

Evaluating eyeYPAG

A co-production project



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Summary

eyeYPAG is a young persons' advisory group (YPAG) for eye and vision research based at Moorfields Eye Hospital which started in March 2019. We wanted to find out what has been good about the group, what difference we have made and how we can develop and improve in the future. So, a group of eyeYPAG members co-produced an evaluation and asked group members, researchers who had worked with us, group organisers, parents and carers and funders for their views.

Main findings

- Group members and their parents and carers talked about wanting to join eyeYPAG to meet other young people with similar interests or experiences or finding this a benefit of being a member of the group.
- Benefits for eyeYPAG members of being in the group include learning about research and eye conditions, developing new skills and confidence and having the chance to do new things and meet new people.
- Group members talked about the importance of feeling that they are making a difference to research. Adults also talked about how involving children and young people in research makes research better, and that children and young people have a right to be involved, as research is something that affects them.
- The way we work together, using a co-production approach and creative methods, was really valued by group members, including the work we have done as a group on our 'shared identity' (including developing a group logo and creating 'shared agreements' for how we work together).
- Most researchers came to work with the group because they already knew about the group or had been told about the group by someone else who knew about us. Most came to work with the group in the planning stages of their research, but some had come back at different stages or wanted to do so.
- Researchers valued the personal experience of the group of having, or knowing about, eye and vision conditions, as well as knowing about research.
- Good planning really helps researchers get the most from working with the group, and sessions worked best when sessions were as interactive and creative as possible, even when meeting online.
- Everyone agreed that there are advantages to meeting online as well as in person, although in person meetings are probably more fun and give us a chance to be more creative.
- Benefits for researchers of working with the group include improved research plans and methods, exploring new perspectives and ideas, learning new things and having fun!

Our recommendations:

- Resume in-person meetings alongside some online meetings when we can
- More creative sessions
- Make sure all research sessions are engaging, accessible and interactive
- Refresh the group membership: get some new members
- Group to develop guidance/top tips for researchers coming to meetings
- Support group members to set personal goals (e.g., write a blog post, give a conference presentation) and make a plan for how to achieve these
- Let more researchers know about the group (e.g., make a promotional film)
- Make sure we continue to evaluate and collect information on eyeYPAG and the difference it makes to research
- Ask researchers to credit the group and, if possible, include them in publications
- Think about the long-term future of the group, including being included in more funding bids





Introducing eyeYPAG

eyeYPAG is a young persons' advisory group (YPAG) for eye and vision research based at Moorfields Eye Hospital funded by [Moorfields Eye Charity](#), National Institute for Health Research Moorfields Biomedical Research Centre ([NIHR Moorfields BRC](#)) and [Santen](#). The group is part of the [GenerationR](#) alliance of YPAGs in England and the [eYPAGnet](#) consortium of European YPAGs as well as the international [iCAN network](#).

Who we are

21 young people have been involved in eyeYPAG since we started in March 2019, and we currently have 14 members aged between 10 and 18. 11 are female and 3 male. 7 have eye and vision conditions. 3 are siblings of group members with eye and vision conditions and the remainder joined because they have taken part in clinical trials and/or have an interest in eye and vision research.

What we do

In our first year (March 2019-February 2020) we met 5 times at or near the Moorfields Children's Eye Centre to:

- Learn about research
- Work with researchers looking at eye conditions and treatments
- Make sure information about research is children and young people friendly
- Share ideas on what should be researched and how
- Use a co-production approach to work together

In the second year we changed to meeting online because of the COVID-19 pandemic.

Key achievements

- Since we started we have worked with 13 different research projects, spoken at 4 conferences and events and made a [podcast](#).
- In June 2020 we won the Moorfields BRC Patient and Public Involvement and Engagement in Research award: <https://moorfieldsbrc.nihr.ac.uk/news-and-events/ppie-award-2020>.
- We worked with artist Sofie Layton and co-facilitator Jacqueline (Jacq) Miller, to develop our group 'shared identify':
 - We co-designed a group logo, for our group member's hoodies.
 - We [worked together](#) to reach six 'Shared Agreements' (ground rules), to reflect our working relationships and co-production ethos, presented in a co-produced film: https://generationr.org.uk/eyeypag_shared-agreements/

For more information about the group, including blog posts about meetings and events by young group members please see: <https://generationr.org.uk/eye-ypag/>.

