

Cystic Fibrosis Transitions Art Project

KIM WILTSHIRE

HELEN KITCHEN

kim@limeart.org/kim.wiltshire@edgehill.ac.uk

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ABSTRACT

This article explores the processes used in a participatory arts and health project in the North West of England, UK. The client group were young people (aged 18 and under) who have Cystic Fibrosis (CF) and the project outcome was to create a pack that would help young people with CF make the transition from paediatric care to adult care at the Manchester Adult Cystic Fibrosis Centre (MACFC) at Wythenshawe Hospital.

Part evaluation and part reflection, the article discusses the response to the project from the participants (young people with CF aged 13-18), healthcare professionals with a specialism in clinical CF care and the creative team who led the project. It makes recommendations about ways of creatively working with this specific client group and ways of making the creative process the main outcome in such a project.

INTRODUCTION

This article is an evaluation of a participatory arts and health project for young people with Cystic Fibrosis (CF) run by Lime Art, an arts and healthcare organisation based at Central Manchester University Hospitals NHS Foundation Trust (CMFT) in the UK. The project was funded by the UK charity BBC Children in Need and the aim of the project was for three artists (Mark Haig, film maker (MH), Kim Wiltshire, writer (KW) and Jacqui Symons visual artist and graphic designer (JS)) to work with young people with CF to create a transitions pack that would be distributed throughout the north west of England to help adolescents with CF make the often difficult transfer from Children's Units to the Manchester Adult Cystic Fibrosis Centre at around the age of eighteen.

The article will explore the unique issues surrounding creative work with young people who have CF, as well as detailing what those issues are. It will detail the evaluation collected, the reasons behind the project, the successes, failures and issues that both the creative project team, health professionals and participants faced and conclude with recommendations for future creative projects with young people with CF, which can also be applicable for other creative project teams working with young people who have long-term, enduring health issues.

Because the nature of the workshops were so individual and often quite personal, due to CF issues detailed below, it was not considered appropriate to collect formal evaluation (through the use of questionnaires for example) as work with participants was often sporadic and spontaneous. It was therefore impossible to know in advance how many times the artists might meet up with a participant – it could be once, many times, or all contact could be via email and SMS. It also became evident early on in the project that formal evaluation methods for participants whilst in hospital would not be viable either as the heavy workload of NHS staff meant they would not be able to oversee this for the team. However, artists were required to keep an artist diary and participant log, which all did. Therefore this article relies on mainly anecdotal evidence from artists, healthcare staff and participants, as well as some more formal evaluation carried out through questionnaires and interviews once the pack was completed. Lime also produced an evaluation film, *CF Transitions: An Evaluation*,ⁱ which included filmed interviews with a number of staff, artists and participants and which also informs this article.ⁱⁱ

The sections of this article will follow the main themes of the questionnaires, including project background, participant involvement, project aims, addressing issues and reducing isolation for young people with CF (YPWCF). Whilst this article is clearly limited to working creatively with YPWCF, it explores community and participatory artistic practice within arts and health, the strategies and protocols that safeguard artists, participants and staff on healthcare projects with such a wide-ranging partnership base.

PROJECT BACKGROUND AND UNDERSTANDING CF

The CF Transitions project arose out of a long established partnership between Lime Art and the Manchester Adult Cystic Fibrosis Centre (MACFC).ⁱⁱⁱ

CF is an inherited, chronic multi-system, life limiting disease with complex, wide ranging disorders. Whilst it is a genetic condition, those with CF also risk cross-infection issues due to what are commonly referred to as 'bugs' in the lungs, which can cause deterioration if people with CF meet or mix; therefore it is advised by health

professionals that CF patients are isolated from others with CF, which in turn can add to a sense of a lack of peer support.^{iv}

Living with CF is difficult and challenging, involving a demanding, time consuming, intrusive daily treatment schedule, making it difficult to lead a normal life, but which is necessary to avoid deterioration that would shorten life expectancy.

Adolescence is a particularly vulnerable time of life. Those with CF experience further challenges making the transition to adulthood, transferring from paediatric to adult healthcare services, leaving behind staff they have known their entire lives and so experiencing a sense of loss. Facing a progressive illness, with increasingly frequent hospital admissions, disrupts education and social opportunities leading to a lack of self-confidence and self-esteem. Those with CF are often underweight and tend to look younger than their age, again damaging self-esteem and body image.

As Oxley and Webb (2005) suggest, psychological problems are frequent in CF patients, including depression, anxiety, and family/relationship problems and therefore 'The importance of quality of life and psychological well being alongside optimal physical health received ever-increasing focus in the CF community.'^v There is much evidence that participation in arts activities can help to reduce psychological issues for those with enduring health issues^{vi} and Staricoff (2004) suggests that:

The use of literature, creative writing and poetry in mental health services produces significant benefits for both the patient and the care provider. It enables patients to regain control over their own inner world, increasing their mental wellbeing. It helps the nursing and medical staff to understand the cultural, social, ethnic and economic factors influencing the behaviour of patients.

