



## Creative, participatory projects with young people: Reflections over five years

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### Abstract

Participatory research is collaborative and democratic, and may be particularly engaging for vulnerable or so-called hard-to-reach groups. In this paper, we describe three creative participatory projects carried out over five years with young people and NHS, social care and third sector partners. Working with young people in care we co-produced a trilogy of films, one of which won the young people a British Film Institute (BFI) award. The films are now used for training throughout the UK. With young people with experience of depression, we co-produced a short, animated film which aimed to offer support to other young people who may be depressed and not know where to turn. Finally, with young people attending or leaving NHS child and adolescent mental health services, we co-produced a transition preparation programme for those leaving the service at 17 or 18. For all the projects, the aim was to maximize involvement and give young people some ownership of the research. We outline our approach and describe some of the challenges and limitations.<sup>1</sup>

**Keywords:** participatory research; young people in care; young people using CAMHS; young people with depression; creative research; collaboration; young people as co-researchers

### Key messages

- Creative, democratic, collaborative group research environments enable young people to explore and share sensitive topics and discover innovative ways to express themselves.
- The informality, lack of hierarchy and trusting relationships essential to the process may be unfamiliar to researchers and can lead to role confusion and blurred boundaries for researchers and participants. Awareness, preparation, training, support and supervision with clear ethical and safeguarding protocols should underpin the process.
- Collaborative working requires partners to take on multiple roles. While this broadens learning opportunities, it may also lead to role uncertainty. Ongoing, open channels of communication are essential during the process to build confidence and maximize involvement.

## Introduction

In 2008, the National Institute of Health Research (NIHR) introduced the Collaborations for Leadership in Applied Health Research and Care (CLAHRCs) initiative. These geographical partnerships of universities and NHS and social care organizations were tasked with collaborating on high-quality applied health research. One of the authors, Valerie Dunn, works on adolescent mental health within the CLAHRC East of England and this shift to a collaborative model offered opportunities to develop inclusive, engaging research approaches with young people and partner organizations.

A study with young people in local authority care was the catalyst for change: members of the research team observed that many participants were challenged by the lengthy, semi-structured clinical interviews and questionnaires, which required on-the-spot responses to complex questions on sensitive, difficult topics. Most participants had experienced trauma and were at high risk of having communication difficulties (McCool and Stevens, 2011). This was a salutary lesson and led us to explore alternative ways of working, both in the interests of the young people and to enhance our own understanding.

This paper describes and reflects on creative, participatory work developed since 2011 with NHS, social care and third sector partners. We outline the projects and summarize some of the benefits, challenges and limitations, and the steps we have taken to monitor and evaluate our practice. We provide feedback from our research partners, members of our creative team and young people.

In a commentary also published in this issue of *Research for All*, two participant-researchers and a member of a partner NHS mental health trust offer their perspectives on one study (Allan *et al.*, 2017). Additionally, one of the authors of this article offers personal reflections in the 'Who inspired my thinking?' article (Dunn, 2017). The projects are outlined in Table 1.

## Background

The 1989 United Nations Convention on the Rights of the Child (Unicef, 1989), which was ratified by the UK in 1991, enshrines in law the rights of children and young people to be involved in the decisions that affect their lives. It provides a moral and legal framework for the participation of children and young people in our social care, education, health and research institutions (the Children Act 1989 (see Department of Health, 1989); NHS England, 2015a; NHS England, 2015b; Department for Education, 2015; Department of Health, 2002). In research, INVOLVE, the NIHR-funded body, recommends that children and young people should be offered a choice of involvement options early in the research process and warns against tokenism (Kirby, 2004). Historically, children and young people have been excluded from research, other than as the subjects of inquiry (Shaw *et al.*, 2011).

Meaningful involvement, which recognizes children and young people's status as 'experts in their own lives', can improve relevance, recruitment, research materials, methodologies and the interpretation of results (Shaw *et al.*, 2011). Young people can learn transferable skills, gain self-confidence, knowledge, self-esteem and a sense of empowerment (Shaw *et al.*, 2011; Day, 2008). Young people want their involvement to be meaningful and routine (Plaistow *et al.*, 2014; NHS England, 2015a; NHS Confederation, 2011), genuine and purposeful, with a realistic possibility of change (Stafford *et al.*, 2003). The quest is ongoing to find feasible, engaging, meaningful and developmentally appropriate ways to involve children and young people in research and health services design.