This evaluation

Some definitions (other words that might need explaining are in bold below)

- **Evaluation** uses research methods and approaches to find out how well a service or project is working and how it could be improved
- **Co-production** is a way of working in which adult professionals and young people work together in equal partnership

We wanted to evaluate the eyeYPAG so that we could learn from everyone involved what has been good about the group, what difference we have made and how we can develop and improve in the future. A group of eyeYPAG members (**the young evaluators**) co-produced the evaluation with the group's facilitator, Louca-Mai, working together from planning the project to writing this report.

Evaluation aims:

- To find out what difference the eyeYPAG has made to research, and to group members
- To understand what has worked well and what could be improved after the first two years of eyeYPAG
- To use what we learn to help improve and plan for the future of the group, and help other people interested in involving children and young people in research.

What we did (methods):

Once we had developed our aims we decided on our methods, **sample** (who we wanted to talk to) and developed our **data collection tools** (focus group questions and surveys). We collected information (**data**) online in March-May 2021 through:

- Workshops with eyeYPAG members in our March (n.8¹) and June 2021 meetings (n.10) led by young evaluators with Louca-Mai and Jacq (who works with us) helping. In the March session we asked the group for their views on eyeYPAG and in June we presented our draft findings to see whether they agreed with these and had anything to add.
- Survey of YPAG members (10)
- Focus group with researchers (n.5) who have previously worked with the group, led by LM with young evaluators helping, as we thought they would be more honest that way.
- Survey for researchers who could not come to the focus group (n.4)
- Survey for parents (n.7)
- Focus group with the people who help organise the group (n.3). The young evaluators planned and ran this session.
- Survey for the eyeYPAG funders (n.2)

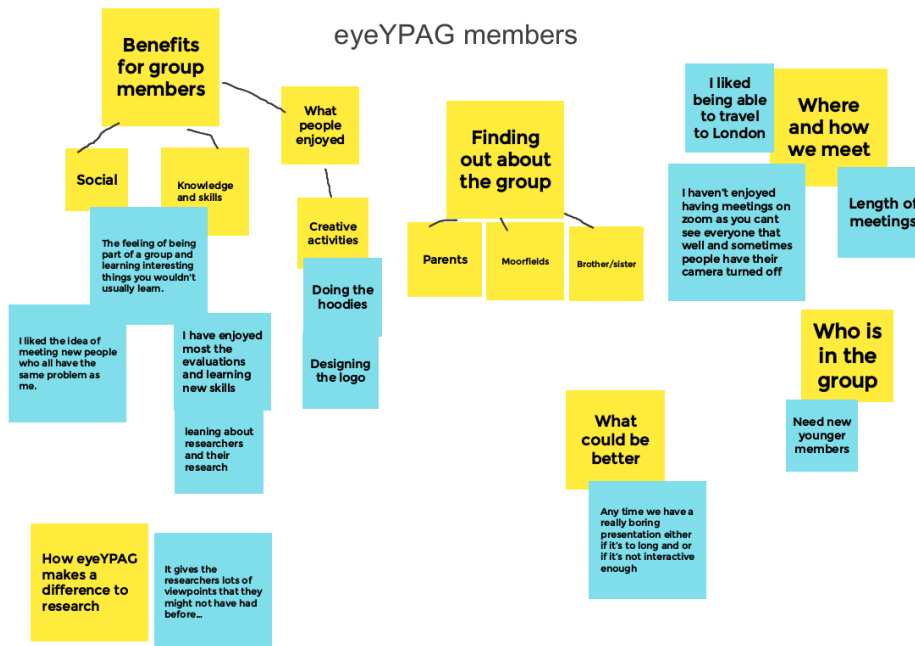
¹ n(number) is how many took part

Analysing our data

We recorded and transcribed (wrote down) the focus group conversations and then analysed this information and the **qualitative data** (words not numbers) from the online surveys using the following steps:

- We all read through the data we had collected and then met online and came up with some ‘themes’. This is a way of organising the data into categories to make it easier to analyse:

Figure 1: Example jamboard from analysis meeting



- Louca-Mai then created a document listing all the themes and we were all given data to analyse. We went through the transcripts and qualitative survey answers and ‘coded’ the answers to different themes (e.g., by highlighting words which related to each theme in a different colour).
- Louca-Mai then put all the data into special analysis software, using the coding the group had done and filling in any gaps to make sure all the information was coded.
- This analysis and the quantitative data (numbers) are the findings you will read about in the rest of this report.

How we worked together:

We met regularly during the project on Zoom, shared information and ideas by email and worked on project documents in between meetings on GoogleDocs. Louca-Mai advised us on methods and ethics but all the big decisions about the project were made together, with young evaluators deciding what they wanted, and were able, to get involved in. We kept a record of how many hours we all worked on the project so that everyone could be paid fairly for their contribution at the end (Louca-Mai was paid to work on the project as part of her job and the young evaluators were paid an hourly rate). For information from the project team on how we found working on the project see [the final section](#).

Findings: benefits of involvement

Belonging. Group members and their parents and carers talked about wanting to join eyeYPAG to meet other young people with similar interests or experiences or finding this a benefit of being a member of the group. They also talked about valuing how we work together, reflecting the work we have done as a group on our 'shared identity', as well as advising on research projects.

I love meeting new people who are interested in the same things as me.
(YPAG member)



Meeting other young people who are also passionate about getting their voices heard and doing it in a way that we can all work together in a family-like way. (YPAG member)

I thought it was great for [my child] to attend as he is a patient at Moorfields with a rare eye condition and it would be good for him to meet other children with eye conditions. (parent)

... being able to identify as part of a group, where she has a voice, has been good for [my daughter]. It has also helped her to identify as someone who has a visual impairment and to recognise that she is not alone in this. (parent)

[Being a member of eyeYPAG] helps me have more confidence in talking to new people. (YPAG member)

Learning. Group members told us how the group had made a difference to them, particularly learning new things

[I like] learning interesting things you wouldn't usually learn.
(YPAG member)

I get to learn about different eye conditions and help take the research forward to help people with the conditions.
(YPAG member)

Knowledge and skills which parents said their children had gained included:

- Understanding what problems children with eye/vision conditions face
- Appreciating how children can help adults design more meaningful and realistic research
- Learning to critically appraise other people's work and ideas
- Empowering them to engage and give their time to take on additional work and responsibilities, completely of their own accord.
- Developing skills working with adults and children they do not know
- More confident about exchanging views in a public forum.
- Participating in a process with tangible outcomes.
- Knowledge and experience of co-working
- Knowledge and experience working independently on projects that have a positive and long-lasting impact.



Making a difference. Group members also talked about the importance of feeling that they are making a difference to research:

I wanted to help young people get their voices heard, especially in a healthcare environment. I thought that I could make a difference.
(YPAG member)

[The researchers need young people's] point of view... because we're the ones they're researching [so] we have our say, and it helps them, it helps us, it helps everyone. (YPAG member)

[Working with eyeYPAG] gives the researchers lots of viewpoints that they might not have had before... I think it makes the research better. (YPAG member)

Adults who worked with the group also talked about the benefits for research of involving children and young people:

Children and young people can have very different perspectives and expectations of research and it is critical their voice is heard. They can have great insights that adults will fail to spot or think less important, but which might make all the difference when engaging their peers in research studies. However, their involvement is not only important in the design of research but also for the future of research as they're helping to shape the research (and researchers) of the future. (funder)