Theatre, drama and visual arts all provide patients with powerful ways of expressing themselves and understanding their own world. This promotes empathy between patients and staff.^{vii}

Whilst CF is a physical illness, the attendant psychological issues are recognized by specialist healthcare professionals, and therefore creative and art activities are considered an important contribution to general good mental health and well-being.^{viii}

Lime became aware that the multidisciplinary team at MACFC was working collaboratively with colleagues from across the North West to improve the experience of transition for those young people who would eventually transfer to their adult centre.^{ix} Surveys carried out by the CF adolescent support worker in 2006 of young CF patients at Booth Hall Hospital, Manchester, identified fears about the unknown practicalities, trusting a new set of staff, and moving on from the known paediatric team. Based on this initial feedback, and working in partnership with paediatric nurses, staff at MACFC identified a need for some sort of flexible pack for young people about to transfer. MACFC and Project Manager Helen Kitchen (HK) from Lime began discussing in 2007 the idea for a pack and a DVD film (based on previous Lime packs around substance/alcohol misuse)^x that would be creatively led by young people with CF. An ambitious project, creatively, process-wise and in the final output, the pack would have around a five year shelf life. HK applied for BBC Children in Need funding (submitted Jan. 2009, acceptance notification April 2009), supported by Lime colleagues and a steering group of CF healthcare professionals.

Extensive project planning took place before artists began working with young people with CF (YPWCF), and because of the heavy workload of NHS staff and the necessity of adhering to NHS protocols this took a considerable amount of time (May to November 2009).

Making links with paediatric CF teams and extending the Steering Group membership was one of the first steps. The project aimed to work with young people from the MACFC patient catchment areas across the North West of England (including Manchester, Preston, Stepping Hill, Burnley, Blackburn, Blackpool, Lancaster, Wigan and Macclesfield). Although Lime Art had delivered creative projects with MACFC for many years, they had not worked with CF paediatric teams before, so this necessarily involved identifying, working and building trust with a new set of staff and NHS Trusts, who were all invited to nominate a CF specialist representative to join the steering group.

This group worked closely with HK to identify all young people aged 13 to 18 from the North West who could potentially get involved in the project. Parental permission was necessary before the artists could contact/work with the young people. Letters explaining the project (with an opt out clause) were sent to parents by the NHS Trusts. Included with the letter was an envelope addressed to the named young person with a postcard invite 'from the artists' (designed by Lime Art). The postcard included details of a dedicated Myspace page, a dedicated email address and the Lime studios phone number, as means for potential participants to contact the creative team. The postcards detailed the range of artistic activities available (film making, animation, creative writing, journalism, graphic design and visual art) and the main purpose/outcome of the project. Healthcare professionals also highlighted the project to potential participants in the target age range during in-patient stays and clinics prior to the project starting.

As well as obtaining CRB (Criminal Records Bureau)^{xi} checks through CMFT, all three artists received Child Protection and specialist CF training and orientation before working with young people. The artists spent time (approx 1 full day) with specialist CF staff at the MACFC and/or Royal Manchester Children's Hospital (RMCH) in order to gain a better understanding of the condition. The training ensured artists were aware of the health, social and emotional issues related to CF and so understood the reasons behind having to run individual one-to-one workshops with potential participants. This training also set in place protocols for artists, as vulnerable young people might disclose information about themselves, their condition and/or family situation. Helen Oxley, the Consultant Clinical Psychologist based at MACFC, agreed to act as a point of contact for the creative team should they need to refer to a healthcare professional or should they need to talk to someone about any issues, emotional or practical, that they might be having during the project.

MH and KW began workshops with individual participants in November 2009. The aim was to make the film over the summer of 2010. This is when JS came on board as graphic designer. The film was edited and approved by January 2011, and the packs were launched in May 2011. The packs were also given out at a presentation on the completed project at the 9th annual Manchester Cystic Fibrosis Transition Event in July 2011, attended by over 50 paediatric and adult CF staff from across the North West.

Just wanted to say how much I love the pack! It's amazing, I never imagined it looking so brilliant! I love the whole thing, the design of it and lay out etc. It's a really great achievement and I'm glad to have been a small part of that. Seriously, I'm so impressed. Well done!^{xii}

PARTICIPANT INVOLVEMENT

Working creatively with YPWCF presented several challenges:

- One-to-one workshops meant artists missed the creative dynamic that group workshops can create. This highlighted issues for ways artists work with participants, the boundary between personal and professional, as well as issues around continuity both in output and creative activity.
- YPWCF are aware of their condition on a daily basis, but it is not what defines them as young people, and very often participants did not want to be reminded of their condition when not in hospital or in clinic.
- The unpredictable nature of the condition meant that workshops could often be cancelled at very short notice (as the artist arrived at the venue occasionally) and this proved difficult emotionally for artists, as well as time-consuming, costly, worrying and frustrating.^{xiii}
- The one-to-one workshop strategy/methodology involved artists visiting participants in their homes, in outpatient clinics, in hospital wards and other non-healthcare venues including Lime studios and coffee shops. It became quickly apparent that clinics were not a suitable place for creative workshops, as patients wanted to be in and out as quickly as possible and did not want to engage with a creative activity. Also, healthcare staff in clinics were fully engaged in clinical activities and therefore unable to identify potential participants for artists. Whilst a few home visits were carried out, this method also proved unsatisfactory, as families felt the need to ensure the house was 'presentable' to 'guests' (participant comment) whilst artists MH and KW felt unable to make any sort of creative 'mess' working in someone's lounge or kitchen.^{xiv}
- As often as possible artists worked in pairs, for both child protection and ethical reasons, which increased artist costs and also 'outnumbered' the participants.
- One-to-one workshops were often out of many young people's comfort zone, in terms of meeting up with one or two artists and inputting creatively into an end product; young people either had to be very passionate about issues around CF and transition, or very interested in the art form on offer (animation, scriptwriting and graphic design proved the most popular). A few participants wanted to only participate via email or mobile phone.
- The majority of participants reported enjoying sessions to the artists, and seemed keen to continue work once started, although a few young people did not engage again after the first session.
- Often parents were more enthusiastic about workshops than the young person, especially so with participants under fourteen years of age. Participants of this age, for whom transfer was a distant issue, did not engage fully unless they had a real interest in the creative aspects. However some YPWCF in this age group did disclose information about their concerns around growing older with CF and did contribute ideas for the script and the pack.
- Participants for whom transfer to the adult unit was about to happen engaged much more fully, recognizing that their younger selves might not have been as keen, and this added awareness to the creative content of the final pack.
- To ensure participation, artists had to be very proactive in contacting the young people who expressed interest - unusual for artists, who usually work with a specific group already sourced or set up by the project manager/creative lead, at a specific venue and a specific time.^{xv}
- Family participation underlined the importance of transition for those around the young person as well as the young people themselves. Parents find that the adult healthcare team, whilst still including them if the young person wishes this, direct treatment decisions to the young person with CF once they have

transferred. However, this parental involvement was often outside the artist experience, where usually young people do not wish for family to be involved in creative activities linked to their health issues.^{xvi}

- This was *not* one of our stated targets, but as a point of interest it is worth noting that it was more difficult than anticipated to interest young men in the project (seven males out of a total of twenty-two YPWCF participants). The creative team were disappointed that more young men did not participate, however work with male parents and male partners gave a better gender balance for the end outcome/product.

KW and MH worked directly with a total of twenty young people with CF, and JS engaged with an additional two young people and their parents as well as working with several of those who had already engaged. MH and KW also worked with five adults with CF and directly/long-term with three family members. This totals thirty-two people who inputted into the project creatively. The creative team felt it was important, due to the isolation issues for YPWCF, that siblings, partners and parents were encouraged to join in, even if it was just a chat whilst a creative activity was happening with the young person.^{xvii}

A dedicated project email address was set up from the start, however by the end of the project participants were often contacting artists' individual emails rather than the Transitions email address (which was, however, maintained for the duration of the project) and individual mobile phone numbers. Whilst this was convenient for both artists and participants, it blurred professional boundaries, with, for example, participants texting artists with small personal triumphs (e.g. exam results) and texting when upset or angry about something. This highlights the difficult professional line artists had to tread in terms of the level of access they allowed participants to their own lives, also evident in the nature of the one-to-one workshops, where advice on other aspects of their lives was sought, some disclosure about worries or concerns over treatment or the condition, and even help solicited for homework or boyfriend issues.

The Myspace account (called CF Transitions) was set up to enable ease of access to the artists. However there were only ever seventeen followers or viewers to the account^{xviii} and participants who did use social networking sites reported that Myspace had fallen out of fashion. Suggestions were made by participants to create a Facebook account, however it was felt that as a personal profile needed to be set up for this, difficulties in maintaining a professional distance for the artists could arise. However, there was also the suggestion that keeping contact personal, via mobile phone and email, was the best option because some YPWCF would not want to join, for example, a CF Facebook group, because they may not want to *have* to make their CF public to get involved in the project.

One of the objectives of the project was to set up a participant-led art direction team of four or five members and this proved very successful. The team built up very quickly, close to the start of the project, knew of each other and although they worked separately and did not keep in contact with each other virtually (not one of the objectives but a nice idea) they responded to reported ideas from each other and took their responsibilities seriously (e.g. script editing, writing sections of the booklet, design consultation). This team ended up having the most consistent participation because participant had a vested interest in the project as they were due to transfer to MACFC in the near future.

All in all, participation levels were around what was expected; whilst not all the methods employed were successful in engaging young people, and in fact the social networking methods were the least successful, the more personal approach was appreciated by both healthcare staff and, most importantly, the young people.

