

## **Title of article**

# **Research on preparing transition from child and adolescent mental health services (CAMHS): evaluating a creative participatory approach**

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## **Abstract**

Researchers sought to jointly develop a preparation programme for transition from child and adolescent mental health services (CAMHS) with young service users and recent leavers from three NHS mental health trusts. Creative research methods were used within two day-long sessions of exercises, discussions and games, and the approach independently evaluated. This article reports these evaluation findings.

In the main, we find that creative and participatory methods offer a safe and relaxed yet fun and stimulating environment, conducive to thinking 'differently' about future mental health support. Young people were able and keen to have a voice in identifying important preparations, mechanisms and processes in transitioning from CAMHS. Challenges to working in this way within a relatively short timescale included institutional and procedural delays impacting on recruitment, and resulting in smaller than intended group sizes. The research team worked hard, however, to minimise the impact of these challenges. Collaboration with NHS partners was a key strength in this project, enabling research findings to feed directly into a review of policy and practice.

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## Introduction

Young people in child and adolescent mental health services (CAMHS) are required at age 17/18 to either move back to primary care, or onto an adult mental health service. Current service structures offer limited scope to account for a young person's level of maturity, preparedness, functioning, development, wellbeing or readiness for the transition. Consensus is growing that this 'artificial boundary', based on age rather than need, results in a system which is 'weakest where it needs to be strongest' (McGorry et al. 2013). In response, our researchers sought to co-develop, with young service users and recent leavers, a preparation programme for transition from CAMHS which takes account of these critical facets in a young person's ability to make a 'successful' transition. The key research aim was to identify the most important components to enable a successful transition and to incorporate these into a Transition Preparation Programme (TPP) to assist young people leaving the service.

A participatory method was chosen to encourage young people to be partners in the process, with key data collection via replicable creative 'workshops' led by Tom Mellor, Independent Creative workshop designer/facilitator and Valerie Dunn, Lead Researcher, Department of Psychiatry, University of Cambridge. The challenge was to include activities that were enjoyable, flexible, responsive, capable of exposing diversity of experience and perceptions, as well as being rigorous in quality. This research 'workshop' approach was developed with skilled, artistically grounded practitioners for a previous project working with vulnerable groups of young people in care ([www.youtube.com/watch?v=o17AHhi\\_fus](http://www.youtube.com/watch?v=o17AHhi_fus)), and incorporated activities inspired by teaching, drama, community development and group work practices.

Participative research approaches have their roots in community development and recognise the value of researching 'with' rather than 'on' people. (Angell et al. 2015) The researchers chose this approach as one suitable to facilitating engagement with and giving a voice to vulnerable groups, such as young mental health service users (Lushey et al. 2014; Calderwood et al. 2015). The team built the design around creative methods, also seen as popular with vulnerable groups, in offering alternative tools to a language-based approach to research (Leitch 2006). Creative approaches are also proposed as helpful to exploring sensitive material and in exposing complexity and nuance (Eisner 2008). Methods are said to afford time and space to think, discuss, and develop ideas, in comparison with traditional questionnaire-based methods requiring immediate response (Angell et al. 2015).

The 'Transitions' research project

Although it had been hoped to also recruit young people not involved in 'user voice' activities as well as from CAMH youth participation networks, the relatively short duration of the project and institutional delays meant this was not possible. Eighteen current and recent CAMHS users, aged 17-21 years, were recruited to the project via the Participation Coordinators in each of the three NHS Trusts. The Participation Coordinators day-to-day role is to support involvement of young service users in each NHS Trust. In two of the locations the role was well established and groups had been running for some time, while in one was just beginning. Each group was visited by the Lead Researcher to explain the project, taken through the Participant

Information Sheets, and given consent forms to take away and return if they wished to be involved. Participation Coordinators were the linchpin of any involvement, and were present at all stages of the project, facilitating meetings, and often supporting young people to attend both practically and emotionally. Young people who took part were given a voucher in recognition of their time, plus travel expenses. They were also offered the opportunity to attend training and undertake a review of 'transitions' literature, should they wish.