I feel very strongly feel that children and young people should be involved in research. I think it is my ethical duty to ensure that my research involves young people. (researcher)

[Involvement] makes it much more suitable for the children and young people who take part in the study... you get all their feedback and make the changes... [and] that then just makes it more successful in the end, either in the numbers of people willing to take part, because it's an appropriate project for children, or having a better experience while they're taking part. (researcher)

Children's voice and rights. Adults also highlighted that children and young people have a right to be involved, as research is something that affects them:

[Young people's involvement] makes research better, but also children and young people have a right to have a voice and have a say in things that affect them. (facilitator)

I don't think there's any way that I can know that everything that the group of patients [affected by research topic] want, so for me ... [public involvement] is finding out what [young people] want, either in terms of how we do the research, or even what the research is, right from the very start. What we research and how we do it obviously has a big effect on the patient population. (funder)

It's incredibly unethical not to allow people to have a voice in how research that involves them is being undertaken... [and] your study's going to be better, because it's going to be more effective, it's going to be a more powerful study if patients have been involved in the methodology of it. (researcher)

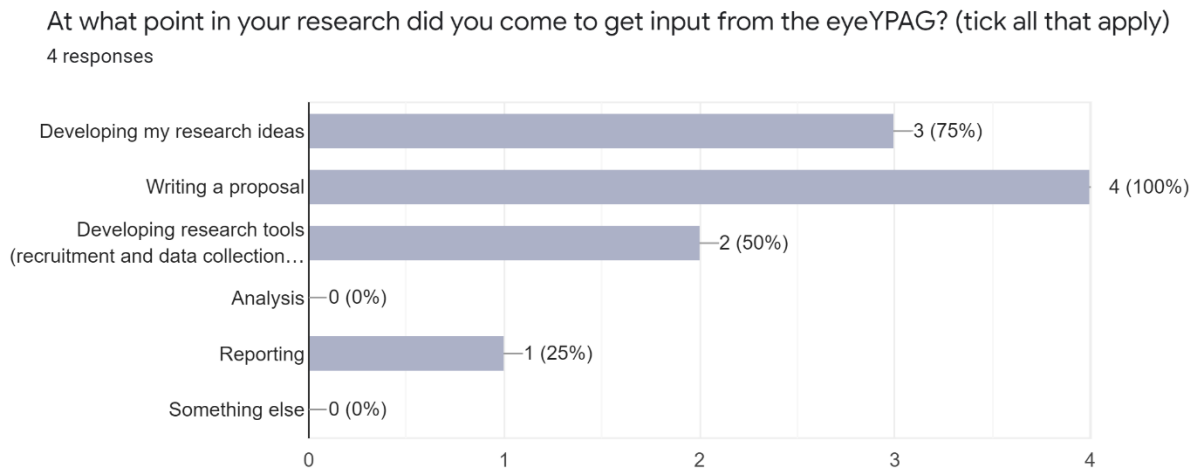
Findings: eyeYPAG meetings

Planning

Most researchers who came to work with the group did so because they already knew about the group or had been told about the group by someone who knew them.

Most came to work with the group in the planning stages of their research, as shown by this graph from the researcher survey:

Figure 2: Research survey - when did you come to eyeYPAG?



But

several researchers had worked with the group more than once and others were also keen to come back later on in their projects. One researcher, Jacq, who also helps facilitate the group, has been working with the group since we started:

[eyeYPAG are] my advisory group for my PhD.. [so] I've been working with the group since the beginning. I've had about four sessions with them exploring different parts of my project, and they've just been totally brilliant, helping me improve it.