PROJECT AND CREATIVE AIMS

The main aim of the project was to create the Transitions Pack, which included a DVD film and booklet for YPWCF that would be creatively led by YPWCF, that is, all creative ideas would come from young people, facilitated by professional artists (the methodology usually used by Lime for participatory arts and healthcare projects). There were three specific aims:

- to create a transition pack for YPWCF, led by YPWCF to help make their experience of transition a more positive one
- to encourage YPWCF to engage with creative workshops, expressing their issues and concerns around growing older with CF and improving their awareness of life choices
- to foster a greater sense of CF community, reducing the sense of isolation YPWCF experience because they cannot mix with each other

CREATING THE TRANSITIONS PACK

The three commissioned artists on this project have a great deal of experience in working with young people and are highly skilled in their own artistic practice – creative writing, film making and graphic design/illustration. They took a collaborative approach that ensured quality of involvement for participants and quality of final ‘product’, ensuring participants were involved in every aspect of the creative process, acting as creative facilitators and passing on creative skills such as animation, film making techniques, script writing and editing, graphic design and interviewing/journalism. Healthcare professionals on the steering group were also involved in final approval (as the group of people who would be giving out the pack) but participants were encouraged to be as creative and innovative with both the film and the booklet/pack as possible. For example, whilst it is useful to have a FAQ section, participants decided to present this as a cartoon in the booklet, and where participants wrote their own experience of transition working with KW, they would then work with JS to create the look of the page through creative graphic design. Artists used the book *The 1000 Journals Project* (2007)^{xix} as a creative springboard. The project this book was based on took place in America and involved journals being sent out to random participants who filled them in with a variety of writing, drawings, collages and even embroidery; these random pages were then brought together in one journal. This aesthetic was something that participants really engaged with and informed the final look of the whole pack.

As I had to work with the YP individually, I felt that a journal style pack would be great, allowing each page to be individual and different, without relying on a ‘house-style’ throughout the book. This also allowed much more hands-on creativity without too much heavy use of technology, computers and equipment, making it more accessible and allowing each person to continue/ develop work outside of our sessions.^{xx}

Artists would go into the initial workshop (usually in a pair) with a loose outline of what that workshop could achieve, for example giving the participant an outline of the project and beginning a creative activity such as animating their own name in clay. All three artists were experienced enough to then allow the participant to initiate the continuing workshop/creative activity in a direction they felt comfortable with, using creative methods they most favoured. For example, if a participant was not comfortable writing their own story of transition, then

KW would interview and discuss on tape their feelings, and then transcribe the work, giving it back to the participant to edit and polish for the booklet.

Initially, the film was conceived as animation, however discussion with participants informed the artists that young people around the 14-18 age range (the age group the pack is aimed at) would find this too childish or young for them. Participants suggested the film should show life as YPWCF found it, with more of a soap opera or, more specifically, a *Skins/Hollyoaks*^{xxi} feel to it; that it should tackle issues but also have humour. KW interviewed and met with fourteen young people to discuss script ideas, sometimes only once but for several hours, others several times. All participants were made fully aware of the reasons behind the film and many openly discussed their views on adolescence and CF, giving anecdotes that were used in the final script. Many parents also contributed views during these sessions, especially when visiting their child in hospital, often mentioning how frustrating they found it when their child encountered people, often on a daily basis who knew very little or had outdated information on CF. Their view was that the pack should not only be relevant for young people in transition but give an overall view of the realities living with CF for young people in the new millennium.

KW decided she wanted as much approval of the script as possible from young people and healthcare professionals before filming began, as it was important to ensure a sense of truth within the drama, which had to be respectful whilst having humour. Four of the fourteen young people worked in-depth on the script, coming back with ideas and suggestions and acting as script editors. Every scenario in the film came from a young person with CF, and these were woven together to create the dual-protagonist narrative of the film.^{xxii}

MH and KW decided to work with a POV (point of view) type camera shot throughout the film, partly because some initial concerns were raised by the steering group, very early on, about the ethics around a YPWCF appearing in the film, but also because the film had to engage with the young CF viewer, and a POV type style (similar to the British Channel 4 comedy series *Peep Show*^{xxiii}) could place the viewer in an 'everyperson' position.

Because of cross-infection issues, again, only one person with CF could work on the film at any one time, and in the end only one participant wanted to be this involved, choosing to act as the female protagonist.

MH taught animation and film techniques to participants ahead of making the film in the summer of 2010; many of the animations were later used in the film, which included a nightmare animation sequence. Young people also suggested the POV virtual tour of the MACFC and the interviews with older people who have CF.^{xxiv}

The script, film and pack were approved at appropriate stages of the project by the steering group of specialist CF healthcare professionals, but the creative team ensured that the young people's suggestions and creative ideas were at the forefront of the process throughout. This meant that whilst there were practical elements to the booklet, such as a map and directions, clinical questions answered and an introduction to the staff at MACFC, there were also stories from young people who had recently transferred, recipes and useful websites/books participants wanted to share.

