

An evaluation of young people's involvement in the 'Teenage and Young Adult Cancer' James Lind Alliance Priority Setting Partnership

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The results of the Teenage and Young Adult Priority Setting Partnership project and can be found here: <http://www.jla.nihr.ac.uk/priority-setting-partnerships/teenage-and-young-adult-cancer/>

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This report is dedicated to the delightful memory of Lara Veitch who joined the Steering Committee for the duration of the TYA PSP and died from her cancer in May 2020.

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Executive Summary

Introduction

With the aim of encouraging more research on the priority topics identified by teenagers and young adults with cancer and the clinicians who care for them, three charities worked together to run a James Lind Alliance Priority Setting Partnership (JLA PSP) on this topic. These were the Teenage Cancer Trust, Children with Cancer UK and CLIC Sargent. The project began in 2016 and the Teenage and Young Adult (TYA) Cancer PSP published its Top 10 in January 2018.

TwoCan Associates were commissioned to evaluate the young people's involvement in the TYA Cancer PSP. The aims were to find out:

- What the young people saw as the impact of their involvement, on the process, the outcomes and themselves;
- What worked well in terms of their involvement and what could have been improved;
- The lessons for future PSPs involving teenagers and young adults.

Method

Four young people, who had all been members of the TYA Cancer PSP Steering Group, took part in semi-structured telephone interviews between January and February 2020. Each interview lasted 25-45 mins and was transcribed. The transcripts were analysed thematically to identify the main points for this report. The interviewees commented on the first draft. Three members of the PSP project team then reflected on this draft to draw out key lessons and recommendations for future PSPs involving teenagers and young adults.

Findings

Impact of the involvement

As fully-integrated members of the Steering Group, the young people involved had influenced many decisions throughout the project. Their impact on the outcome was most obvious at the final workshop. The interviewees believed the final Top Ten would have looked very different if there hadn't been any young people involved.

Reaching the end of the PSP and generating the Top Ten priorities felt like a major accomplishment for the interviewees and they expected it would make a real difference to research on TYA Cancer going forward.

The experience of being involved also had a personal impact on the individuals themselves. They had found it rewarding to be able to put their cancer experience to good use, especially in ways they hoped would benefit others. This had contributed to an improvement in their mental health. They had learnt a lot from talking with other young people affected by cancer, as well as gaining confidence and new skills.

This learning had influenced the clinical practice of one interviewee who was a student nurse at the time, and had encouraged others to become strong advocates for high quality involvement in other research.

Reflections on the process of being involved

The interviewees described working on the PSP as their best experience of involvement, because it felt meaningful and impactful. They mostly identified positive factors that had made their involvement so successful.

It seemed important that the invitation to get involved was timely for some, as it arrived at the end of their cancer treatment, when they felt ready and willing to use their experience for good of others. As young people who were studying or had recently finished college/ university, they had felt able to manage the workload and demands of the project.

They all felt well-prepared for their involvement, based on experience gained elsewhere, or from the support provided beforehand by the Patient and Public Involvement (PPI) Lead. By far the biggest positive influence was the culture created by the PSP team, i.e. their way of working together. The interviewees described this as being '*totally different*' to other projects, because it meant they felt safe to express their opinions and to ask questions, and felt confident their views were being heard.

This culture was created by:

- having four or five young people on the Steering Group rather than only two
- the respect and consideration shown by other Steering Group members
- having time to meet socially and informally with other PSP team members
- high quality practical and moral support from the PPI Lead

Their suggestions for improvements to the involvement included: having more time for preparation ahead of the first Steering Group meeting; reimbursing out of pocket expenses more quickly; meeting young people at the train station/ airport when they arrive in London for a meeting; paying young people for their time if this is essential for their involvement.

Lessons & Recommendations

The young people who were interviewed were unanimous in their encouragement to other teenagers and young adults to get involved in a JLA PSP.

The academic project team made the following recommendations for other PSPs involving young people:

Recruitment

- In any advertising for young people to be part of the Steering Group it is important to emphasise that no prior knowledge or expertise is needed, other than an experience

of the health condition, and that support will be provided to enable people to contribute all the way through.

Support pre- and post- meetings

- Recruit an experienced and dedicated PPI Lead to provide continuous support to the young people involved.
- Arrange for pre- and post-meeting calls with young people and check all their various needs have been met (See Appendix 2). Keep in regular touch and encourage a two-way conversation so that young people feel comfortable raising any problems or concerns.
- Be prepared to offer additional support to young people outside of meetings to manage the workload, particularly during the phase where survey questions are being processed and categorised as in or out of scope.
- Ensure the PPI Lead and other team members have sufficient prior knowledge of the JLA process to be able to support the young people involved for example through peer-to-peer support from other more experienced PSP teams.
- Ensure there is adequate budget for providing this support in the PSP project plan.