Researchers highlighted the importance of planning their sessions well before coming to the meeting and valued the support they had had from the group facilitator to do this. Their 'top tips for planning a YPAG session include:

- Think carefully about exactly what you want to get out of the session and how to make best use of the time
- Work with the facilitator beforehand and plan the session well
- Don't just do a presentation and question and answer session: "Consider activities for children with all needs, to ensure maximum participation"
- Make sure you explain your ideas/technical terms clearly and in a way that young people will understand.
- Be prepared to make some changes to your project

Try and make it as easy to understand as possible... break it down... and really just focus on one single element, because it's quite difficult to cover lots of things at once. It takes time to explain, make it fun, and give enough time for everyone to express their views on what you're saying and input into it. (researcher)

Researchers valued the personal and practical experience of the group of having, or knowing about, eye and vision conditions and in research. In a group with a range of visual impairments and other access needs accessibility is also an important planning consideration:

A challenge that you need to overcome for this group is the accessibility of the information that you're presenting. Even harder online, because you have no idea what device people are using or what their internet's like, or how many devices they might have, or how interactive they can be with their device and, most importantly, how much they can actually see. You really have to think how I can make this accessible to everyone? (researcher)

Where and how we meet

eyeYPAG meetings take place on Saturdays around 5 times a year, before COVID-19 we met at the Children's Eye Centre in London and the nearby St. Luke's Community Centre; since then we have met online. We're currently deciding what we'd like to do in the future. Most adult and young participants were happy with how often we meet and the length of meetings.

Online meetings were more convenient for some researchers, especially those who don't live in or near London or have children. But most researchers were willing to travel into London on a Saturday if needed as they appreciated that this was what worked best for the group. People also acknowledged that, while online was more convenient it was also harder to make sessions interactive and fun:

You get so much feedback when you're [there] in person from the faces in front of you, but it's hard getting that feedback as to how things are landing when you're looking at the squares on a screen. (researcher)

But some adults and group members also talked about how online meetings worked better for some young people than meeting in person:

meeting online... there are definite benefits in the sense that certain people who might feel shy about speaking out in a real setting, in a room, can use the chat function to get their point across at the time that is right for them, rather than feeling that they have to jump in, interrupt somebody, or they've missed their opportunity to say something and then the conversation's moved on ... I don't know how you could recreate that in a real setting (researcher)

While many group members said that they missed the social and fun aspects of meeting in person, the preference of most group members and parents was for a mix of online and in person meetings, when these are possible again:



A mix would be nice to bring back the social aspects of the meeting, whilst online is easier on family time. (parent)

What we do in meetings: working with researchers

The feedback from researchers about coming to eyeYPAG meetings was really positive, with comments about ‘invaluable advice’, ‘insightful comments and suggestions’, ‘excellent engagement’ and – most importantly – having fun!



They have so much knowledge, and they are able to provide their suggestions in a constructive, collaborative way (researcher)

As we have discussed, good planning is important, but so is flexibility and changing plans if needed:

Because we'd had a rehearsal [with the facilitator], it probably went better than it could have done, but even when you do rehearse what you're going to say to children and young people... there are always things that you assume would be really obvious... and you're seeing the blank faces, you're thinking ‘oh we could really have explained that better’. (researcher)

Although, as discussed elsewhere, group members, really valued being able to make a difference to research and that meeting online was necessary during the pandemic and more convenient for some – some said that they found online sessions less engaging:

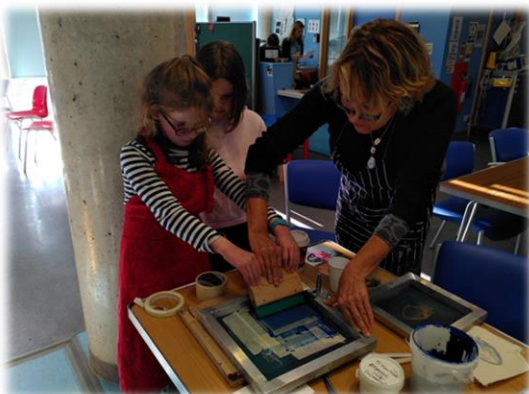
When we were at Moorfields we had games [in researcher sessions] but we can't do that as easily when you're in lockdown. I think that's really made it harder to do things with the research, because all we're doing now is looking at a slide and then occasionally doing some things. It's still pretty interactive, but it's harder to get involved... and do things because you're always on the screen. (YPAG member)