Table 1: Summary of projects

	Film work	Non-film work
<b>Referred to in the text as</b>	<p><b>1: My Name is Joe, Finding My Way, Our House: a trilogy of films made with young people in care about aspects of the care system, 2011–14</b></p> <p>In-care film project</p>	<p><b>3: Co-design a CAMHS (Child and Adolescent Mental Health Services) Transition Preparation Programme (TPP), 2015–16</b></p> <p>TPP project</p>
<b>Partner organizations</b>	<p>Cambridgeshire County Council, Children's Services and Youth Offending Service; Cambridgeshire Film Consortium; Simply Sonic Studios; Spellbound Animation.</p>	<p>Three NHS Mental Health Foundation Trusts: Cambridgeshire and Peterborough; Hertfordshire University Partnership; Norfolk and Suffolk; Tom Mellor; University of Cambridge Department of Public Health (evaluation).</p>
<b>Young people</b>	<p>Film 1: 11 young people in/recently left, care, ages 14–21</p> <p>Film 2: 7 care leavers, ages 17–23</p> <p>Film 3: 7 young people, ages 13–17, in residential care; 3 mentors who had been involved in earlier films.</p>	<p>17 young people, ages 17–21, using/recently left CAMHS, across three trusts: 4 in trust 1, 9 in trust 2 and 4 in trust 3.</p>
<b>Recruitment</b>	<p>Films 1 and 2: recruited via routine meetings of the Children and Young People's Participation Group via the coordinator. Taster session held, attended by lead researcher, workshop facilitator, animator and sound artist.</p> <p>Film 3: via visits to residential children's homes in the region.</p>	<p>In two trusts, participation workers (PWs), responsible for each trust's Young People's Participation/Inclusion Network, recruited participants at routine meetings/activities. The lead researcher attended a meeting to explain and discuss. In the third trust, the PW displayed flyers in waiting rooms, contacted young people on her email list and asked clinicians to distribute flyers to potential participants.</p>
<b>Team</b>	<p>Researcher, research assistant, animator, sound artist, film-maker, workshop facilitator, film educator, social worker, animation assistant.</p>	<p>Researcher, workshop facilitator, regional NHS participation worker, evaluation researcher.</p>
<b>Procedure</b>	<p>Four-day workshop in a professional environment.</p>	<p>Two-day workshops in each region culminating in one-day production workshops.</p>
<b>Project aims</b>	<p>The original aim was to make a training film to provide insight as to a child's experience of being removed from family and placed into local authority care, for a mental health training course for foster carers. Young people broadened this and aimed to reach a wide audience of service providers, policymakers and decision-makers, commissioners and funders.</p>	<p>To co-produce, with CAMHS users/recent leavers and clinical staff, a prototype CAMHS Transition Preparation Programme to improve experience and outcomes for young people leaving CAMHS.</p>