In terms of engaging with creative workshops and the final outcome/product, CF participants reported that they saw their input as:

- Writing the introduction to the booklet
- Offering advice and support on the content of the booklet
- Offering advice and support on the design of the booklet
- Collaboration
- Giving insight into what it is like to live with CF
- Helping with writing the script
- Learning how to use the camera/animate
- Having fun, learning something different, never had the opportunity to do before

Healthcare professionals felt that:

- Whilst many young people did engage, it was mostly whilst they were in-patients, and mostly because they were bored due to the isolation policy
- The young people who were around transfer age who engaged found it really useful being involved
- Without young peoples' involvement, there is no way MACFC would have produced anything that looked remotely like the pack – there was nothing for young people before this
- The pack is something that has been needed for quite a while

The artists felt that:

- The young people got a lot from the process
- Working in hospital because participants were 'bored' is not necessarily a negative thing, in fact it helps with their mental well-being
- Whilst it was more difficult working on a one to one, individual basis with YPWCF, the project achieved the aim of being creatively led by young people
- The art direction team idea worked well, as it gave an opportunity to be more consistently involved to those who had more of a creative interest in the project

Sessions were great and it was a luxury to work on a one to one basis, though they did lack a certain dynamic you get from a group working together. I found sessions tended to last longer and be much more relaxed without necessarily completing more work than you would usually! I also felt that more sessions were needed with each person as you had to explain concepts and look at inspiration, then move onto developing ideas before actually creating pages with each new young person.^{xxv}

ADDRESSING ISSUES

Initial work by the artists centred on fact-finding sessions around issues, discussed above, and finding creative inspiration. These interviews then formed the basis not only for the script for the DVD, but also content, such as the interviews with older patients.

Once the pack was launched, staff from both the Royal Manchester Children's Hospital and MACFC reported that they believed the pack addresses the main issues young people have about transition and CF, and that there is a good balance between what staff thought *should* be included and what young people *wanted* included. Participants thought on the whole that the pack addresses most issues. One participant thought the pack had been a little constrained by NHS staff involvement (in terms of what staff thought was and was not acceptable to put into the pack) but the general consensus was summed up by this participant response:

On the whole I believe it fulfills the expectations of highlighting the concerns that young people with CF have. By working in unison with myself and other CF patients the booklet offers insight from a genuine perspective and as such is reflective of many people who suffer with Cystic Fibrosis.^{xxvi}

Artists also felt the pack fulfilled its objective in addressing transition concerns young people with CF might have, although they also noted tensions between what young people suggested they wanted in the pack and what the steering group thought was appropriate. Artists also felt that whilst having an overview of the issues around CF was helpful, not being 'expert' in the condition allowed artists the freedom to allow participants to lead the process, with issues being led by creative choices and not the other way around.

CREATING AN AWARENESS OF CF AND LIFE CHOICES

Throughout the creative process it became clear that young people felt that there was a need to have something they could show to friends/family/partners that explained some of the issues they faced. The creative process involved some young people visiting the CF Trust website for the first time, and some young people faced certain fears around CF through talking to the artists. Two participants, for example, told KW (unsolicited) that they were scared about a possible transplant issues and about their condition deteriorating (whilst in hospital). Even though they became quite upset during these discussions, they made it clear that they wanted to speak about their fears and issues because they felt family members became very upset and that healthcare professionals were there on a more clinical basis.^{xxvii} This information was passed on to healthcare professionals after the sessions, but the fact these participants felt comfortable enough to discuss issues with the artists testifies to the relationship that grew between participants and the creative team.

Through discussion of ideas and experiences with the young people it became clear to artists that having the space to allow exploration and discussion of issues and life choices was often as, if not more, important than engaging in the creative process. This was where the importance of the training and the protocols for the artists became clear, with artists knowing where and how to flag up issues with healthcare professionals. This mix of interest from participants, partly creative and partly an interest in CF issues, was vital to the creation of the pack. However, it was also at times emotionally difficult for artists, especially when working alone with a young person who became upset or who discussed emotive issues during a session.

Members of the art direction team reported that they felt they did have increased awareness due to being part of this virtual 'team' and becoming aware of what other members of the team were thinking/suggesting ideas for the pack.

As a teenager preparing to complete my transition to the Adult Centre, I have found that working on the project has helped me to gain a greater awareness of what will be expected of me during the process and how I can remain positive about the move without feeling anxious.^{xxviii}

Staff responses reported the feeling that the pack would have a wider remit, possibly in colleges or schools, but definitely with the CF community, in creating awareness.

I think it's going to capture a bigger audience than we think – we showed it to some multi-professional people and looking at the DVD especially I think a lot of our families, especially newly diagnosed families, are going to want to watch that because the inspirational stories are brilliant, and even for me as a healthcare professional I found it exciting to watch them and to see how a lot of the adults are living 'normal' lives [...] I think it is something that can be expanded on and be shown to some of our young families who are worried about the future [...] when it comes out I think we'll be using it a lot, I don't think we'll be waiting for transfer [...] I was really proud to show it to other professionals.^{xxix}

Artist responses mirror those of the staff and participants, with the belief that the pack has gone beyond its original remit and provided a useful resource for CF specialist workers across the North West.