It's been much harder to interact with the researchers' presentations and what they're talking about. I personally think it would be nicer to see people face-to-face (YPAG member)

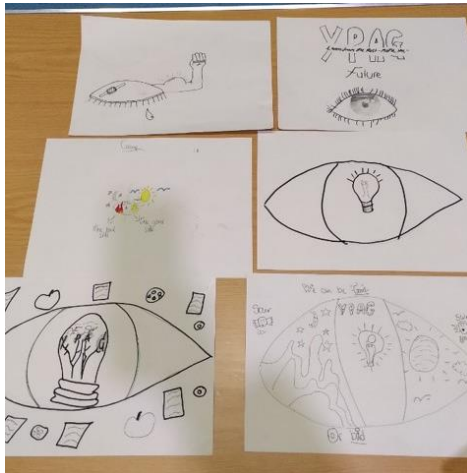
I find it easier to learn things and also feel like my voice is being listened to when we do things creatively instead of just sitting there (YPAG member)

Being creative

Alongside working with researchers one thing group members really valued, and had missed during the pandemic, was the creative work we have done together. In particular the work the group did with the artist Sofie Layton on developing a shared identify for the group, which led to the creation of an eyeYPAG logo and hoodies.



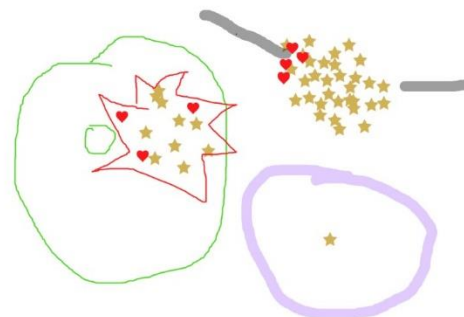
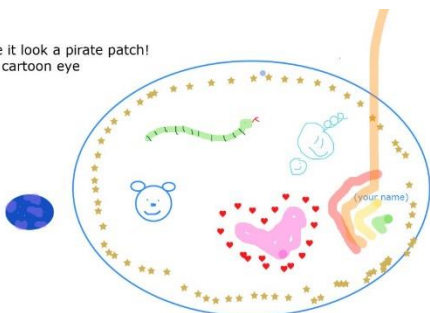
When we met at Moorfields we used to make our meetings really creative, because that helps engage everybody and be interactive... which is why we involved the artists. Then COVID took that option away. So I felt quite nervous about how we were going to manage to keep people engaged... [but] we made some real progress with making things interactive and creative in online meetings too (facilitator).



Creativity and flexibility were also valued by researchers:

We had an activity where we all drew what we think eyepatches should look like, and I felt that that was really good at helping people to contribute, the young people to contribute what they thought... the creativity in particular was something that I've not seen before and was really impressed with.

Make it look a pirate patch!
Or a cartoon eye



How we work as a group

In the group members survey we asked young people to rate their experience of the group in relation to the following statements as always, mostly, sometimes or never.

During eyeYPAG meetings I feel that....	Always	Mostly
My views are listened to	8	2
Things are explained in ways that I can understand	10	0
I'm able to ask questions	10	0
I can get involved in decisions about the group and how we work together	7	3
Information given before and during meetings is accessible to me	8	2

While it's great that we had no 'sometimes' or 'never' answers one of our recommendations is for the group to explore how we can make the 'mostly' answers 'always' for everyone. Some things group members said eyeYPAG does well:

I feel that eyeYPAG explains everything very understandably and everyone is heard.

they allow everyone to have a voice and make everything accessible to everyone.

it's really nice and comfortable to be in [eyeYPAG]

I think that we are good at listening to each other.

