

Involving young people in research during the COVID-19 Pandemic: The BRIGHTLIGHT experience

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Responding to COVID-19

- What is BRIGHTLIGHT?
- Our previous patient and public involvement strategy
- Why we needed to rapidly mobilise to online engagement
- What we did
- What we learnt



BRIGHTLIGHT BRIGHTLIGHT: Do specialist services for young people with cancer add value?



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https://www.journalslibrary.nihr.ac.uk/pgfar/pgfar09120#/abstract



Unanswered questions...



Patient and Public Involvement Strategy







How we used to live







March 2020

Final BRIGHTLIGHT results workshop planned March 2020

New Cancer Research UK study funded which requested a PPI workshop prior to study starting.







Seven Ps of PPIE

P for Pandemic P for Platforms

Table 6 Guidance for researchers: the Seven Ps of PPIE

| 1.0.1 | |
|----------------------|--|
| 1. Passionate People | The right professional team is crucial. If the team do not believe in PPIE then it will be difficult to move beyond tokenism. |
| | Always have a key person for people to contact, who will be the main link into the team. Decide in advance who this will be and allow sufficient resource for that person to manage the group. This person has to be committed and passionate about PPIE |
| 2. Preparation | Take time to think about what you want your group to do. Be clear with them about their tasks and input. Be open to different ideas if planned activities are not viewed favourably by the group. Good PPIE events take time to plan and execute. Allow sufficient time to make documents explaining complex ideas. Decide in advance who is going to do this. Ensure you have the aims of face-to-face workshops clearly visible during the meeting. Let participants know in advance who is will be workshops clearly visible during the meeting. Consider how people are going to travel to face-to-face meetings. Who is responsible for sorting out travel tickets, room bookings, and reimbursement? Is the venue too clinical and so may inhibit free speech about their experiences? Is the venue too clinical and so may inhibit free speech about their group or the researcher will need to break. Have an agenda with flexible break times, the content of the workshop may mean breaks are needed sooner or later than initially thought, you cannot always predict when the group or the researcher will need to break. If the group are presenting, who is preparing the slides? Who is going to practice with the group prior to presentation? Plan for a member of the team to contact each PPIE member individually after the event to ensure no distress. Have in place processes for sickness, adverse weather, travel disruption and a key contact for participants to contact by phone. Prepare an evaluation sheet and seek feedback. |
| 3. Practice | Events will get easier and better with time: the more you do the more familiar you will become. Just like professional groups, PPIE groups can take a while to gain momentum. Take notes after each event of what went well and what did not, then build on processes or activities that worked with that particular group. Make a list of venues participants particularly like or dislike. Use the evaluation feedback to build on previous events. |
| 4. Pounds | PPIE can be resource intensive, plan a budget in your grant application. At submission stages if you have no budget to reimburse time, explain to participants prior to the event, or utilise existing subsidised groups. Reimburse travel and provide food as a minimum. If participants are leaving at lunch time or dinner time provide food or food vouchers such as supermarket or restaurants. When costing a grant, budget for relaxed creative environments, workshop materials such as printing and props, travel and overnight stay if you think needed and conference costs for participants to present. Budget for open access publication of your PPIE. |
| 5. Perseverance | It may take a while to find the right people to become involved. The group may be in flux establishing its core members and this can take time. |
| 6. Post it notes | Post it note methodologies are useful, however there are a realm of activities in healthcare and beyond, which lend themselves well to PPIE. Look outside of your normal genre for suitable activities, for example advertising, business trouble shooting activities. Always have post it notes and glitter in your tool box for PPIE. |
| 7. Patience | Effective PPIE groups and events can take time to establish. Complex research ideas can take time to explain and write down. Be patient with yourself, your group and colleagues as you all learn how to work together. |

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https://researchinvolvement.biomedcentral.com/track/pdf/10.1186/s40900-018-0135-x.pdf

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Online workshops 2020-21

- Six online workshops between June 2020-March 2021
- Invites were sent out via Facebook messenger
- Attended by approximately 9 young people each time
- Sessions were approximately 2.5 hours with break
- An artist animated focus group discussions and results
- Each workshop would have two facilitators and two 'safeguarders'
- Follow up for distress by the PPI lead





How we live now



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Workshop 1: MIRO

- Pre-workshop packs (physical)
 - Information sheet
 - Online workshop conduct policy
 - Consent form
 - Contact numbers
 - Activities
 - Evaluation form
 - Demographic form
 - Stamped envelopes
 - Snacks









Workshop 1: Outputs







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Workshop 1

- MIRO allowed interaction but couldn't see everyones face
- Facilitator was kicked out early on
- Session ended abruptly
- Young people requested more time to talk
- Zoom was the preferred app





Workshop 6

- Patient secure zoom
- Artists animated results while researcher spoke
- Google Jam board
- Pre-workshop materials all online (email and Facebook)
 - Consent form
 - Contact phone numbers
 - Information sheets
 - Zoom agreement form





Workshop 6: Outputs

Diagnostic intervals









Google Jam board







What we learnt: drawbacks

- Very resource intensive in researcher time
- Safeguarding of young people more difficult
- Peer to peer support for researchers more difficult
- Young people missed meeting each other





What we learnt: positives

- We rapidly mobilized our PPI to online activities
- New ways to present complex data
- No travel or venue costs
- We could do more workshop with shorter notice
- More accessible to young people:
 - Less constrained by work
 - Travel
 - Isolation
 - New mums





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