Practical support - travel and finances

- Ensure someone with capacity (if not the PPI Lead) is responsible for supporting young people with practical aspects of involvement such as arranging travel and reimbursing expenses.
- University and NHS Trust finance departments are often unwilling to change their expenses policies to support involvement, and PSP teams may need to push for new processes to ensure young people are reimbursed quickly. Alternatively, expenses may need to be handled via a PSP Partner who has more flexible policies for example, if there is a charity involved who can do this.
- Build-in regular checks to ensure young people aren't out of pocket at any time, as even the best systems may fail on occasion, through no fault of anyone involved.
- Be prepared to reimburse the expenses for a carer or friend to accompany young people to meetings if required.
- Check that accessibility requirements are being met, such as special assistance from rail companies and if not arrange for a team member to support young people with accessibility needs when using public transport.

Creating a positive culture for involving young people

- Create opportunities and time for the young people to meet informally with the team, for example over lunch or post meeting dinners.

- Allow sufficient time and resource for young people to spend time bonding together, this could be over lunch or dinner after meetings.
- Ensure there is sufficient budget for the PSP to include young people in the post-Top Ten phase of dissemination.
- Ensure young people are included as co-authors on manuscripts.
- Prepare for closure at the end of the PSP, so that there is a clear and natural end to the involvement and expectations are well-managed.
- Look for new opportunities for involving young people in the post-PSP work of translation and research development, which can make best use of the skills and experience they have gained from working on the PSP.

Introduction & Methods

1. Background

- 1.1 Young people, specifically teenagers and young adults (TYA), aged 13-24 years old at cancer diagnosis, are said to inhabit a "no-man's land" between the healthcare systems mainly centred around children or adults. The cancers young people develop are often different to those of adults or children. Their physical, psychological and social responses to these life-threatening diagnoses are unique, and the outcomes from their cancers are distinct, sometimes better and sometimes poorer than older adults.
- 1.2 Young people with cancer are less likely be involved in clinical trials than children, which means the specific aspects of the cancers they develop and the way common drugs are handled by their bodies is less well understood than for children or older adults.
- 1.3 To encourage more research which focuses on the priorities jointly identified by young people with cancer, their carers and the professionals that work with them, three charities funded a Teenage and Young Adult Cancer James Lind Alliance Priority Setting Partnership (TYA Cancer JLA PSP). These were the Teenage Cancer Trust, Children with Cancer UK and CLIC Sargent.
- 1.4 The first meeting of the PSP took place in November 2014. Recruiting members to the Steering Group took some time as the TYA cancer community is relatively small, which meant that the PSP was not 'formalised' until 2015. Young people were invited to join via a nationwide advert. They met with the Steering Group in July 2015, and those who were interested in carrying on attended the first official Teenage and Young Adult (TYA) Cancer Steering Group meeting in February 2016. The final workshop which generated the TYA Cancer Top Ten was held in January 2018. Dissemination has continued since the final report was launched in September 2018. The evaluation of their involvement in the PSP was commissioned in December 2019.
- 1.5 Young people on the Steering Group attended face to face Steering Group meetings in London and Manchester, regular teleconferences and email communication, as well as email/phone contact from the PPI lead and project coordinator to arrange travel. Their contribution was mainly equally shared with professionals, although there were key points in the process where if there was disagreement within the Steering Group the young people made the final decision. Each meeting required a minimum of three young people to be able to attend before going ahead.

Steps in the James Lind Alliance process and young person/professional contribution:

- Protocol development - Shared
- Development of surveys - Shared
- Dissemination of surveys - Shared
- Removal of out of scope questions - Young people made final decision whether a question was out of scope if there was disagreement between the team
- Formatting survey submissions into questions - Shared
- Literature searching - Young people made final decision if there was disagreement as to whether the question had been answered
- Analysis of results - Shared
- Prioritisation of questions for second survey - Shared
- Top 10 workshop - Shared

About this evaluation

1.6 TwoCan Associates were asked to evaluate the involvement of young people in the PSP. The aims of the evaluation were to find out:

- What the young people involved in this PSP saw as the impact of their involvement, on the process, the outcomes and themselves
- What worked well in terms of their involvement and what could have been improved
- The lessons for future PSPs involving teenagers and young adults.