Reducing A Sense of Isolation

I spent a large amount of time in RMCH today, giving out journals and explaining the project, trying to get six patients inspired and ready to work. They all seem enthusiastic, but not much work has been done since I last visited, and also they're very bored in the hospital, and it is a case of whether or not they keep the work up when they get home.^{xxx}

One of the project aims was to foster a greater sense of CF community and reduce the sense of isolation young people with CF experience. Whilst there are online forums and social networking sites, what became obvious was that some young people rarely got the chance to discuss concerns, worries or issues around CF with their peers – especially if they chose not to go onto those sites. However, there was also the suggestion that sometimes YPWCF do not want to be defined by the condition and therefore do not feel isolated from a CF 'community' they do not necessarily recognize. In fact several participants made it clear they don't regularly use CF forums at all and pointed out that they did not necessarily want to 'advertise' their condition by joining such groups, that in fact participation in the project should not be dependent on joining such groups. This suggested that one of the main aims of the project was perhaps not an actual concern for many YPWCF. More research would have to be done on whether the young people who engaged in the workshops were more confident, therefore did not need the support of a CF 'community' or whether those young people who have grown up with the idea of isolation and segregation from others with CF do not necessarily feel any need for that community, unlike older patients with CF who have had to learn to accept this isolation.

Staff at RMCH reported that they did not feel the aim of tackling the sense of isolation had been met and felt their young people did not have any greater sense of the CF community. However, some young people felt that the project did add more to a community feel and artists noted that some young participants accessed the CF Trust's website for the first time during this project, as research for a creative activity. Staff at MACFC suggested the project enabled participants to engage with CF in a way that didn't feel medical, and participant responses echoed this.

I think [the sense of a CF community is] a really important part of it, because of all those involved in this one thing gives a sense of community which is important – the illness doesn't define your personality, but it does give a bonding feeling. People without it struggle to grasp what it must be like – other people with CF completely get that.^{xxxii}

A consequence of the segregation policy on CF wards, however, is a sense of more immediate, day-to-day isolation, meaning that young people are often extremely bored during their regular Hospital admissions for intravenous (also known as IV) antibiotics.^{xxxii} This boredom and frustration at having nothing to do can affect mental health and well-being and as such some of the young people artists worked with often defied the segregation policy and would meet up to chat with other CF patients in ward corridors/hospital cafes. That the workshops would provide some relief from this boredom and sense of isolation was part of the original plan, providing a relief from the lack of contact from other young people and the repetitive nature of the clinical treatment regimes.

Discussion between artists and participants that referenced other artist/participant discussions were useful in combating this sense of isolation. As one participant put it:

It can help to put your mind at ease knowing that you are not alone in dealing with the illness.^{xxxiii}

It was widely acknowledged by participants, staff and artists that this project was unusual mainly because of the one-to-one nature of the workshops and all believed that despite the difficulties encountered, the project team had done well to get as many participants and viewpoints as it did to creatively inform the pack.

What was reported as important to participants was the forethought that had gone into having a travel and subsistence budget, so that they could travel, for example to Lime studios and be fed (a very important aspect for young people with CF due to the amount of food they need to eat to keep healthy). All participants reported being happy with the way the artists positively responded to the individual ways they wanted to engage.

There were concerns that artists, also isolated to a certain extent, would get emotionally attached to participants, having to sometimes deal with very sick participants or indeed participants who might die, and that this would be emotionally difficult. Indeed, this happened to one artist, whose first participant passed away a few months after their first couple of meetings. It was difficult for the artist working with a young person who was so ill and in such pain and emotionally difficult when the artist was told of the passing over the phone. As this was very early on, the artist did not discuss her feelings with any healthcare professionals, but did discuss this with the other artists and the Lime project manager, proving to be a valuable support system.

Artists also had to be mindful of how ill participants were during workshops and during filming, as often work had to stop because a young person was not feeling well; this was especially difficult during the filming of the short drama, but artists were prepared and recognized the warning signs when a participant began to feel unwell due to the extensive training around the condition that they had undergone at the start of the process.

HEALTHCARE PROFESSIONAL RESPONSE

The transitions pack was launched on Monday 23rd May 2011. Healthcare professionals who work with young people and around CF were invited to the event in central Manchester. Some attendees were interviewed by MH and KW for the evaluation film, mentioned above, whilst others filled in a questionnaire, the responses to which are detailed in this section.