	<p>During the making of film 1, young people were asked for their opinions about the key topics for further attention. They identified leaving care and residential care, which became the focus of the two companion films. Young people were keen that their films spoke to other young people in similar situations.</p> <p>Each film was launched at a screening event at the Cambridge Arts Picturehouse in central Cambridge, where the young people held question and answer sessions with invited audiences; <i>Finding My Way</i> won a BFI documentary award; films are freely available on YouTube with over 15,000 views; supported by young people's charities, training organizations, local authorities, Ofsted and fostering agencies; widely shown at conferences and training events throughout the UK; <i>My Name is Joe</i> has been adopted into The Fostering Network's Skills to Foster Training for prospective foster carers; won a Children and Young People Now award.</p>	<p>The films were launched at an official screening event at the BFI South Bank, London, hosted by mental health campaigner Jonny Benjamin. Young people held a question and answer session with an invited audience. The films are freely available on YouTube and <i>Facing Shadows</i> has had over 8,000 views. The films have been shared on Twitter and by major young people's mental health organizations, and shown at training events and conferences. One young person won a citizenship award for his contribution and the project attracted much press coverage.</p>	<p>Two trusts are reviewing their CAMHS transition protocols and procedures and the research findings are informing these reviews. It is important to note that trusts have given no firm undertaking to implement the programme.</p>
<p><b>Dissemination and impact</b></p>	<p>Young people created images and sound for the films; set the agenda for two of the three films; presented to many audiences, from council meetings to national conferences, including the Prince's Trust.</p>	<p>Young people fully participated in consensus discussions throughout, on content, process, technique and method; agreed and 'signed off' on final versions of the films; interviewed each other; provided the images and sound for the film.</p>	<p>All young people were involved in agreeing on the salient points to take forward at each stage of the research. Nine young people took on co-research roles: co-planning and co-hosting clinician workshops; co-designing a conference poster for the Royal College of Physicians national conference in 2016; attending bespoke research literature search skills training run by University of Cambridge Medical School librarian – although none went on to review the literature (discussed in the text); dissemination within their trusts and beyond; co-authoring an article (also published in this issue of <i>Research for All</i>: Allan et al., 2017).</p>
<p><b>Co-research opportunities and uptake</b></p>	<p>Behind the scenes films; informal feedback session with three young people and the PW involved throughout the three years.</p>	<p>Behind the scenes film; interviews with AFC research staff and members of the creative team were carried out by the workshop facilitator for his master's dissertation.</p>	<p>Process and summative evaluation by independent researcher (Lee, 2016), based on observation (n=9), focus groups (n=9), questionnaires (n=13), e-survey (n=8); lead researcher held informal feedback sessions with two participants; two participants co-authored the accompanying commentary (Allan et al., 2017).</p>
<p><b>Evaluation</b></p>			

## Developing our creative, participatory methods

Our key aim was to maximize the involvement of young people in the research process in work relevant to them. We opted for a participatory research (PR) model. With its roots in community development, PR is collaborative, democratic, pragmatic, usually solution-focused and aspires to effect change. The experience and skills of all stakeholders are given equal value, to redress the traditional researcher–participant power imbalance: studies are carried out ‘with’ rather than ‘on’ people (Heron and Reason, in Reason and Bradbury, 2001). This equity of roles can present researchers and participants with opportunities to rethink and question (Bergold and Thomas, 2012). PR approaches are tailored to the needs of participants, which can be empowering and engaging for vulnerable groups (Lushey and Munro, 2015). PR addresses some of the barriers to young people’s participation: low motivation, the researcher–participant power imbalance and poor self-esteem (Lushey and Munro, 2015).

PR offers a diverse range of creative approaches designed to enable participants to explore, reflect on, share, revisit and re-present experiences, ideas and opinions (Cornwall and Jewkes, 1995): focus groups bring together small groups, typically with between six and ten members, from similar backgrounds or with shared experiences, to explore a given topic; mapping techniques, for example timelines, flow diagrams and body-maps, provide participants with the means to present and explore experiences visually; arts-based techniques enable participants to draw on emotion, experience and imagination as well as on cognitive capacities (Finley, 2008); narrative inquiry explores experience through stories. These techniques are well-suited to small group work where the interactions can bring new perspectives and learning.

We adopted a range of these techniques in our creative workshop approach, combined with activities and exercises inspired by active group work used in transformative theatre by groups such as the Geese Theatre Company and Cardboard Citizen. We drew predominantly on the Geese model (Baim *et al.*, 2002), which was designed to enable offenders to gain new perspectives on past experiences, roles and responsibilities in order to make positive life choices in the future. The co-author (Tom Mellor) is a trained practitioner, experienced in using the Geese techniques with offender and non-offender groups across the age range. The approach focuses on the ‘shared predicament’ (Baim *et al.*, 2002) and incorporates a range of drama and non-drama exercises and activities to build confidence and a safe team dynamic. Exercises are followed by carefully scaffolded discussions to build meaning. Participants have opportunities to work at a personal level or ‘one step removed’, which provides a safe distance from which difficult topics can be explored. The model can be used with non-offending groups, including young people.

### The workshops

Workshop duration and group size were important to maximize young people’s involvement and to create safe, creative, confidential and mutual learning environments. It was important to provide young people with the time and space to think, explore, reflect, share and distil their ideas.