The research was carried out in two stages:

- Stage one of the research was a two-day flexible framework of activities, including games, targeted exercises, and discussions, during which participants explored and shared their experiences, ideas and suggestions.
- Stage two was a 'production' stage, intended to bring the material together in a draft TPP – the key aim of the project. The main themes and action points were agreed with young people as the work progressed via a verbal group roundup for feedback after each activity, day and workshop, and circulation of written summaries after each stage inviting comment as a means of achieving 'ongoing consensus'.

Between the two stages were shorter, 2 hour, workshops with clinicians from two NHS Trusts employing some of the creative exercises and involving some of the young participants summarising findings and outlining proposals for change produced during stage one. Table 1 provides an illustrative summary of some of the key workshop activities, and Box 1 an overview of the resulting prototype 'TPP'. For greater detail on workshop activities, including conception, development, implementation and research findings, see forthcoming paper (Dunn et al. 2016).

**Table 1: Sample framework of workshop activities**

<b>DAY ONE (breaks and lunchtime removed for brevity)</b>	
<b>Introduction and warm-up</b> (10- 25 mins)	'Name ball' game
<b>Thinking about transitions &amp; What works in terms of preparation?</b> (1 hour approx)	Thinking about a known transition (e.g. primary to secondary school) Paired work followed by group discussion
<b>What else is going on in young people's lives which might impact on their transition from CAMHS?</b> (1 hour approx.)	'Socks' game with whole group, followed by: 'Character Creation' in pairs or small groups
<b>How can MH services improve engagement of young people?</b> (1 hour approx.)	'Anti-model': Small groups/pairs design a poster/leaflet
<b>CAMHS/AMHS: what are the main differences? Being a young person in an adult service.</b> (30-45 mins approx.)	Whole group or discussion in pairs via characters.
<b>Round up, consensus, thanks.</b>	Group reflect on day, feedback, evaluation questionnaire.

**Box 1: The Young People's Transition Preparation Programme (TPP)**

Young people spent two days working together in creative, participatory workshops based on a series of planned exercises lasting a couple of hours each, and designed to get them thinking about specific themes around transitioning from child to adult services. Exercises were interspersed with games and breaks. Table 1 illustrates the typical organisation of a workshop day and briefly describes a few of the games and exercises. Overall young people felt that mental health service providers under-estimate the anxiety young people feel as they leave CAMHS and, as a result, the amount of preparation many require. Young people agreed and with researchers drafted a first outline of a CAMHS TPP, which encompassed:

- a range of transition information requirements along with recommendations for content, access, and methods of delivery
- a range of staff training suggestions to improve awareness and sensitivity to the specific needs of vulnerable young people transferring to adult mental health services
- core person-centred aims
- a set of preparation requirements, activities and tools
- preparation timings and structure for monitoring and recording progress
- a set of transition supports for young people in transition

The transitions study opened important dialogues between children and adult mental health services which are set to build in the future. Feeding into the development of the TPP, thirty clinical staff commented on the perceived barriers to implementing the young people's recommendations in routine NHS mental health settings. Two participating trusts plan to develop the young people's recommendations.