It's a fun, interactive and very interesting group

Even in lockdown, we've still been pretty good at working together and getting to know each other better, so it's not as lonely, and we know that our voices are valued more, and that people are actually going to listen

It has been a great way for them to feel part of a group where they can listen, but also be heard. The enthusiasm when they give feedback from the meetings, is lovely to see (parent)

I appreciate the commitment of the EyeYPAG team. it works hard to include my daughter (parent)

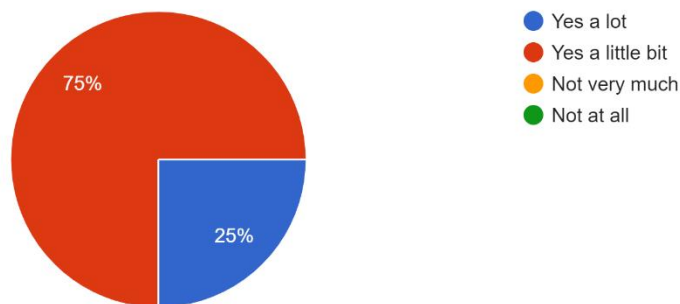
In the eyeYPAG member focus groups, young people discussed how doing projects like “designing our own logo” and developing the group’s shared agreements (see Introduction), gave them a sense of “unity” and helped them “make friends with each other”. They also commented how they are “more willing to share ideas with people we know better”. These sorts of comments show the real value in investing in the development and relationships of the group. Researchers also said that they found the film a really helpful way to understand how we work and one of our recommendations is to show this film at the start of each meeting and also revisit them in a year or so and see if we want to change anything.

Findings: impact

Our final findings section is about impact – how eyeYPAG has made a difference. We’ve discussed earlier in the report how being a member of the group has made a difference to eyeYPAG members. It has also made a difference to research:

Figure 3: Researcher survey - did working with eyeYPAG change your research?

Did working with eyeYPAG change your research?
4 responses



Researchers mentioned impacts including:

- Changes to methodology
- Changes to research protocols and participant information leaflets, including improved accessibility
- “I changed the way I thought about the group I was selecting to join as participants in the study”
- “It helped me to think about the direction of my research and to think about how to include young people in my project more extensively”
- “Good for seeing what does/doesn't work at an early stage”
- “Some good concrete feedback about specific issues, some of which I had not yet considered”
- “Good for taking a step back and doing some ‘blue sky thinking’”
- “We have taken some concrete suggestions on board, and made tweaks to tests... It also provided helpful supporting material for at least one grant application and one peer reviewed paper”

When I was at the [eyeYPAG] meeting I was very early on in my research, it was pre-applying for funding, so it was very easy to change lots of things... I think that was a good time to come to the group. (researcher)

There were things that the group told us they wanted to change I never thought about in the first place. It really opened my eyes and gave me a different perspective... it was incredibly helpful (researcher)

Researchers also talked about how much they learnt from working with eyeYPAG:

I also think it's actually changed, not the research, but me as well... learning what children or young people can say, how much they can give to research, has actually set me up quite early on in my career to make sure that I continue to [work with young people] to make the research better. (researcher)

As discussed in 'making a difference' above young people also talked about the importance of knowing that researchers will make changes as a result of their input:

[Researchers who come to the group] will build on the idea you've given... if you give an idea, they'll tell you maybe, why they can't do it, or suggest a better alternative using your idea or that they'll just say 'yes, that's a really good idea' and they'll note it down. (YPAG member)

Funders also provided some great feedback

It is clear that the group has developed and engaged really well

I think the YPAG have done some amazing work, I think the members feel valued and that their opinion really counts

'Always room for improvement': Recommendations

We wanted to evaluate the eyeYPAG so that we could learn from everyone involved what has been good about the group, what difference we have made and how we can develop and improve in the future. Our questions were:

- What difference has eyeYPAG made to research, and to group members?
- What has worked well and what could be improved after the first two years of eyeYPAG?
- How can we improve and plan for the future of the group, and help other people interested in involving children and young people in research?