About the author of this report

1.6 The evaluation was carried out by Dr Kristina Staley from TwoCan Associates, a PPI consultancy that carries out research and evaluations. TwoCan helps organisations to develop PPI strategies, and to improve their policies and practice to meaningfully involve people who use services in their work. For further information see www.twocanassociates.co.uk

2. Methods

- 2.1 Five young people, who had all been members of the TYA Cancer PSP Steering Group, were invited to participate in the project by email. This introduction explained what taking part would involve and the steps taken to ensure confidentiality and data protection. One participant did not to take part due to poor health.
- 2.2 A semi-structured interview schedule was developed by TwoCan drawing on previous experience of conducting multiple evaluations of patient and public involvement in research. This schedule (see Appendix 1) was agreed with the evaluation commissioners.
- 2.3 The interviews were all conducted by phone in January and February 2020, each one lasted 25-45 mins (average = 30 mins). At the start of each interview, the interviewees gave their consent to take part, to be recorded and to be re-contacted when a draft report was available for comment. The interviews were digitally recorded and transcribed. The recordings and transcripts were deleted at the end of the project.
- 2.4 The transcripts were analysed thematically to identify the main points for the report. Sub-themes were identified using inductive thematic analysis, i.e. they were generated from the data up, rather than being shaped by existing theory. In the report, direct quotes are presented using italics. The interviewees were the first to comment on the draft report and agreed to how their quotes had been used. The commissioners, the three members of the PSP project team, were invited to reflect on the final draft to develop the key lessons and recommendations for future PSPs involving teenagers and young adults.

Findings

3. Impact of the involvement

- 3.1 The interviewees identified three ways in which their involvement had made a difference to the PSP and beyond. They described an impact on:
- The outcomes of the Teenage and Young Adult Cancer PSP
 - Themselves as individuals
 - Their lives and work after the PSP

These will now be discussed in turn.

Impact on the outcomes of the TYA Cancer PSP

- 3.2 When patients are genuinely involved in a project, it can be harder to identify the precise points at which they have an impact. As full members of a team, their voice is one of many that influence decisions on an ongoing basis, and it can be difficult to remember the exact contributions made by any one individual. For this reason, it proved difficult for the interviewees to describe their impact on the ongoing work of the PSP, except at the final workshop. In this workshop, a mixed group of stakeholders review a short list of prioritised questions to agree a final top ten. The interviewees felt the outcome of the workshop would have looked very different if there hadn't been any young people involved.

We spent more or less a whole day putting the top ten into order. That was a battle of getting your voice and your opinion heard. So that day was the day that counted the most, because for professionals something might be in the top ten, but it might be different for a young person... if young people weren't there, it might have been more medical, or there might have been priorities in the top ten that wouldn't have been there for a young person.

You could literally see the impact you were making, because the questions were printed out on a piece of A4... and if you made a contribution, and everyone said that was a good point, you'd literally move the paper round to fit the ranking!

- 3.3 One interviewee thought it extremely important that the workshop gave participants time and space to make the case for their priorities, as this provided an opportunity for patients to inform clinicians about what really matters from the patient perspective.

To be able to explain why things should be in the Top Ten, meant so much to me as a patient, because I was able to say, 'This has directly impacted my life. You might be a clinician and you might find that annoying, but this has had a huge impact on my life personally, and I know it has impact on so many other patients

as well, and their families, so listen to us on this one - this is really, really important.'

- 3.4 Reaching the end of the PSP and generating the Top Ten priorities felt like a major accomplishment for the young people involved, as it represented the culmination of years of hard work and they expected it would make an important difference to research on TYA Cancer going forward.

Being there [at the final workshop] and finally seeing them [the Top Ten] was quite big. Seeing the project through to the end was of great value to me... I found it quite rewarding... because previously I'd just been looking at leaflets and stuff like that, whereas this one was a bigger scale and it had more of an impact.

We've addressed things that have niggled away at us like late diagnosis or poor treatment outcomes or a negative approach to life after treatment... that's incredibly important. I feel like I've actually achieved something out of this that's probably going to be really worthwhile and is probably going to benefit cancer patients of the future, and their families, and clinicians.

Impact on the individuals involved

- 3.5 The interviewees reported that the experience of being involved in the PSP had also had an impact on them personally, in many different ways. Firstly, they had found it rewarding and affirming to be able to put their experience to good use, especially in ways they hoped would benefit others. They found this had improved their mental health.

I always say that I didn't want my diagnosis to go to waste, and now something tangible came out here that could help other people in the future. That feels amazing. Just because, when this happens to you so young, you need to be able to find a positive that comes out of it, just for your own sanity. This is a huge positive for me.

The whole process has had a very positive impact on my mental health. I didn't realise how much of a mental impact it would have on me in a positive way. Just being able to have a group to discuss the negative experiences with, and to get those out and in the past, and having that opportunity to turn something that was a very horrible experience into a positive outcome, it definitely changes your mentality. It's an opportunity to reflect and see how far you may have come.

- 3.6 One interviewee reported that the PSP had helped her to resolve some of the frustrations she had experienced during her cancer treatment and therefore she was finally able to let go of some of the negative emotions.