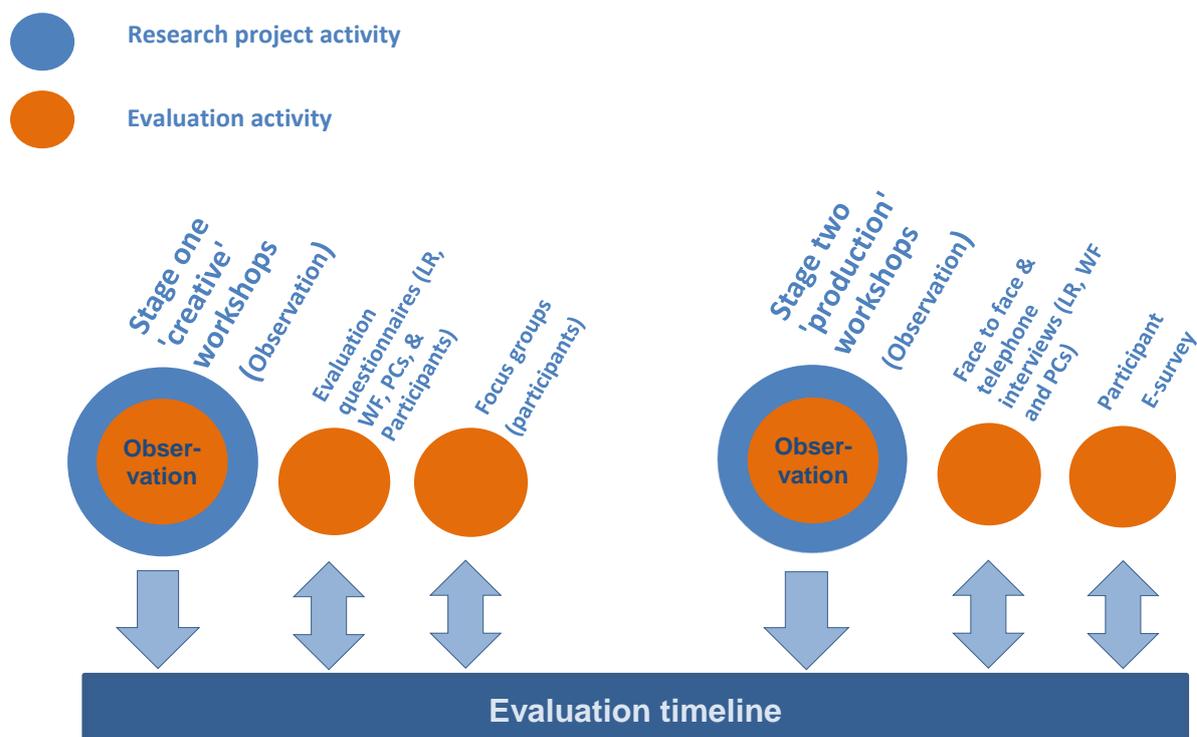
Thirteen young people took part in stage one workshops: five in one location, and four in locations two and three. Numbers of young people increased overall during stage two, while some participants ceased to be involved, five new participants came on board in one location where the NHS Trust participation group was particularly well established. Unfortunately, after the first stage one Trust (location two) was unable to continue involvement through to stage two. This was due to an overseas opportunity for the young people's participation group, and both young people and their Participation Coordinator commented in evaluation questionnaires on how important this project was, and how much they had enjoyed taking part.

**Evaluation method**

The structure adopted for evaluating the approach is illustrated in Figure 1, and aimed to assess the extent to which the creative, participatory, methodology enabled young people to meaningfully collaborate with researchers to produce a prototype TPP. The lenses of effectiveness and acceptability were employed as they reflect the

value and rationale for selecting creative, participatory methods. I.e. Are the methods effective at enabling sensitive material to be explored? Do the young people find the approach acceptable, and engaging? Feasibility was selected to reflect on whether the approach taken is relatively straight forward to implement, and one that could be employed in similar or different contexts?

**Figure 1. Evaluation Structure**



Data collection was based on:

- **Observation** and reflection during workshops, noting on an observation grid (stage 1 only): engagement with activities, opinions, attitudes and evaluation reflections on the process as well as non-verbal behaviour, atmosphere, and adaptations, adjustments made by the Lead Researcher (LR) or Workshop Facilitator (WF) to the workshop plan. N=5 (location 1), N=4 (location 2). Due to scheduling constraints, no independent observation took place in location three.
- **Questionnaires** to young people at the end of each day during the stage one workshops. (N=13) focusing on preparedness for participation, workshop practicalities and facilities, content/activities, and output/impact, triangulated with questionnaires to the Lead Researcher, Workshop Facilitator, and the three Participation Coordinators (PC). All participants completed evaluation questionnaires at the end of the stage one workshops.
- **Focus group** discussion with young people, without researcher or facilitator. N=5 (location one), N=4 (location two) to share overall impressions, probe observations noted and elicit opinions and feelings about the activities completed

during the two days. Due to scheduling constraints, no focus group took place in location three.

- **Semi-structured telephone or face to face interviews** after stage two workshops with Participation Coordinators from locations one and three, the Lead Researcher and Workshop Facilitator, to reflect fully on the creative, participatory process, and explore any themes emerging from questionnaires
- A short **e-survey** issued to participants following stage two (n= 8 out of total 18) to gather opinions on the participative process and outcomes, and reflections on involvement in the various activities.