The previous sections provide lots of information to answer the first two questions, and we hope also provide some useful information for others interested in involving children and young people in research. Here are our recommendations for the future of the group:

- ✚ Resume in-person meetings alongside some online meetings
- ✚ More creative sessions
- ✚ Make sure all research sessions are engaging, accessible and interactive
- ✚ Refresh the group membership:

I think it would be good if there were more people in the group (YPAG member)

It would be nice if there were some younger people (YPAG member)

- ✚ Group to develop guidance/top tips for researchers coming to meetings
- ✚ Support group members to set personal goals (e.g. write a blog post, give a presentation) and make a plan for how to achieve these
- ✚ Let more researchers know about the group (e.g. make a promotional film)
- ✚ Make sure we continue to evaluate and collect information on eyeYPAG and the difference it makes to research
- ✚ Ask researchers to credit the group and, if possible, include them in publications

Researchers should be asked to put an acknowledgement of the eyeYPAG's contribution in their publications (researcher)

- ✚ Think about the long-term future of the group, including getting included in more funding bids

We would be interested to see the impact on funding applications/project progress where the group was used to get a sense of longer-term outcomes related to the group (funder)

And finally...

Thank you for reading our report! We have learnt so much from doing this project and so we're ending by each sharing our reflections on being involved in this project.

Berkley

I wanted to get involved in this evaluation because it sounded like a very unique experience. I expected the evaluation to only be a page on how the group was doing, when in reality it was lots of meetings, spreadsheets, online forms and Jamboards full of data. I have enjoyed being a young evaluator immensely and it has provided me with in-depth insights into evaluation and assessment of data.

Elena

The most interesting part about the evaluation project was the data analysis. Some of the things I have been involved in allowed me to have experience in areas such as data collection, but it was brilliant getting to know the data analysis and make conclusions from my results. It has been wonderful working with so many other people my age on a project and a report that is so professional.

Eleri

What I have learned while being a young evaluator is how to work together for a beneficial topic. I loved working with other people with similar conditions to me and eyeYPAG has opened up so many other opportunities for me. It's truly an amazing group that should have the chance to progress into the near and far future.

Jasmine

I think it was really useful to be involved in the evaluation, and it gave me an even deeper idea of what goes on behind the scenes of research.

Rhianne

I originally wanted to get involved with this evaluation, because I was interested in what people thought about the group, and how it could be improved. I have really enjoyed learning new skills and I have seen a side of research that I hadn't seen before. I especially enjoyed creating surveys and running interview sessions, because it opened my eyes to new perspectives. I also enjoyed working together as a team, and I am excited to use the skills I have learned in the future.

Louca-Mai Brady

I have learnt so much from working on this project with such an amazing team, and it is even more impressive that we have done it all online during a pandemic! Watching the young evaluators grown in confidence, facilitate focus groups and doing some amazing qualitative analysis has been a real privilege. After just over two years of setting up and working with the eyeYPAG I am so pleased to be able to end my time at Moorfields with this amazing report. Thank you so much to the young evaluators for all your hard work and brilliant ideas.

Jacq Miller

It has been a pleasure to support this evaluation and contribute as a researcher and facilitator. The young evaluators have shown huge commitment to the project and remained motivated and creative throughout every stage. In my opinion, this report is an accurate reflection of all the group has achieved, the impact they have made and the journey we have all been on together. Huge congratulations to the young evaluators, and to Louca-Mai for enabling them to create, conduct and report such an important and useful piece of work. We are in safe hands, with this bright young team driving the future of eyeYPAG!

Annegret Dahlmann-Noor

I have not been involved in running the evaluation, though I have taken part in the surveys as a parent, a researcher and a group facilitator. Reading the report, I am profoundly impressed by the solid methodology that this work has been based on, and the detailed findings Louca-Mai and the young people have been able to tease out of surveys and interviews. This is co-production with young people at its finest – deciding about the questions, the methods, working together on the analysis, and writing the final report. Thank you so much to the whole evaluation team!

Acknowledgements

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