders (e.g., NIHR) will fund patient and public involvement for a discrete research project there is a lack of funding sources for sustained PPI involvement such as Youth Speak. However, enhanced

non-tokenistic PPI, which is often developed prior to the submitting of grant applications and, indeed, aims to be sustainable long term requires start-up funding and support over a prolonged period. Delivering PPI that develops a youth culture can be expensive given the need to utilise youth friendly locations, travel costs for members, youth friendly refreshments, and activities, training and mentoring. The average pre-funding PPI bursary award of £308.72 by a Research Design Service in the East Midlands for example would barely cover the expenses for one of our monthly meetings (Walker & Pandya-Wood, 2013). Furthermore, when considering young people and sustainable engagement over time, fun activities such as team building days are important but rarely the focus of research grant applications.

Another challenge is that young people have complex and dynamic lives. For example, young people often balance education, part-time employment, sport, and social activities. It is anticipated that young people will come and go from the group (due primarily to lifestyle changes and developmental needs) resulting in fluctuating numbers and membership. Minimising disruption caused by this is key to the success of the group, thus on-going recruitment is necessary. We are also conscious that we do not want young people to develop a self-identity that is bound by a mental health problem, alone.

While groups that follow a model of consultation with expert oversight will be confronted with power struggles and difficulty reaching consensus, our model ensures the group itself will resolve differences of opinion. The underpinning philosophy of Youth Speak, is that of youth-led research. In this manner, the young members of Youth Speak take the lead for the meetings, determine priorities and paths for action. Thus in any meeting a decision is reached by the young people through consensus.

[INSERT TABLE TWO HERE]

Conclusion

Meaningful involvement of young people in mental health research is poorly documented or significantly lacking given the dearth of published literature, despite evidence suggesting that PPI involvement results in more robust research outcomes. The lack of access to capacity building funding for valuable initiatives such as Youth Speak hampers progress in this field. However, by describing the work of Youth Speak as an innovative and practical initiative we hope that other research groups and services may be able to gain funding to replicate our approach and increase meaningful youth involvement in mental health research and thus reshape the landscape of youth mental health.

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