I was so angry with GPs when I first got involved. That was the thing that I championed the whole way through, because I wanted there to be a better

approach taken to educating GPs. It's quite funny because it's almost as if now I've achieved getting that into the top five priorities, I feel like I can relax on that. I can rest easy now that that's there and hopefully work will be done on it.

- 3.7 These benefits were also felt by wider family members who not only contributed to the work of the PSP themselves, but were also delighted to see the positive change in their loved ones.

It was really good for my family as well. They liked being involved in the survey. It was good for them to see that I was putting this driving energy into something so positive... because obviously it's a really dark and negative time, so for there to be some kind of good to come out of it is incredible.

- 3.8 Working with other young people with experience of cancer, both on the Steering Group and in the workshop, for some interviewees had been a welcome confirmation of their shared experiences and their similar views on priorities for research.

It was so nice for other patients to come [to the final workshop] and then advocate for the same priorities... it makes you realise that what happened to you isn't as unique as you think, other people are struggling too, and that makes you feel far less isolated....

- 3.9 For others, it was learning about the variation in people's experiences of treatment and care that had proved particularly valuable. It prompted them to think about how they might encourage a wider range of views to be heard when involved in future research projects, and for one of the interviewees who was a student nurse, this learning subsequently had an influence on her clinical practice (see section 3.12).

- 3.10 The JLA process had been challenging for the young people in having to learn about the technicalities of research, but they felt they had managed it very well. Having been involved in the PSP had since enhanced their reputation and given them recognition in other research projects.

Each time I went to a PSP meeting, it felt it was getting more difficult, but as it was getting more difficult I was developing the skills to match the demand. I felt quite proud that I kept up with it from the start and didn't drop out... it's known in the projects that I'm involved in now, that I was part of the PSP, so that can be a bit rewarding as well...

- 3.11 All of the interviewees were involved in the dissemination of the TYA Cancer PSP Top Ten, and two reported finding this aspect of the project particularly enjoyable. It signified a commitment to their genuine involvement throughout the PSP. They had been rewarded by positive feedback from the audiences they had engaged, and through this experience they felt they had gained valuable new skills and greater confidence.

I've done a lot of dissemination work for the JLA project... what's clear is that the project team are really conscious about patient involvement to the extent that they include patients even after the project has finished...even this interview shows that... For me, it's been a massive confidence and career boost... it's given me a load of transferable skills that I wouldn't otherwise have had... because of the JLA, I feel like I'm a better public speaker. I'm more confident with scientific writing, more confident when I go on research boards, because it gave me the kind of grounding in what patient involvement should be.

Myself and another young person presented our top ten at a funders' meeting, so that was a very important meeting to attend. It was nerve-wracking at the start but it was a really good experience... Everyone was welcoming and they expressed how much of an impact our voices had, and that was from the funders themselves... So yes, we've heard that it's made a change, it's made a difference... and it's been good for confidence building.

Impact on life and work after the PSP

- 3.12 Gaining a greater understanding of different patients' experiences of cancer through working on the PSP, led one of the interviewees, a student nurse, to change her clinical practice:

I'm now almost qualified... and to have all the information that the PSP gathered from the questionnaire, and even just from the young people at the meetings, because we had healthcare professionals there, and there was so much discussion around it... I didn't plan for it to have an impact on my practice, but I feel like it has, just to have that understanding.

- 3.13 In common with other patients' experiences of being involved in a PSP¹, the interviewees described this as being their best experience of involvement. They were keen to share the learning with others to advocate for high quality involvement elsewhere, and to help to spread this best practice.

It was a real paradigm shift for me. It certainly made me argue the case in other projects where patient involvement hasn't necessarily been as good, for them to look to the JLA as the gold standard... and as I'm at medical school, one thing I'd like to do, is to do some research projects with clinical academics, or run a research day on what patients can do for medical research... I'd like to find a way make sure that patient involvement is part of the medical curriculum because it makes such a big difference to research. That's the long-term goal - my absolute biggest ambition would be to change the curriculum.

¹ Staley K and Crowe S. (2019) More Than a Top 10: How James Lind Alliance Priority Setting Partnerships transform research, people and organisations. TwoCan Associates, UK and Crowe Associates, UK.

4. Reflections on the process of being involved in the PSP

- 4.1 The interviewees' reflections on the process of being involved mostly identified the positive factors that had made their involvement so successful. Their suggestions for improvements were few and relatively minor.

The JLA project was the shining example of how patient involvement should be done... I still hold it up as being the best experience I've had of being involved as a patient and actually having my voice heard - really heard, really being listened to. Looking back on it, I think it would be tough to do it any better.

