



Young people and an NHS participation worker reflect on their involvement in a creative, collaborative mental health research project

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Abstract

Most UK child and adolescent mental health services (CAMHS) support young people up to the age of 17/18, at which point they are discharged, or transition to an adult service. This transition is often difficult for young people, as they also face the complex physical and psychosocial changes of adolescence. Transition from CAMHS is often poorly managed, with negative outcomes for young people. Improved preparation may improve both outcomes and experience. We worked with 17 young people and staff from three NHS mental health foundation trusts to co-produce the CAMHS Transition Preparation Programme (TPP), deliverable in routine NHS settings. We took a creative, participatory approach to maximize young people's involvement in the research. Young people steered the direction of the work, and were involved in decision-making and dissemination both nationally and within their trusts. In this commentary, two young participant-researchers and one NHS staff member describe the project from their perspectives.

Keywords: transition; CAMHS; involvement; creative; participation; preparation

Key messages

- Young people value the time and space to think 'outside the box' that creative, collaborative research approaches offer.
- Researchers may underestimate the amount of time needed to prepare, train and support young people to maximize their roles as co-researchers.
- Young people gain confidence from full, meaningful, well-supported involvement.

Introduction

Under the aegis of the National Institute of Health Research Collaborations for Leadership in Applied Health Research and Care (NIHR CLAHRC) East of England, the CAMHS Transition Preparation Project (outlined in the companion paper in this issue: Dunn and Mellor, 2017) brought together researchers, service providers and young people with experience of CAMHS from three NHS mental health foundation trusts. Young people were recruited via trusts' participation/inclusion networks run by participation workers (PWs). The study adopted a creative, participatory approach to achieve its aim of co-designing a prototype preparation programme to improve experience and outcomes for young people leaving CAMHS. In this commentary, two participants and a PW reflect on their experience and offer advice to researchers considering similar work.

Sophie Allan, Head of Patient and Parent Involvement in Cambridgeshire and Peterborough NHS Foundation Trust's (CPFT) Community CAMH Teams, coordinated this commentary with two young participant-researchers, Fran Dunn and Kelly Davis-Steel. Sophie emailed a set of questions to Fran and Kelly: How did you come to be involved with the project? What was good about being involved? What didn't you like? What were the challenges? How did involvement in this project compare to other participation activities? What advice would you give to other researchers? Responses are unedited.

Background

Involving service users and carers in the design and delivery of health services is an increasingly high priority for the NHS (for example, Department of Health, 2010; Department of Health, 2011; NHS England, 2014); child and adolescent mental health services are no exception to this (for example, NHS England, 2015). Meaningful involvement is key to Children and Young People's Improving Access to Psychological Therapies (CYP-IAPT), a CAMHS transformation programme that began in 2011 and facilitated the employment of a number of dedicated participation workers across England; the first author was one of these. As with patient and public involvement (PPI) in research, user involvement recognizes the unique contribution that people with lived experience of mental health difficulties can provide, with an emphasis on professional expertise (whether clinical or academic) being valued as highly as personal experience. However, user involvement in service delivery plays a far less prominent role in the academic literature than PPI in research and has a relatively scarce evidence base demonstrating its impact. As a participation worker, the first author was excited to become involved in the CAMHS Transitions Preparation Project (TPP), as working together provided an opportunity to 'bridge the gap' between PPI in research and involvement in service delivery, and to have tangible impact on young people's experiences of leaving CAMHS.

How did you come to be involved with the project?

SOPHIE: Valerie Dunn, the TPP lead researcher, approached me about the project and asked if I would be interested in collaborating. I wanted to become involved as I knew from feedback we'd received in the service that some young people found leaving CAMHS was problematic, and I was keen to address this. The participatory approach Valerie had chosen to adopt, collecting data using a series of interactive and creative workshops rather than traditional focus groups or questionnaires, was

attractive as it fitted well with the work I was doing to engage young people about how services should be run differently. It also meant that the young people I worked with in my newly formed participation network would benefit from taking part, including by taking on participant–researcher roles. The first step, which was also adopted by my participation worker colleagues in Hertfordshire and Norfolk/Suffolk, was to introduce the project to the young people and see if they would like to get involved. As with any other participation or research project, becoming involved was optional and there was no pressure put on any of the young people to be involved if they didn't want to. The fact that I and the other participation workers already knew the young people meant they were able to explore any concerns they had about the project which meant it felt safe and supportive from the outset.

FRAN: I first became involved in the Transitions Preparation Project through my participation worker. I was then invited to meet with the researcher where she explained what the project was and all the things I could be involved in – if I wanted to be!

KELLY: I became involved with this project when the researchers had contacted our youth council. I have been in the youth council for nearly four years and was excited about a new project to be involved in. We had an initial meeting with the researchers and they told us all about the project, their aims, what they wanted to achieve and why they would like us to be involved. We also had a brief discussion about some of our transition experiences.