In line with focus group practice, we considered that workshops for groups of six to ten young people would provide a range of experience, encourage participation and give the young people some ownership and investment in the work.

On the advice of our first research partner, the Cambridgeshire Film Consortium, we adopted a four-day summer school format on film projects, which was judged

to provide sufficient time to build cohesive, trusting teams, explore the topics and generate audio and visual material. The transition project workshops were delivered in three stages: two-day exploratory sessions, followed by short, two- or three-hour workshops for clinicians and finally, one-day 'harvesting' sessions to bring the material together.

For each workshop, flexible frameworks of activities were devised, informed by research evidence, discussion with young people and partner organizations and, on the Transition Preparation Programme (TPP) study, short questionnaires. Flexibility ensured that we were able to respond to group characteristics, needs and emergent topics, as well as the limitations arising from venues. This responsiveness enabled young people to influence and steer the direction of the work.

Activities were carefully balanced within, and between, each workshop day to maintain momentum and energy, offer changes of pace and choice of active and static activities. This variety enabled young people to develop their strengths and learn new skills. A range of lone, pair, small group and whole group work activities was included.

It is beyond the scope of this article to describe all the exercises, but an outline of key activities, with broad application, may be useful:

- *Games* fulfil a number of important functions, including team-building, energizing, changing pace and mood, encouraging problem-solving and having fun. In the interests of unity, equity and cooperation, adults and young people alike were encouraged to take part in games. Difficult or complex topics can be introduced with carefully selected games, bringing focus and new perspectives to familiar situations.
- *Characters* provide participants with useful distance from which to explore and share experiences. A character can be created through stories, puppetry, drama, role play, image creation and, most commonly in this work, through body-mapping. In pairs or small groups, young people drew round a volunteer on a large sheet of paper. A selection of pens, pencils and sticky notes was provided and features were added, along with a full backstory and current concerns, imminent life events, family situation, mental health problems and friendships. The created character reflects the joint experiences of the pair or group. On completion, pairs or groups introduce characters to the whole group and common themes are recorded, which can provide the basis for future work. Characters may be referred to or used throughout the workshops.
- *Scaffolded discussions* led by the workshop facilitator (WF) followed each activity to draw out meaning and identify common themes. Notes were written up on flip charts for future reference.

### **Data synthesis/making sense and meaning**

Involving young people in these processes was central to our approach to ensure fair reflection of views and to minimize researcher or partner organization bias. Workshops generated an abundance of 'data' in novel formats – mind-maps, drawings, posters, lists, leaflets, timelines, Post-it notes, quotations and, specific to the film projects, audio, images and animation. The necessity to edit and distil material was fully explained to participants. The material required careful synthesis, rather than complex analysis.

An ongoing process of reaching consensus operated through the post-activity and post-workshop reflective discussions. On film projects, discussions



with young people and participation workers about content and narrative style took place throughout. Most of the image and audio selection, and editing and ordering of material into a narrative structure, was carried out after workshops by our animator/editor with the sound artist/engineer, who worked closely with young people, were sensitive to their wishes and held the project aims in mind. The skill was to balance aesthetics with fidelity to the young people's voices and the agreed aims. The editor produced a rough cut for review by all parties.

## Personnel

The co-author, Tom Mellor, is an experienced workshop facilitator (WF). Group work requires a skilled WF with a host of techniques to call on. The WF is master of ceremonies, advocate, listener and clown. The WF co-designed the workshops with the co-author, Valerie Dunn and, on film projects, the film team. The WF is responsible for timekeeping and is aware of, and sensitive and responsive to, individual needs. The WF introduces topics in lively, interesting ways; judges when to intervene; ensures the voices of less confident individuals are heard; adjusts the pace, energy and direction of sessions; manages dissent to ensure it contributes to the learning; scaffolds conversations and leads reflective feedback sessions.

Valerie Dunn is the researcher on the team, and translates research evidence to non-research partners to ensure workshops are evidence-based. The researcher liaises with partners to ensure appropriate governance and ethical procedures are followed, acts as co-producer on film projects, participates in all workshops and keeps field notes, organizes and carries out dissemination activities, coordinates co-researcher opportunities for young people, co-designs workshops, participates in editing and distils data.