A lovely, lovely piece of research, and it was a really good experience and I miss it now!

- 4.2 Their feedback will now be now discussed in relation to:

- Why they got involved and their expectations of the project
- Preparing for involvement
- The culture of the TYA Cancer PSP
- Practical support during their involvement

Why the young people got involved and their expectations of the project

- 4.3 For two of the interviewees, joining the TYA Cancer PSP was their first experience of being involved in a research project. The invitation had been timely, as it arrived at a point when they felt ready to move on from their cancer experience. They thought it was important that they had completed their cancer journey before getting involved.

During my time being a patient I was asked to attend other groups, and at that time it just wasn't for me... I think there must have been a shift in my mentality when I heard about the PSP, because I was more looking ahead to what I could use out of what I'd experienced, rather than being stuck in what I was actually going through. It had been more difficult to look past that beforehand.

At that stage in my journey I was desperate to use what had happened to me to do some sort of good, so I was quite keen to proceed with the PSP... I was not long cancer-free. I'd been given the all-clear only about 9 months before then.

- 4.4 The opportunity to make a difference to the future of young people's cancer care via a new focus for research was what appealed to some of the interviewees and informed their decision to get involved.

It was going to highlight topics that had been ignored before, and have a bigger patient and family and carers input than would normally be the case. So it was going to highlight things that would be high on the list of priorities for young people and their carers – that's what seemed important.

- 4.5 Others had had some prior experience of involvement and saw the PSP as simply another opportunity to contribute their views to research. They based their expectations of the project on previous experiences of involvement. They hadn't completely understood the JLA aim to change the research agenda and the major difference the TYA Cancer PSP hoped to make.

I hadn't quite appreciated how big the project was at the very beginning... Now what I'm starting to realise is that this project has real implications for what gets funded. Perhaps not as fast as we were hoping it would ... but it will make a huge difference to what the research landscape looks like for the next 10 years...

I just expected that I'd be there as an extra voice with what I'd been through with my treatment and stuff. But I feel like I got a lot more out of it than just being an extra voice.

Preparing for involvement

- 4.6 The interviewees who had considerable experience of being involved in other projects felt they didn't need much information or support beforehand. The introductory booklet that had been given to every Steering Group member helpfully explained what their role was. They also had prior knowledge of the role of involved patients.

We didn't need training as such, because everything as we went along was explained to us. We always had support on hand if we weren't sure about anything or if we needed to ask any questions. Also the group of people that were involved, they were lovely and they couldn't do enough to support us.

- 4.7 The interviewees who were new to involvement felt that the support provided by the PPI Lead had been very good and had made sure they didn't feel intimidated going into the Steering Group meetings. However, one felt they would have liked more time for discussion of their role ahead of the first meeting.

We got quite a lot of information at the very start, quite close to the first meeting, a day before... prior to that we did speak to the project lead, so we were well supported. But if that information pack had come a bit earlier, we could have had time to chat about it, just to go through and process it, as it was a new experience.

- 4.8 All of the interviewees were at University or starting their career having left University at the time of the PSP. Although this had been an intense and busy time of their lives, the pace of the meetings had been manageable. One interviewee commented that the demands of being involved in a PSP might have been more challenging for younger people and children, or for people who hadn't any experience of further education.

You do that heavy literature, loads of going through things, and it was a lot of commitment going down to London, and the young people involved who stayed on the longest, they were at Uni or they'd been to Uni and I think they were used to that kind of workload... I can't speculate for other people, but the pace and the context of the material was heavy... it's just the nature of research.

The culture of the TYA Cancer PSP

- 4.9 By far the biggest factor that contributed to the successful involvement of the young people was the culture created by the PSP team, i.e. their way of working together. The interviewees described this as being '*totally different*' to other projects, because it meant they felt safe to express their opinions and were confident that their views were being heard.

Some things that you get involved with, sometimes they're like tick-boxes... Whereas this one, whatever you said was discussed, and you could freely say what you wanted to...

- 4.10 Importantly it also meant that the young people felt comfortable asking questions when they didn't understand what was being discussed.

As a cancer patient I know my own illness, but not others. But I didn't feel any embarrassment or difficulty in asking about the technical questions relating to other cancers... that made me realise this was a good way of doing things. Being able to ask questions that might seem perhaps slightly naive to professionals is harder than you think, and so what was really nice about this project was how easy it was to do that.

The first meeting was quite confusing for us. I found the abbreviations and technical terms a bit overwhelming at first, but the good thing was that everyone was open to us saying, 'We're not actually sure what's going on here'. So they were saying, 'Let's take a pause, let's go over it with you, let's see where we are', which was really helpful.

- 4.11 A number of factors contributed to creating this positive working culture. One was ensuring a greater number of patients in the meetings, and another was the respectful attitudes and consideration shown by other Steering Group members.