Attendees were asked to describe the pack in one word:

- Informative (10 responses)
- Excellent (5 responses)
- Brilliant (3 responses)
- Fantastic (2 responses)
- Funky (2 responses)
- Inviting (2 responses)
- Appealing (2 responses)
- Fabulous
- Wonderful
- Inspiring
- Amazing
- Interesting
- Professional
- Reassuring
- Contemporary
- Dynamic

Where appropriate, all respondents could see themselves using the pack^{xxxiv} and all respondents considered the pack to cover relevant and appropriate topics and that the pack was useful for young people with CF when making the transition from paediatric to adult services. Other comments suggested the pack was:

- user-friendly
- the DVD was excellent and focused on a young person's perspective whilst acknowledging parental anxiety
- eye-catching
- challenges preconceived ideas about living with CF
- beautifully presented
- exemplary
- full of useful info
- teenage friendly, with good Q&A section
- a well targeted pack for a difficult gap
- a really useful resource
- very impressive
- compact and easy to use.

One respondent wished there was something more about CF and diabetes in the pack, however the steering group had made a conscious decision not to overload the Transitions Pack with too much information, and is planning to give additional information tailored to each patient as required.

CONCLUSION AND RECOMMENDATIONS

This project was carefully planned from Lime's years of experience of working with CF patients and the multidisciplinary staff team at MACFC. However, this was the first time young people with CF *not yet* receiving adult care at MACFC had been targeted, and therefore a few recommendations could be made:

- Initial home visits by artists to meet potential participants work, however home workshops do not. A better process is to run workshops either at the hospital during in-patient stays or at Lime studios (ensuring the participant has visited Lime with an artist before the first workshop, so they know what to expect and how to find it)
- Creative workshops alleviate boredom/tedium for isolated participants whilst in hospital as in-patients, making this a valid creative outcome working on positive mental well-being
- Participants particularly liked the fact that the project had an end product with such relevance to CF (the Transitions Pack)
- Participants liked the structure of the workshops as it enabled them to focus on particular creative aspects at particular times, for example the first few months involved animation and writing, moving on to filming, moving on to graphic design and journalism
- It would be advantageous to bring the graphic designer into the project earlier on in the process, so there is time to work with the young people without pressures of looming print deadlines for the end product
- Trying to create virtual space for the project did not work (i.e. the Myspace page). Few young people accessed it and no one commented or responded to the blog or introductory video. There are already well-established virtual spaces for young people with CF, so they do not necessarily need/want additional ones. Contact through mobile phone/email proved sufficient
- An expert patient on the steering group might be beneficial, as the artists often had to be the participant voice at these meetings, often feeling isolated if they were the only creative voice in the group
- Consideration must be given to issues around securing funding to cover the cost of the time it takes to set up, deliver, manage and support projects such as this including: careful negotiation with new project partners/paediatric hospitals, complying with NHS protocols around patient care and confidentiality, working in partnership with extremely busy NHS staff, securing parental permission. Artists cannot just walk into a Hospital and start working with patients and/or staff
- Protocols should be in place for informing artists about very ill participants and about the death of participants.

That the project overall was a success, broadly met all its aims and indeed surpassed some, can be seen throughout this article and through the pack itself. Those participants who engaged consistently with the creative workshops learned skills such as editing and writing, using animation and design software and using film equipment. Artists learned new ways of working, and challenged their own experience by working in such a different environment. Healthcare professionals involved learned how to work in a more creative way, helping to

produce a pack that was both informative and art-led. In conclusion, here are some quotes from artists, participants and staff that support these findings:

I think everyone [in the creative team] who is working on this is really invested in it, it's not just something they've been assigned to, it feels really heartfelt. (Participant)

It was good talking to Kim and Jacqui 'cos they're doing now what I think I'd like to do with my career, and Jacqui really helped me with my coursework, on photoshop, and I got a B! (Participant)

The pack contains inspiration and support for young people in a subtle manner – the inclusion of artwork and stories from YPWCF gives a real and believable tone to the pack that I think would otherwise have been unachievable. I also think it is a great source of information for those that support, know or care for someone with CF and could certainly help with answering questions they may have.

The end product has exceeded my expectations – I like all the pack. It was nice for the older patients to be given the opportunity to pass on advice to the younger generation.

It's that sort of normalising process, saying oh gosh, I thought I was the only one who thought this, but I'm not. (Participant)

There is only really one thing I need to say, and that is, thank you! I have really enjoyed being a part of the project and it is humbling to know that my opinions and contribution are greatly appreciated and that I have played a role in helping to produce such a constructive resource. I have no doubt that the CF Pack will be a great success and I can't wait to see the final result! (Participant)

A fundamental key to the success of the Transitions project has been working with a team of NHS staff, including the clinical director, who is open to the idea of working with artists, and values the role that they can play in healthcare contexts. Not a superficial role, but one deeply embedded in the holistic quality of care they want for their patients, as whole people/individuals. The excellent professional artists commissioned for this project brought their specialist skills and way of looking at the world to explore issues relevant to young people with CF and create a truly amazing piece of work, the Transitions booklet and film.

NOTES

ⁱ For more information on Lime Art, please visit www.limeart.org

ⁱⁱ 3 participants answered formal questionnaires, 2 members of staff at MACFC, 1 specialist CF nurse at Royal Manchester Children's Hospital, CMFT, the project manager and all three artists. At the launch of the pack, questionnaires were also filled in by staff who attended – around 40 health professionals in total attended this event, 32 of whom completed questionnaires, the results of which are discussed in the Healthcare professional responses section of this evaluation.