The focus, therefore, was on the implementation of the creative, participative workshop methodology. Frequency analysis from evaluation questionnaires was used to pinpoint popular and less popular activities, overall value attached to participation by young people, and specific elements within the project. Open text from questionnaires fed into the overall thematic analysis of data from focus groups, feedback sessions and adult interviews. Framework analysis (Gibbs, 2007) was employed in order to code the narrative data into common 'ideas', then group and organise it according to the three conceptual lenses of effectiveness, acceptability, and feasibility.

## Findings: effectiveness

### Creative methods

In considering the lens of 'effectiveness' we were thinking about the extent to which the creative methods enabled young people to share, explore their diverse and shared experiences, and also generate ideas and recommendations. The value of creativity was related strongly to capacity to 'unlock' thoughts and ideas, and the Lead Researcher reflected on the methodology as one where '(we) are ... creating an environment where creative thinking might take place'. The key to the value of 'creative' methodology, in terms of data generation, was that young people and adults alike emphasised the importance of 'thinking differently'. Participants reflected that the workshop exercises provided a conduit for approaching a topic from another direction: 'good to think about things in different ways'; 'helped me think outside the box'.

Hence, ideas may not be so obvious unless first introduced by an exercise, activity, game or product which symbolises or acts as a metaphor for a situation. In reflecting on the popular game: 'Socks!', both young people and Participation Coordinators agreed that it provided a visual way into a discussion around the demands of adolescence, with lots going on and limited control over what is happening. One young person was very sceptical of the game as it began, and asked what 'the point' was? Following the game, this participant did see the value and reflected that it was 'very representative of what is happening (at the time of transition) – lots going on and not in control of anything'. Participation Coordinators equally saw the importance of this exercise: 'It worked so well because they saw how it represented their lives'.

Whilst arts-based activities could be drawn on, researchers reflected that they were not essential to the method: 'We're using 'creative' in the sense of innovative (or inventive) rather than 'arty' (Lead Researcher); '(it's about) different ways to

approach finding things out ... bringing on board more arts-based practice, but not necessarily arts' (Workshop Facilitator). This rationale was also understood by the young participants who expressed how much they valued having a selection of 'art' materials and stationery which gave them, 'flexibility in how to address the activities', even if the activity itself was not overtly 'creative'.

### **Workshop approach**

One of the key factors identified as important by the Lead Researcher and Workshop Facilitator to developing a better understanding (of what is going on for the young people) is the allocation of sufficient 'time' to each activity. The 'workshop' structure afforded young people time and space to reflect, consider, share and explore thoughts and experiences, which is not always there in traditional interview or even focus group situations. The Workshop Facilitator summarises thus:

'The way of working is a short cut to bringing people out of their shell. .. about giving them time to think about. ... and tools to think about it.. (it gives) a different quality to the conversation'.

As well as specific activities within the workshop day, we wanted to understand how the content of the day worked as a programme. Researchers designed a framework with a mix of high energy (e.g. throwing and catching socks, moving about the room) and low energy activities (e.g. paired discussion, drawing), and the participants were positive about this design, stressing the role of games in energising the group: 'high energy activities make the day better', 'keeps energy levels up, 'really fun, nice and active'.

The majority of participants reported in their questionnaires that the workshops were a good way of doing research. It helped them share thoughts: 'Working in a relaxed way enables people to open up'; 'it's a more positive and interactive environment'; 'keeps young people alert and because its fun we are more interested in giving ideas instead of just sitting and talking'. The participation workers echoed many of these reflections of the young people, reiterating the importance of 'high' and 'low' energy mix: 'getting up and moving around physical space helped with concentration, helped make people feel at ease and helped generate discussion'. Observation data supported this with participants recorded as laughing, giggling, and an atmosphere of palpable enjoyment, leading into periods of stimulated, lively discussion.

The mixed evaluation methods exposed how much different groups and individuals enjoyed different activities. For example, while observation notes indicated that participants in all locations were fully engaged in and enjoyed the workshop games, questionnaires and focus groups revealed that some groups, and individuals, preferred thoughtful discussion whilst others very much preferred to be drawing and writing their thoughts and ideas (e.g. in a poster or leaflet). Overall indications were that variety and flexibility during the day is vital. The Lead Researcher and Workshop Facilitator stressed that having a range of activities to draw on, with a 'Plan B' in reserve was important, as was accepting that not all participants will enjoy every activity.