They were probably the best steering group I've experienced in terms of inclusivity... it had a high patient to professional ratio. Sometimes I'm on with two others in about a group of 30 to 40 doctors, whereas in the JLA project, it was about 5 or 6 of us with about 20 other doctors, so there was much more of a collective voice, and we all felt it was a little bit easier to share our opinions because we were around peers as well as professionals. There's strength in numbers!

It's the people that were involved, the healthcare professionals and even the researchers. They were really nice people. It might be that they're used to working with young people... they need to have certain characteristics because it takes that openness...having a sense of humour, being patient. It's just genuinely being welcoming...

4.12 In the final workshop, the skills of the JLA facilitators were thought to have been crucial to keeping a balance of views in the room. The discussions got quite heated because people felt so strongly about the priorities, but the facilitators ensured that *'Everyone did work well as a group in the end'*.

4.13 Equally important was what happened outside the meetings. The young people were given time to get to know each other by having meals together, travelling together or taking part in informal debrief sessions with a member of the PSP team. This additional social and discussion time contributed to their effective engagement in the business meetings.

It was quite nice to have a moment to get to know everyone [all the young people taking part], because we were so focused on the project while we were in the meetings, so it was nice to have that afterwards. We then had that bit more confidence to voice our opinions, because we knew everyone...

Practical support

4.14 The interviewees were grateful for the excellent support they had received from the PPI Lead throughout the project, who was *'always available, whenever we needed help.'*

4.15 One area where they felt the practical support could have been improved was in relation to their travel. They explained that the team had heard their requests and made significant changes to make their travel easier, including booking flights and hotels the day before a meeting, so they wouldn't be tired during the meeting. Their flights and hotels were paid for in advance, but the additional costs from the journey took a while to get reimbursed. Some of the interviewees would have found it helpful if they could have had these additional expenses reimbursed sooner or even paid up front.

Travel costs were an issue for us. Although the main expenses were covered, there were several trains that I had to get, and the Underground, things like that. They seemed like little costs but they actually added up. The last one actually cost £75 which was quite a chunk when you're a student and you've not got a lot to begin with... and it took three months to get our expenses back, which could have an impact on people being able to attend.

- 4.16 An additional travel-related issue was providing practical support for people in wheelchairs. One of the interviewees who uses a wheelchair, reported that being reliant on Network Rail staff to help with getting on and off the trains can be worrying. She hadn't thought to ask for help from the Project Team, but if someone could have met her from the train it would have helped. In fact such support might be welcome for any young person who feels daunted by coming to London for the first time.

I have a lot of health issues so managing that was quite difficult for me... it's just having to get through things on the day of the meetings. The travel aspect was difficult as well... My worry was mainly people not being there, the Network Rail staff that got you on and off the train. Sometimes there wasn't anyone and I just had to roll my chair out of the train. Or you rely on people around you to help you, which I was quite surprised at... but actually some young people might just find somewhere like London overwhelming and feel afraid of getting lost...

- 4.17 One of the interviewees took time off work to take part in the project, which was not a problem for her because her employer was willing to be flexible. However, she commented that this might not be possible for everyone, particularly if it meant they lost out on their wages. Some young people might also need their time reimbursed to be able to attend.

5. Advice to other young people

- 5.1 When asked what advice they would give to other young people considering whether to get involved in a JLA PSP, the interviewees said the following:

You don't need to have any prior experience to be really active in an easy way. I was relatively new to research and that wasn't a barrier to me being genuinely involved in the group. So I'd say to anyone, if they have experience as a patient or carer, to get involved with the JLA as a whole just because it's a fantastic concept and a brilliant idea. The people who work for it are genuinely interested in fairness, not only hearing patient voices but also making sure that they influence medical research. It's an entirely democratic process, and I would recommend it to anyone.

At the beginning you might find it's overwhelming, but as you get into it and you're involved more, you get used to the pace of work. Don't be afraid to ask questions and if you need any support just ask. The end result is really rewarding and you feel proud of yourself afterwards. A real achievement.

Grab the opportunity, because it's a unique opportunity and you might surprise yourself. You might think at the start that you're not going to have much of an impact, but you will grow in yourself throughout the process, and not a lot of people get that opportunity. I would definitely recommend it, if you're in the right space to do it. It's not going to be for everyone, but I could see that it would be a good experience.

Get involved. Your voice will be heard, it'll be listened to. You'll be treated as an equal and what you say matters, and what you say can change things for other people in the future, so please get involved.

6. Lessons and recommendations

6.1 The three members of the TYA Cancer PSP project team reflected on the final draft of this report and their experience of involving young people to draw out key lessons and recommendations for other PSPs. These related to:

- Recruitment
- Support pre- and post- meetings
- Practical support - travel and finances
- Creating a positive culture for involving TYA

These will now be discussed in turn.