ⁱⁱⁱ A partnership that has been in existence since 1995

^{iv} For more information on CF go to: <http://www.cftrust.org.uk/aboutcf/whatiscf/> last accessed July 2011

^v Oxley, H and AK Webb, 'How a Clinical Psychologist manages the problems of adults with cystic fibrosis' in *Journal Of The Royal Society Of Medicine* Supplement 45, Volume 98, 2005 pp. 37-46 (P.37) <http://www.ncbi.nlm.nih.gov/pmc/articles/PMC1308807/pdf/16025766.pdf> last accessed September 2011

^{vi} For example, Sixsmith, J and C Kagan's report *Pathways 06* (Manchester: RIHSC, 2005)

^{vii} Staricoff, Rosalia Lelchuk, *Arts in health: a review of the medical literature* Arts Council England Research Report 36 <http://www.cms.newcastle.edu.au/Resources/Research%20Centres/ArtsHealth/Arts-in-health.pdf> last accessed September 2011

^{viii} See also the Five Ways to Well-being at www.neweconomics.org/projects/five-ways-well-being last accessed September 2011

^{ix} Expertise is shared at the annual CF transition event, attended by paediatric and adult staff from across the North West

^x *Losing It* (Manchester: Lime, 2008) and *The Amazing Doctor Sober* (Manchester: Lime, 2009)

^{xi} In the UK, artists have to complete CRB (Criminal Records Bureau) checks before they can work with young people under 18 or vulnerable adults

^{xii} Email from S, a participant, 3 June 2011

^{xiii} If a young person with a chronic condition had to cancel a meeting because they did not feel well, a freelance artist could not claim that time back, they had still set aside one of their contracted days to work on the project (KW and MH were contracted for 63 days work each and JS for 30 days). This meant that artist time, which can often be expensive, had to be generous on the project, to allow for the extra time one to one workshops would take and the level of cancellation. In terms of timing for the project, what took around 150 artist days and eighteen months with another participant group could have taken less than a year with around 12-18 group workshops. This is an important aspect of planning for participatory workshops, and HK's experience with this client group allowed her to project manage and budget realistically for the best participant experience possible

^{xiv} However, some participants reported that they appreciated an initial home visit, but not a workshop, from an artist because it meant they got to meet the artist in a comfortable environment and therefore felt more confident in meeting up elsewhere for subsequent creative workshops. The Lime studios proved a very popular venue with some of these more engaged participants, as they reported feeling creative in a creative space, and workshops would often last anywhere between two and four hours.

^{xv} Of course, on contracting all artists were aware of the unusual nature of the project and were assisted as much as possible by the CF specialist nurses and healthcare professionals. However, much more time than anticipated was spent following up potential participants, trying to engage through initial meetings and consistently 'chasing' up creative work and scheduled meetings.

^{xvi} For example, projects focussing on substance use and sexual health that the artists had previously worked on.

^{xvii} Most parents and family members participated in this way, in terms of talking to one of the artists whilst the other artist was working with their young person, however this was not considered full participation

^{xviii} An introductory video featuring Kim Wiltshire and Mark Haig was uploaded onto the account prior to the project commencing, and a blog was set up, but there was very little traffic on this site.

^{xix} Some Guy (Brian Singer), *The 1000 Journals Project* (San Francisco: Chronicle Books, 2007)

^{xx} Jacqui Symons, Artist Diary Extract

^{xxi} Both popular television dramas for young people at time of writing,

^{xxii} More information on the Transitions pack can be found at www.limeart.org

^{xxiii} *Peep Show*, Objective Productions for Channel 4, 2003 – ongoing

^{xxiv} Whilst all young people were aware that CF is a very individual condition with unpredictable outcomes and so there was no real 'advice' an older person with CF could give a YPWCF, what participants wanted were inspirational stories of adults (interviewees were aged between 28 and 70) that they could find life affirming.

^{xxv} Jacqui Symons, Artists Diary Extract

^{xxvi} Participant response to KW

^{xxvii} This was of course only the opinion of two of the YPWCF who were participants.

^{xxviii} Participant response to KW

^{xxix} Staff questionnaire response

^{xxx} Kim Wiltshire, Artist Diary Extract

^{xxxi} Participant response to KW

^{xxxii} Depending on the patient, these can happen roughly every three months and last anywhere up to three weeks

^{xxxiii} Participant response to KW

^{xxxiv} 3 said they would not use the pack because they did not work in transition

SOME USEFUL READING AND WEBSITES

<http://65redroses.livejournal.com>

www.cff.org

www.cftrust.org

www.cfvoice.com

www.cfww.org/who

www.limeart.org

www.livingwithcf.co.uk

www.sickgirlspeaks.com

Some Guy (Brian Singer), *The 1000 Journals Project* (San Francisco: Chronicle Books, 2007)