Partner organizations employed participation workers (PWs) or research assistants to run young people's participation/inclusion networks. PWs handled all liaison with young people and were key members of research teams on each project, active in all workshops, supporting young people, providing practical assistance, and providing invaluable insights based on their extensive 'insider' knowledge. PWs ensured the projects maintained a high profile in their organizations.

On film projects, an experienced animator, film-maker and sound/recording artist/engineer were responsible for the practical, technical and artistic aspects of film production. Lizzy Hobbs, our animator, is experienced at working with groups of children and young people. She creates and holds the artistic vision, selects appropriate animation techniques, designs and leads animation sessions and edits the material. Two film-makers have been involved, Ryd Cook and Andy Dunn, who have been responsible for behind the scenes films, for instructing young people in film-making techniques and for working with the animator at the post-production stage. Good people skills are essential, as is sensitivity to the subject matter.

## Ethics

All projects were carried out with the appropriate university, social care or NHS ethical approvals. For the TPP project, the NHS ethics committee expressed concerns about the exploratory nature of the process (we were unable to be precise about which activities and discussions would take place) and possible breaches of privacy via social media. Consent forms enabled young people to agree or not, to the use in reports and presentations of anonymous quotations and, on film projects, to be audio recorded.

On film projects, it was agreed that young people would not be identifiable, so neither faces nor full names appeared on screen. Two young people, both over 18, who took on co-researcher roles as co-authors (on a conference poster and the commentary accompanying this article), wished to be identified by name. Researchers and PWs discussed the implications in full with young people before they made their final decisions.

Workshops were underpinned by confidentiality agreements based on those routinely used in the participation networks. The WF outlined these at the start of each workshop day. The agreements prioritized personal safety and confidentiality, including regarding sharing on social media. Regarding personal safety, all participants were clear that if concerns were raised about the safety of any person, within or external to the group, this would be shared with the PWs, who would act according to their organization's procedures.

## Reflections and feedback

Feedback and reflections are based on informal conversations with participants, PWs, creative team members and partner organizations; independent evaluation (for the TPP project; Lee, 2016); a taped, transcribed feedback session with three young people in care and their PW, carried out by Valerie Dunn, and interviews carried out by Tom Mellor for his MSc dissertation, which focused on the AFC film project.

### The process

#### *Recruitment and attrition*

On the TPP project groups were smaller than expected. Recruitment was handled by PWs during routine NHS/social care participation activities, so we do not have information on how many eligible young people did not participate and why. Informal feedback from PWs indicated that illness or competing commitments dictated non-participation and dropout between stages. One group withdrew after stage one due to a major fundraising drive and overseas travel. Across projects, we know of only one young person who did not take part because the work was not 'their thing'. On the in-care projects, staff took an active role in recruiting and encouraging young people to attend. One withdrew due to ill health and three were involved throughout the three years, acting as mentors to their younger peers on the final film. On the AFC film project, work commitments prevented two young people from attending all sessions but we made special arrangements to enable them to contribute. On all projects, we ran taster sessions to enthuse and inform potential participants.

#### *Young people as co-researchers*

At the preparation stages, we consulted national and local young people's groups and participation networks on the relevance of the research topics, our proposed methods, recruitment and study literature.

Young people taking part in the first in-care film set the agenda for the subsequent films. Leaving care and residential care were selected as topics urgently requiring attention, about which young people's views were rarely sought or heard.

On the TPP project, we were unsuccessful in our aim to involve young people in the thematic analysis of short parent questionnaires. The start of the study was



delayed due to lengthy ethical and governance procedures that impacted on the time available to plan, train and support young people in these pursuits. The practicalities of gathering young people from a wide geographical region was also a barrier.

Although five participants attended bespoke literature search training run by the University of Cambridge medical librarian, none went on to review literature. We underestimated the preparation and support required by participants to put their training into practice, and the inaccessibility of much research literature may have also acted as a deterrent. Structured, guided, small-group sessions were needed, but neither time nor budget were sufficient to allow these to take place.

A number of young people co-presented to a variety of audiences regionally and nationally, including presentations to the Prince's Trust and a poster presentation at the Royal College of Physicians national conference in 2016. On the TPP project, young people fed research findings into ongoing CAMHS transition reviews in two NHS trusts. On film projects, young people held question and answer sessions at launch events and gave press and radio interviews.