Recruitment

6.2 Teenagers and young adults with cancer were recruited to the Steering Group via an advertisement that went to all treatment centres in England, Scotland and Wales. Notably, the young people who came forward had all either been to, or were currently attending college or university, which raised some concerns about the diversity of experience amongst those involved.

6.3 Some TYA who initially came to the first meeting, then decided not to take part. This was part of the natural attrition that happens with all involvement. Not everyone wants to make a commitment once they find out more about a project, or their circumstances may change which makes their involvement no longer possible. Some loss of numbers from initial recruits is therefore to be expected.

Recommendation: In any advertising for Steering Group members, it is important to emphasise that no prior knowledge or expertise is needed, other than an experience of the health condition, and that support will be provided to enable people to contribute all the way through.

Support pre- and post- meetings

6.4 The JLA process can be challenging and the workload demanding, as much for the project team members as for the young people involved. The outline of the process provided by the JLA proved helpful, but even the academic Steering Group sometimes felt unprepared for meetings because the process was new to them. This meant the PPI Lead wasn't always able to help prepare the young people for meetings in the way she would have liked. In spite of these difficulties, everyone on the Steering Group rose to the challenge because they were committed and determined to see it through to the Top Ten.

Recommendations

- Recruit an experienced and dedicated PPI Lead to provide continuous support to the young people involved.
- Arrange for pre- and post-meeting calls with young people and check all their various needs have been met (See Appendix 2). Keep in regular touch and encourage a two-way conversation so that young people feel comfortable raising any problems or concerns.
- Be prepared to offer additional support to young people outside of meetings to manage the workload, particularly during the phase where survey questions are being processed and categorised as in or out of scope.
- Ensure the PPI Lead and other team members have sufficient prior knowledge of the JLA process to be able to support the young people involved for example through peer-to-peer support from other more experienced PSP teams.
- Ensure there is adequate budget for providing this support in the PSP project plan.

Practical support - travel and finances

- 6.5 The practical support for the young people in this PSP was provided by another team member in order to share the workload with the PPI Lead. They aimed to make the practical arrangements for the young people as easy as possible by planning every stage of their journey and offering different options for travel times (See Appendix 2).
- 6.6 To ensure the young people weren't out of pocket at any time, the staff member reimbursed the young people for minor travel expenses from her own money and then claimed this back from the University. This was a change in the organisation's policy that the project team managed to negotiate with their Finance Department.
- 6.7 Although the team endeavoured to reimburse the young people quickly, on occasion this didn't happen for reasons that were beyond anyone's control, e.g. organisational and structural changes in institutions reimbursing travel.
- 6.8 This PSP was unable to pay the young people for their time, due to the funds available and the length of time the project took to complete. This is a complex issue, and will need to be decided by each PSP on a case by case basis.

Recommendations

- Ensure someone with capacity (if not the PPI Lead) is responsible for supporting young people with practical aspects of involvement such as arranging travel and reimbursing expenses.
- University and NHS Trust finance departments are often unwilling to change their expenses policies to support involvement, and PSP teams may need to push for new processes to ensure young people are reimbursed quickly. Alternatively, expenses may need to be handled via a PSP Partner who has more flexible policies for example, if there is a charity involved who can do this.
- Build-in regular checks to ensure young people aren't out of pocket at any time, as even the best systems may fail on occasion, through no fault of anyone involved.
- Be prepared to reimburse the expenses for a carer or friend to accompany young people to meetings if required.
- Check that accessibility requirements are being met, such as special assistance from rail companies, and if not arrange for a team member to support young people with accessibility needs using public transport.

Creating a positive culture for involving TYA

- 6.9 The project team included people who had worked for decades with young people and this experience enabled them to create an enabling culture for involvement of TYA in the Steering Group.
- 6.10 The team ensured there was time and budget for the Steering Group as a whole to socialise, and for the young people to spend time alone as a group. This allowed everyone to bond as a team, and for the young people to connect with each other and gain confidence. This gave the team a strong sense of solidarity, which limited tensions and made any conflict easy to resolve.
- 6.11 At the same time, the boundaries of roles and responsibilities were clear and maintained, so that Steering Group members developed mutual respect for the different kinds of expertise in the team. The academics and health professionals also demonstrated their willingness to share power with the young people, for example, by giving the final decision about categorising questions as being in or out of the project scope to the young people, if the Group as a whole were undecided.
- 6.12 The young people have continued to be involved in the dissemination work post publication of the Top Ten, through attending meetings with funders and being co-authors on a journal article. They have shared their personal experiences and

opinions on why the Top Ten priority topics are important to them, which has proved very powerful to different audiences, particularly funders. The PPI Lead has kept in touch with the young people all the time she has continued to work on the project but this will soon end, once she moves onto other work. The young people have been invited to get involved in research projects that are planned by the project team in response to the TYA Cancer PSP priorities.