## Findings: acceptability

### Popular and Safe

The lens of 'acceptability' focused on the extent to which the young people engaged willingly with the workshop activities, and whether they found them interesting, fun and worthwhile. We found that the 'fun' factor was certainly heavily emphasised by young people and Participation Coordinators as their experience of the research: '... such an interactive and fun two days'. 'I enjoyed it so much'. (Participants); '...so much fun in what they were doing, felt like not doing work, even though they were'. (Participation Coordinator) The importance of enjoyment and of young people feeling relaxed was indeed central to the research design and the rationale for choice of method, as the Workshop Facilitator states: '(it is) difficult to make a 1-1 interview fun, but in games-based workshops, fun is inherent'.

'Feeling safe' was another clear theme to accepting engagement in the research, articulated in both questionnaires and interviews: 'I felt at ease ... and felt that I was able to talk freely' (Participant). Creative activities also appeared to offer the possibility to put distance between personal experience - another aspect of methodological 'acceptability', and especially important where question areas are potentially difficult or sensitive. This was again a key influence on the research methods chosen: '(We) realised the potential (of using arts-inspired practice in research) and see it worked as a good way to talk to more vulnerable groups of people' (Workshop Facilitator). Participation Coordinators identified that this was indeed what was experienced. Commenting on the 'character creation' exercise, one Participation Coordinator said it offered a 'safe exploration without becoming too personalised', and another agreed it 'felt like a safe way of talking about difficult things'.

### Participatory methods

Calderwood et al. (2015) report how 'being listened to' is a key factor in securing participation from young people in research. This was also true of participants in this project, as they themselves articulate:

'Some people find it hard to speak up and get a chance to speak ... it was helpful because everyone could be included and get a chance to say what they wanted'; '... great at keeping us engaged and being patient with us and our individual needs'. 'You guys, like, listen. Didn't feel like research!'

Participation Coordinators acknowledged that the young people had a voice in the research: 'seeing the participants expressing their views with increasing confidence, and seeing how their experiences are valued', and reinforced how important 'being listened to' is to young people accepting the process: 'That's why they were engaged – they could see that their voices were being heard (...) young people felt listened to.'

This study aimed to build a meaningful collaboration with young people through an explicit participatory approach. In the stage two workshops, participants decided for themselves which aspects of the TPP they wished to take forward – an aspect highlighted by the Lead Researcher as a demonstration of young participants influencing research direction, which could also constitute a step up the 'ladder of participation' (Arnstein, 1969). The Workshop Facilitator confirmed that 'the sessions weren't concrete – they went with the direction that the young people wanted', and

this was corroborated by Participation Coordinators: 'The approach has been tailored to them and how they want to work'; 'they (participants) could steer the session and that worked really well'.

## **Findings: feasibility**

A strong collaboration with the three NHS Trusts was a key factor in how 'feasible' the research was to undertake in the first place, as well as being a strong determinant of impact.

It is important to reflect on how easy it was for our potential participants to get involved and to remain engaged. Illness/wellness, anxiety, time burden and transport issues can impact greatly on research viability. For these reasons, the support role provided by the Participation Coordinators to young people and research team proved invaluable, from: advocacy and arranging transport; to being aware of each young person's mental wellbeing and providing emotional support during workshops, where appropriate.

Insight was also gained into the complexity of mental health service pathways, thanks to the collaboration with the NHS Trusts. The researchers invited mental health practitioners to a separate 'workshop' so that staff from CAMHS, adult and specialist services could hear feedback from the stage one research, as well as from colleagues in the various mental health services. A Participation Coordinator summarised the relevance of this as follows: 'A lot of adult and CAMHS knew there were gaps in service, but didn't know how young people were truly feeling at that time'. The young service users also gained understanding from the collaborative aspect, and participants commented on how much they got out of seeing things from the 'other side': 'helped to see it takes a lot of thought to change things', and were surprised by the empathy they felt for therapists, 'made me realise how much services have to think about in order to think about changes. I realised they have a lot to contend with as well'. Although assessing the collaborative aspect of the project was not an explicit evaluation objective, this aspect appeared influential to achieving consensus around what might be achievable in a TPP.