These co-researcher opportunities are identified as key in the young people's accompanying commentary. Fran Dunn said:

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! ... 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.

### **Young people's strengths and interests**

The TPP project evaluation revealed that participants appreciated the flexibility and variety of activities, with some preferring discussions and others the more active exercises. PWs agreed: 'The approach has been tailored to them [the participants] and how they want to work.'

The approach enabled young people to use their expertise and exploit their strengths, but also to experiment and learn anew. For example, two young people on the in-care films focused on sound recording; a skilled artist chose to focus on drawing and animation; a third took on a 'site foreman' role, organizing the team to ensure that deadlines were met; a passionate musician wrote and recorded a soundtrack. Most enjoyed the animation: 'I enjoy seeing everyone's work and creations come to life.'

A young person in care commented that the process 'maintained the group democracy'. A reticent, less confident participant felt included in discussions, able to speak up and be listened to: '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.' Another TPP participant summarized:

I liked how as a group we built good communication to be able to not be scared to say something wrong for instance, it is rare you can be honest if you don't agree on something. The project was unique and helped me feel more confident and build transferable skills ...

### **Creative thinking and new perspectives**

For young people, partner organizations and researchers, the creative approaches facilitated creative thinking. A young person on the in-care film projects explained:

'I'm quite impressed with how ... well we all bounced off each other's sort of ideas and were very creative about it, because other people were creative about it.' The young person who created a soundtrack about life in care explained: 'I wouldn't be able to just tell you that stuff, I can only do it like this.' Thinking differently also emerged as a theme in the TPP evaluation (Lee, 2016): 'good to think about things in different ways'; 'helped me 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.'

Young people valued the supportive group atmosphere, which enabled exploration and sharing of personal, often difficult, experiences, as Kelly Davis-Steel explained in the accompanying commentary:

Any challenge that we did face at the time was always solved because we were supported by the researchers. ... We were supported all the way through and I really feel that our input was valued. ... I was able to change my negative transition experience into something positive and that has really helped me move on.

Adults gained new perspectives too. An AFC researcher explained: 'It feels like a stand-alone piece of collaborative research.' Their colleague added:

... this is just as valid a way of doing that [research]. So did we learn something about depression in young people? Yes, we did. Did we learn something about experiences of therapy? Without a doubt. Did we see it again with fresh eyes? Yes, we did.

Many of the images produced by young people provide nuanced insights unlikely to emerge through questionnaires or interviews. For example, Figure 1, taken from the film *My Name is Joe*, shows an image of a foster carer receiving a child into their care for the first time.

**Figure 1: 'I wonder what my new carer will be like?' An image from *My Name is Joe***



The young person's juxtaposition of halo and devil horns is a powerful visualization of the confusion and uncertainty associated with a new foster placement. In the film, we

hear the young person's voice: 'I wonder what my new carer will be like'. Mainstream methods that rely on verbal or written competence may provide limited access to emotional and symbolic aspects of young people's experiences (Bragg, 2010: 47): 'some knowings cannot be conveyed through language' (Ellsworth, 2005: 156).

### Decision-making

On film projects, young people were involved to varying degrees in decisions about the style, tone and direction of their films but were led by the professional animator and film-maker. The editor's rough cuts of each film were viewed and discussed by all parties. Where there were differences of opinion, the editor either amended the film as requested or explained why adjustments would not be possible, usually on aesthetic or technical grounds, or because the changes would distort the young people's message. The trusting relationships between researchers, partner organizations and young people meant that these situations were fully discussed and resolved. The editor explained:

for me it boils down to making sure that we use all the precious artwork, in conjunction with a selection of the voices and sounds, and from these trying to make a narrative that represents the themes and discussions of the workshops. Editing decisions are about finding a truthful voice and inclusion of all the different points of view.