Recommendations

- Create opportunities and time for the young people to meet informally with the team, for example over lunch or post meeting dinners.
- Allow sufficient time and resource for young people to spend time bonding together, this could be lunch or dinner after meetings.
- Ensure there is sufficient budget for the PSP to include young people in the post-Top Ten phase of dissemination.
- Include young people as co-authors on manuscripts.
- Prepare for closure at the end of the PSP, so that there is a clear and natural end to the involvement and expectations are well-managed.
- Look for new opportunities for involving young people in the post-PSP work of translation and research development, which can make best use of the skills and experience they have gained from working on the PSP.

Appendix 1: Interview Schedule

1. Can you please tell me a little bit about yourself and how you became involved in this JLA PSP?
2. What made you want to get involved? What were your expectations of getting involved?
3. What information and support did you have before your first meeting? What did you find useful? Could anything have been done better? Was there any additional training or support that would have been useful? Was it clear what you can expect from involvement?
4. What was it like being on the Steering Group/ attending the final workshop? (discuss each in turn)

What worked well and why? Is there anything that could have been done better? Were your expectations met?

5. Were there any challenges or difficulties in being involved? Were these resolved at the time? (*if not*) How might they be overcome in future?
6. What difference do you think your involvement made to the project? How do you know what difference you made – did you get feedback from others? What kind of feedback did you receive? Could that feedback have been improved in any way?
7. What has been the most significant change for you from being part of this project? Were there any surprises for you?
8. Would you want to be involved again (in the follow up to this project or in research projects that address priorities)? Why do you say that?
9. What would you tell other young people about being involved in JLA PSPs?
10. Is there anything else you'd like to add?

Appendix 2: Checklist for PSPs involving young people

- 1) Advertise the opportunity to be involved widely, to try to reach a diverse range of young people. When advertising make clear that no prior expertise/knowledge is required other than experience of the health condition that the PSP is focusing on.
- 2) Aim to have around one third of the Steering Group represented by young people, over-recruit to allow for a few people to drop out, and be prepared to add new members if the numbers become insufficient to allow young people's voices to be heard.
- 3) Have a dedicated project team member who leads on PPI, who is supported by another project team member.
- 4) Have a dedicated team member who is responsible for practicalities such as arranging travel, this would allow the PPI Lead to focus on supporting the young people.
- 5) Make it as easy as possible for young people to attend meetings:
 - Ask about what timing and location of meetings works well for them.
 - Look up travel times for them and suggest routes to use on public transport.
 - Offer the choice for them to get a taxi from the station to the meeting venue if preferred.
 - Offer hotel booking the night before/after the meeting if they are travelling a long way.
 - Offer funding for someone to accompany them if they wish.
 - Offer to meet them at the station, particularly if they have access needs.
- 6) Make contact with young people before each meeting to check:
 - Their travel has been booked.
 - If they need any further help with travel or how to get to the meeting.
 - They know what to expect at the meeting.
 - If they have any queries about documents or information sent out prior to the meeting. Be mindful that as the PSP progresses the 'work' gets more challenging and more support may be needed.
- 7) Make contact with young people after each meeting to check:
 - They are OK following the meeting, no upset or distress has been caused.
 - Was there anything they wanted to say and didn't feel they could?
 - Their journey home was OK.
 - If they have any queries about what was discussed at the meeting.
 - They are clear about next steps in the project.
 - Their expenses have been reimbursed.

- 8) Maintain contact in-between meetings to keep young people updated on the progress of the project and to offer support with any work the Steering Group have been asked to do in-between meetings (e.g. reviewing the survey).
- 9) Have in place a process to support young people if one of them becomes unwell and is unable to continue to participate as a Steering Group member; or if a young person becomes very unwell once the project ends – consider how this information will be communicated to the young people and support offered.
- 10) Keep expenses for young people to a minimum:
 - Offer to book travel for them so it is paid for in advance.
 - Reimburse any out of pocket expenses at the meeting in cash if possible.
- 11) Offer the opportunity for young people on the Steering Group to attend the final workshop, as well as recruiting additional young people to attend.
- 12) Offer opportunities for young people to be involved in dissemination of the Top 10, such as presenting at patient and professional conferences and as co-authors on publications.
- 13) Offer opportunities to young people to be involved in future studies that emerge from the priorities.
- 14) Make time to 'end' the relationship, this will give young people a sense of closure and 'permission' to move on to other PPI activities.