This research was indeed close to practice, and Participation Coordinators raised the profile of the project and acted as a conduit for the research findings, ultimately enabling the Lead Researcher to be part of CAMHS 'transitions' review panels in two of the NHS Trusts. As one Participation Coordinator remarked on the strength of influence of this project's findings: '(it is) quite unusual for research to be so directly fed in ... signs are good compared to other research projects'; 'the research is very much being used – the Trust are now reviewing their transition policy'.

## **Challenges (and overcoming challenges)**

In considering the limitations of the creative, participatory workshop methodology, we acknowledge a number of challenges, which the project team addressed or minimised impact, where possible.

**Reliability and replicability:** The project repeated the creative, participatory methodology in three different NHS Trust locations in terms of specific techniques, (games, exercises, types of questions and prompts). However, the locations and venues were different, start times and arrival times differed so that each group could have experienced the workshop differently. Further, the make-up of groups was different in each place, reflecting service and pathway differences across locations, and differences in NHS patient and public involvement infrastructure. Such differences are inevitable, and rather than aiming for the exact same experience in each location, the techniques used allow the researchers to respond flexibly to each group within the broad workshop approach. The combination of skilled arts-grounded practitioner with experienced scientific researcher enabled the sort of collaborative team Eisner (2008b) puts forward as a means of enhancing rigour in arts-informed research.

**Researcher bias:** Ethical participatory research suggests that participants should not only have a voice, but also have the opportunity to analyse and interpret research data (Centre for Social Justice and Community Action, 2012). The research design strove to minimise researcher misinterpretation by including young people in analysis, interpretation and reporting, via the 'ongoing consensus' process during and following each stage. It is difficult to conclude with absolute certainty that participants felt they had the capacity or power to offer different interpretations of the data generated. Nevertheless, the evidence supports their agreement with the themes identified for the prototype TPP, as all respondents to the e-survey felt they had had input into it, and most that they and their ideas had been taken seriously.

**Sample bias:** The young people who took part were already active in organised 'patient involvement' networks and may not, therefore, be representative of the wider CAMHS population. Ideally, participants would have been recruited over a longer timeframe from more diverse groups of young people but this was not possible within the limitations of a 12-month grant. Specific under-represented groups may have particular preparation needs not uncovered in this research.

## **Conclusions**

The value of the creative, participatory approach lies in the bringing together of activities and methods which are acceptable and enjoyable to the young people involved in the research and which are also effective in generating evidence. In this project, the approach did demonstrate the immediate value to young people in participating with enjoyment, as well as in generating credible findings with a real potential to make a difference.

There is clear evidence of acceptability, and indeed the popularity, of the creative, participatory, workshop method according to indicators of: fun; safety; feeling relaxed and listened to, which support the case that it is well suited to working with vulnerable groups. Shared agreement was reached amongst participants and researchers over the content and process for implementing a TPP. Built on strong collaboration, the research project has been able to go that step further. The demonstrable commitment to patient involvement in the three NHS Trusts was facilitated by key individuals from these organisations, providing practical support to

both the research team and young participants, acting as conduit to awareness within the organisations, and ensuring research is not remote from practice. The production phase was only not possible in one of the areas as the group became engaged in work overseas.

This evaluation study concludes that a creative, participatory approach can be valuable where researchers require a depth of understanding, nuance, and insight, e.g. into what sort of service change is necessary and why, 'how' it might come about, and where the research team and funders are also prepared to allow the research to observe and respond to participants' interests. Stage two of the research explicitly focused on solutions and collaborative ways of working, and meant that there was an in-built intent to bridge the gap of getting research (and policy) into practice (GRIPP), reflecting the rationale behind the CLAHRC programme. ([www.universitiesuk.ac.uk/aboutus/AssociatedOrganisations/Pages/NIHR-CLAHRC.aspx](http://www.universitiesuk.ac.uk/aboutus/AssociatedOrganisations/Pages/NIHR-CLAHRC.aspx)).

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