### The end products

On each project, the discovery process was focused on the production of an end product – a film or a tool. This focus served to unite participants and build an inclusive group identity with a common aim. It provided a relevant, clear and achievable reason to be involved and was an important motivator for those whose aim was to change perceptions and raise awareness – of mental health, of therapy, of life in care. An AFC participant said: 'we've all come together as one to create something that is definitely going to change the way that depression and mental health is treated and that was the whole concept of this and why I was determined to get involved'. An in-care film participant said: 'we're trying to make people think'. A PW on the in-care films said: 'when you listen – when you look at the film and you listen to the film, it's all from them and I think we've never been able to capture that in such a way ... and I think that's what makes it so powerful'.

It was important to our young people to 'make a difference'. A participant on the in-care project explained that the film would help:

... [young people] to feel less alienated and they're going through the same stage as everyone else and it helps the older people, the service providers, to provide a better service because now they have knowledge of the different emotions and things they're going through.

Our evaluations, feedback sessions, observations and informal discussions indicated that the young people were immensely proud of their achievements. A participant on the in-care project said:

... it was just like an emotional like experience, to be honest. When we watched it in the cinema, it was just like wow we've actually achieved something and then when we did the second one and we got the BFI

award for it, like I'd never won anything in my life like that, I never thought I would – it's just such a weird experience and when they told us we'd won, I literally just sat there like oh my god, like we've actually done something ...

Two NHS trust partners in the TPP project are committed to implementing the study findings and developing the work beyond the end of the study. The service manager overseeing the work in one trust commented: 'The project has already, and will continue to have, a big impact in shaping how we support young people who are moving into, out of or between services in the future.' Similarly, a senior manager at another trust explained:

This piece of research, which has included young people, their parents and staff, has produced an extremely useful set of recommendations which the Trust is now planning to implement in discussion with its commissioners and which I am certain will be considered by most trusts across the region.

The in-care films are being used throughout the UK to train foster carers and social workers. Ofsted gave the film work special mention at the last inspection.

## Challenges and limitations

We worked with small purposive samples recruited from pre-existing participation networks that may not represent wider populations. Specific groups may have particular needs and experiences that are not represented.

These approaches require a substantial commitment of time and resources, a range of expertise and considerable planning and preparation. Liaising with, and coordinating, multiple research partners can be challenging and time consuming. Ethical and governance procedures were lengthy, which restricted some of our activities.

A democratic, safe and trusting environment is fundamental to the approach. Informality and a relative absence of hierarchy are important contributory factors, but these may also lead to confusion over roles and boundaries for both young people and researchers. During workshops, adults and young people work, play, lunch and take tea together for some days. Perhaps inevitably, as relationships develop, boundaries can blur. For example, an invitation to link on social media may feel perfectly natural to a young person, and lunchtime exchanges of personal information are routine. But these are unfamiliar scenarios in a research setting, both for researchers and participants. Awareness, preparation, clearly drawn and agreed boundaries, open lines of communication, training and supervision are essential. Equally, robust ethical, safeguarding and confidentiality protocols and procedures, clearly understood by all, should protect all parties.

On occasion, adults voiced confusion over their roles within the workshops. One described their uncertainty whether to 'stand back and not to steer ... it wasn't always clear.' One research partner found the shift from their more familiar leadership role to collaborative working a challenge: 'from being in a position of leading things and deciding things to suddenly not being in that position, I think I found that quite hard in places'. Due to the fluid nature of the work, some uncertainty is inevitable. Regular debrief sessions ensure that these potential difficulties are discussed, understood and, usually, resolved.

On the whole, young people shared negative experiences more readily than positive. Through scaffolded discussion, we asked young people to consider the positives in any given situation, being careful not to lead or bias the discussion.

Responsiveness is both a key strength and a potential limitation. Hyper-responsiveness could result in lack of direction, topic divergence and failure to fulfil the project remit. However, attempts to standardize or manualize practice would stifle the inherent creativity and erode the democratic nature of the investigation. To strike a balance, we built in, and adhered to, a number of core activities that ensured key questions were addressed, recorded significant deviations from plans, worked with trusted multidisciplinary teams who shared the project aims, and, in the most recent project, undertook an independent evaluation (Lee, 2016).