What was good about being involved?

SOPHIE: The collaborative nature of the project was its key strength. The fact that it was an independently run research project meant that findings were seen as objective and taken more seriously as a result. Working closely together from the outset has meant the findings (at the time of writing) are beginning to have a tangible impact on trust-wide policies and practices, as they have directly fed into a trust-wide strategic board. I feel this may have not been the case if the research team hadn't developed such a strong working relationship with the team. It was fortunate that as a participation worker I was able to act as the 'link' person between the young people and researchers, as I think it's unlikely the project would have worked so well if this task fell to a clinician or manager, given the pressure faced by our services at present.

Having an existing relationship with the young people prior to the project starting was important as it meant that they felt safe and supported throughout the process. The other two participating trusts had well-established participation groups, whereas I had only just started setting up the young people's participation work, so did not know all of the young people as well. I wondered if this was one of the reasons why we recruited fewer numbers in Cambridgeshire. However, having an existing relationship with the young people and being an employee of CAMHS meant that young people who needed to seek support could do so from someone from the service with whom they had a pre-existing relationship, which was important when topics being discussed could have been distressing. I feel that having a known person in the room during the workshops also helped the young people be honest about their experiences and feel able to trust the researchers, which gave richer quality of data, particularly in the other two trusts.

As a participation worker, I felt I was a partner in the team and that any ideas I had about how the project should be run were valued. The project gave me an opportunity to learn more about creative methods of engaging young people, which

I have gone on to use in other groups with young people and in participation training for professionals. Most importantly, it has been very rewarding to see the young people who have been most involved grow in confidence and gain valuable skills from the project, which they will use in the future.

FRAN: The best thing about being involved in the Transitions Preparation Project was all the additional opportunities that were given to me as a member of the research team and not just a participant or 'young person'. As well as being a participant in the study, I co-facilitated the clinician workshop and have presented to a number of different groups of people including researchers and members of our trust board. I, and some of the other young people who were interested, were involved throughout the duration of the project. This was great because we could see where our ideas were going and that it was going to be pushed to be integrated into CAMHS procedures, which made us (and our views, opinions and experiences) feel valued!

Another thing that was really good about this project was how the researchers went about collecting the data. Unlike in other research studies I've been involved in, we were thoroughly involved in the running of the project and were not just 'subjects' who would be sat down in a room and asked lots of questions! Instead, creative workshops were used to help the young people to 'think outside the box'. I think that we retrieved great ideas from everyone involved because we were encouraged to think about issues surrounding transitions as a team. We weren't just asked a simple question, we discussed problems through activities and games, which got us all to think creatively and in a different way.

More than anything, being involved in this research project has increased my confidence and self-esteem. Through this project and the opportunities that have been offered to me, I have pushed myself and have done things I thought I couldn't do. For example, when I was discharged from CAMHS, I never thought I would be presenting our project to the trust board. Nor did I ever expect to be giving presentations to researchers and clinicians.

KELLY: There were many good things about being involved with the transition project, I enjoyed the structure of it and knowing that we had a lot of support during the project made the whole experience even better. I was already interested in this project because I myself have transitioned from CAMHS to adult services and it wasn't the best experience, so being able to share that and give ideas that can help improve the transition experience for other young people was exciting and also a great opportunity. I really enjoyed the workshops we did throughout the project, they were organized well by the researchers and were always interactive, for example Lego games, sock games, chair games. We were also able to show our creative sides and create posters and leaflets; this ensured we didn't get bored or lose concentration because the workshops were usually all day. It was interesting to see how many ideas we had come up with collectively and how it could make a big difference in services. Not only were we involved with the workshops we also got to go to Cambridge and have research training. This was very useful and helped us learn new skills.

What didn't you like? What were the challenges?

SOPHIE: Of course, like any project, the TPP was not without challenges. It was a significant time commitment and took place at a time when my role was expanding, which meant prioritizing the project wasn't always possible. I was relatively new in post when the project started and did not have regular group meetings for young people.

This posed challenges for recruitment as there was a smaller pool of young people to recruit from, and meant Valerie and I needed to meet individually with people rather than having a one-off meeting with a group. This was time consuming and we did not recruit as many young people as I would have liked, which was a shame as I'm sure others would have benefited from the project. For me, we may have had higher numbers if we were able to advertise the project in the waiting rooms and via clinicians, but unfortunately ethical approval did not come through in time for this.

It was frustrating that the ethical approval process and governance processes were so lengthy, as it delayed the project. However, I'm very proud of all that has been achieved in only 12 months. Overall, I feel that the benefits of the project by far outweighed the challenges.

FRAN: I really struggle to think of things that I did not like about the project because it was so different to anything that I had been involved in before and every opportunity that I was given helped me to push myself and improve my self-confidence. The only thing that I didn't like was that one of the many opportunities that the young people were offered had fallen through. At the start of the Transitions project, we were invited to be trained to analyse questionnaire responses but unfortunately this didn't happen.

I think that one of the biggest challenges we faced during the project was a lack of time. Had we had more time I think that more young people could have been involved and we could have done more.

KELLY: It was challenging at times, having quite long days and it could get quite emotional when we would discuss our experiences. Sometimes it would get tiring and the group would feel a bit low, however the researchers were always aware when the mood was dropping and adapted the workshops by getting us to do something interactive which would bump up the energy again. Any challenge that we did face at the time was always solved because we were supported by the researchers. I didn't dislike anything in particular about this project because I enjoyed every bit of it. I do feel it would be beneficial to have follow-up meetings just to see how we could move forward with our ideas because I feel we came up with a lot of great stuff that could be implemented.

How did involvement in this project compare to other participation activities?

SOPHIE: Being employed on a temporary contract sometimes makes longer-term planning of projects more difficult: the fact that the project was meticulously planned over several months and lasted for a full year was advantageous and allowed young people to take ownership of the project. I had not worked on a project with other participation workers before; the opportunity to share our experiences of work in a post that can feel isolated at times was very beneficial. As discussed, the nature of this being a research project led to a greater level of bureaucracy than other projects I have run, but the benefits more than outweighed this.

FRAN: This research project was unlike any participation activity I have been involved in before. In other research projects I was either sent proposals to evaluate or I was invited to discuss them with the researchers. But in this project, I was far more involved and everything was followed up on. Unlike in other experiences I have had with participation, no activities were done that were not used. There have been too many times where young people give their honest views and opinions on an issue that are

never taken any further. I don't think that the two-day workshop was a waste of our time at all.

I was also a member of the research team. Whenever we held presentations, I was always introduced as a 'young researcher' which was special because I wasn't 'just a subject' of the project. I was actually part of it all the way through it!

KELLY: I feel this project was better than some participation activities I have been involved in because it was well thought through and the workshops were well organized and structured so that each activity we did got the best engagement from us. We were supported all the way through and I really feel that our input was valued. I have also never been in a project that has lasted one year so it was a great experience to have the time to really work on something. I was able to change my negative transition experience into something positive and that has really helped me move on. It has also helped me change my outlook on services as a whole because I know some of what goes into the planning and preparation of transitions.

What advice would you give to other researchers?

SOPHIE: Developing a good relationship with the services is vital, and knowing Valerie prior to this project was helpful, but I don't think it would be essential for other researchers. I would recommend as flexible an approach as possible to ensure young people remain engaged and enthusiastic about the process.

FRAN: Make research fun and exciting! Keep the young people involved all the way through and let them have a say in important stages at every opportunity. Make them feel valued and part of the whole team. Be honest about everything and above all, we want you to involve us as much as you can!

KELLY: Advice I would give to other researchers would be to definitely include interactive and creative activities because it worked very well and kept energy levels high but also made us want to keep coming back to do each workshop. Also to be open-minded and know that even if you have organized and prepared the research days well, depending on how the group is that day it is useful to be able to improvise and change things up if needed.

Conclusion

SOPHIE: The project has been among the most enjoyable of all the participation activities I have helped deliver for CPFT. It has been valuable for the service to gain an in-depth understanding of how we should be preparing young people for leaving CAMHS and I am pleased to see it is already contributing to tangible changes in how services are run. For instance, young people are designing a transitions preparation booklet, developing the role of a transitions peer support worker, and helping build the case for flexibility in the age of transition. Involving clinicians from CAMHS and adult mental health services not only helped ensure the young people's ideas were feasible, bringing more weight to the findings, but also brought clinicians together, many of whom had not met face-to-face before. Being able to think together about the challenges of the transition process and share their own anxieties was a powerful experience, and further joint sessions, including on shared decision-making, are being planned.

Personally, it has been an important lesson in the benefits of working together with researchers, and seeing the growth in young people's confidence from taking part has been particularly rewarding.

FRAN: The whole procedure for this project was so much more creative and meaningful than any other I have been involved in. The creative workshops were great and really helped us to think about issues from a different perspective! I was 'kept in the loop' and had many opportunities to be involved in the project further to just participating. Everything had a meaning and, through my ongoing involvement, I helped to push the findings further so that action could be taken on them.

KELLY: Overall this was one of the best involvement activities I have been involved in and I have taken valuable skills and memories away from it.

Notes on the contributors

Sophie Allan is Head of Patient and Parent Involvement in Cambridgeshire and Peterborough NHS Foundation Trust's (CPFT) Community CAMH Teams.

Kelly Davis-Steel and Fran Dunn are experts by experience in CPFT and Hertfordshire Partnership University NHS Foundation Trust (HPFT) and were participant-researchers on the project.

Valerie Dunn is a mental health researcher at the National Institute for Health Research (NIHR) Collaboration for Leadership in Applied Health Research and Care (CLAHRC) East of England*/University of Cambridge and is a founder member of the Creative Research Collective.

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