The third of the trilogy of in-care films was challenging for young people and researchers. The age range, 11 to 17, was wider than on other projects, young people did not know each other and many were experiencing emotional or behavioural problems or learning difficulties. Trusting relationships were difficult to establish and concentration was poor. Many had been motivated to participate through boredom or persuasion, rather than genuine interest. On day three, planned activities were replaced by singing, games, drumming and drawing as participants from one home had been very upset on arrival, following a crisis the previous evening. By day four, young people were settling, engaging and growing more confident. A longer preparation and orientation period would have been useful.

## Discussion

Young people took on dual roles as both co-researchers and research subjects, in effect researching themselves and their peers. The creative, collaborative research process, and the focus on co-production, provided young people with motivation, skills and confidence. Researchers and partner organizations gained new insights from close, creative collaboration with young people. The end products were relevant, practical and informed by young people's experiences: the films are being used for training across the UK and the CAMHS transition preparation programme is being developed and implemented in two NHS mental health trusts.

The difficult experiences on the third in-care film highlight the importance of tailoring the approach to the needs of each group. A 'one size fits all' approach is inappropriate, undermines the experience for young people and jeopardizes the quality of the learning experiences for all concerned.

For some researchers, the worlds of creativity and research are incompatible: 'research is the child of science; art is something altogether different' (Barone and Eisner, 2011: 6). But Edwards (2008: 96, in Kara, 2015) suggests that social science researchers and artists are natural bedfellows in some ways, as the creative process works similarly for both. Participatory, creative methods can provide fresh approaches and different perspectives (Barone, 2008) for all involved.

Researchers using arts-based techniques may be tempted to prioritize the product over the process (Eisner, 2008). This requires awareness and careful management by researchers. A research team where all partners are represented, with a shared commitment to prioritizing young people's voices and with honest, open lines of communication, is key to maintaining a balance.

## Conclusion

We used creative, participatory techniques at different stages in the research process. Our evaluation and feedback discussions showed that adults gained new insights and that participants enjoyed the process, felt involved and listened to, and took great pride in their achievements. One participant said: 'we all worked together to create something really beautiful and this came out of some feelings that were really bad'.

The young people we have worked with are often labelled 'hard to reach', but perhaps it is incumbent upon researchers to reach out in appropriate, engaging ways. Public services and research increasingly promote the involvement of patients and the public, including the young. Creative, participatory approaches that are flexible, responsive and engaging, may be a way forward for researchers and public services.

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## Watch the films here

### In-care films:

<i>My Name is Joe</i>	<a href="http://www.youtube.com/watch?v=ArBjWe3lWs0">www.youtube.com/watch?v=ArBjWe3lWs0</a>
<i>My Name is Joe: Behind the scenes</i>	<a href="http://www.youtube.com/watch?v=o17AHhi_fus">www.youtube.com/watch?v=o17AHhi_fus</a>
<i>Finding My Way</i>	<a href="http://www.youtube.com/watch?v=L1qZggHoFmM">www.youtube.com/watch?v=L1qZggHoFmM</a>
<i>Finding My Way: Behind the scenes</i>	<a href="http://www.youtube.com/watch?v=pgPu_iHZvL4">www.youtube.com/watch?v=pgPu_iHZvL4</a>
<i>Our House</i>	<a href="http://www.youtube.com/watch?v=fs-RVgsFfcA">www.youtube.com/watch?v=fs-RVgsFfcA</a>

### AFC Films:

<i>Facing Shadows</i>	<a href="http://www.youtube.com/watch?v=LdmRPKUhNEY">www.youtube.com/watch?v=LdmRPKUhNEY</a>
<i>Facing Shadows: Behind the scenes</i>	<a href="http://www.youtube.com/watch?v=qklckvB5c6Q">www.youtube.com/watch?v=qklckvB5c6Q</a>
<i>Journey through Shadows</i>	<a href="http://www.youtube.com/watch?v=luU81p-lVe4">www.youtube.com/watch?v=luU81p-lVe4</a>

## Notes

- 1 This is a summary of independent research funded by the NIHR CLAHRC East of England Programme. NIHR CLAHRCs bring together local providers of NHS services, commissioners, universities, local organizations and the relevant Academic Health Science Network in England. CLAHRCs conduct applied health research across the NHS and translate research findings into improved outcomes for patients. The views expressed are those of the authors and not necessarily those of the NHS, the NIHR or the Department of Health.



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