<table>
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<tr>
<th>Author, Year, Country</th>
<th>Aim of PPI</th>
<th>PPI Term, Definition &amp; Underpinning Concepts/Theory</th>
<th>PPI Population &amp; Underpinning Concepts/Theory</th>
<th>Design and Stages of Involvement</th>
<th>Methods by which PPI was evaluated</th>
<th>Evidence of Impact of PPI</th>
<th>Conclusions &amp; lessons learned from PPI</th>
<th>Limitations related to PPI</th>
<th>Recommendations arising from PPI</th>
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<tr>
<td>Beatriz et al. (2018), USA</td>
<td>Aim: To go beyond individual prevention tactics to build a community-wide, rigorously researched teen dating violence prevention model.</td>
<td>Term used: Peer researchers. <strong>Definition:</strong> NR Concepts/Theory: Youth Participatory Action Research.</td>
<td>PPI (YP): Peer Researchers (n=9; 18-23yrs, Black or Latino). PPI (Others): N/A.</td>
<td>Training, developing materials, collecting and analysing data. Internal. Reflection on contributions of peer researchers.</td>
<td>Impact on Research: The inclusion of youth Peer Researchers is both acceptable and feasible. Framework strengthens teams’ ability to design and conduct a thoughtful and rigorous study. Impact on Young People: Helped to develop their capacity and skills for future research, and professional efforts. Impact on Policy: NR.</td>
<td>Conclusions: Young adult peer researchers shaped study instruments and were often more familiar with intervention settings than researchers. Their suggestions were frequently very useful to both the research and program teams. Lessons learned: Need for support and flexibility, communication and flexibility, contextualising research challenges for youth researchers.</td>
<td>NR²</td>
<td>The used of the framework is useful in an interdisciplinary evaluation team.</td>
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<tr>
<td>Best et al. (2017), N. Ireland.</td>
<td>Aim: To test the feasibility and process of Participatory Theme Elicitation (PTE).</td>
<td>Term: Patient and Public Involvement (PPI). <strong>Definition:</strong> NR. But set within wider context of co-production. Concepts/Theory: Participatory Theme Elicitation.</td>
<td>PPI (YP): Young advisors (n=8) representing those: physiologically active and inactive (12–14yrs; 4 male, 4 female). PPI (Others): N/A.</td>
<td>Analysis of data. NR</td>
<td>Impact on Research: Proof of concept demonstrated. Recruitment, retention and training of YAP members appeared successful. Impact on Young People: NR. Impact on Policy: NR.</td>
<td>Conclusions: Proof of concept demonstrated through the ability of thematic patterns to be generated from PTE groupings. Recruitment, retention and training of YAP members appeared successful. Lessons learned: A strength of PTE is that its implementation requires little prior knowledge or specialist skills on behalf of users or researchers.</td>
<td>Possibility of selection bias in selection of excerpts shared. Difficult to claim data saturation using only 40 excerpts.</td>
<td>Future PTE research should consider greater involvement of users, what is an 'appropriate' and 'sufficient' number of excerpts, the number of sorters, the number of excerpts, the training time needed for co-researchers and the use of alternative algorithms to produce groupings.</td>
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<tr>
<td>Boote et al. (2016), UK.</td>
<td>Aim: To involve children with asthma in the design of a trial intervention to reduce unscheduled medical contacts in children with asthma.</td>
<td>Term: PPI. <strong>Definition:</strong> PPI classified into consultation, collaboration or user-led (Fleming and Hudson, 2009). Concepts/Theory: NR.</td>
<td>PPI (YP): Event 1: Children (n=5) with asthma (7-14yrs; 4 girls). Event 2: Children (n=4) with asthma (11yrs and under; 2 siblings; 3 girls; 2 Caucasian, 2 Asian). PPI (Others): N/A.</td>
<td>Research design, development of documents and design of logo NR</td>
<td>Impact on Research: Reorientation to the study, ahead of the discussion that followed. Impact on Young People: NR. Impact on Policy: NR.</td>
<td>Conclusions: The work contributes to the small but growing number of examples of PPI in trial design and conduct. Lessons learned: Inconsistency of attendance between events was not problematic and allowed introduction of fresh perspectives.</td>
<td>Number of people in the consultations small due to difficulties recruiting people to PPI. Children in first event may have known facilitators.</td>
<td>Researchers should consider holding post-award, pre-commencement PPI consultation events, as they provide a useful means of providing feedback to lay people on how their input has contributed.</td>
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<td>Brady et al. (2018), UK.</td>
<td>Aim: To explore whether and how young drug and alcohol service users could be meaningfully and effectively be involved in an RCT.</td>
<td>Term: Involvement. <strong>Definition:</strong> Discussed in terms of “research [...] carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or for ‘them”</td>
<td>PPI (YP): Young advisors (n=17, 16-21yrs; 12 female, 5 male). PPI (Others): N/A.</td>
<td>Involvement in all three phases of study as advisors. Internal feedback.</td>
<td>Impact on Research: Opportunity to reflect on how involvement was operationalised and to reflect on the learning that emerged. Impact on Young People: Young advisors spoke about the benefits of involvement for</td>
<td>Conclusions: Involvement of young people needs to be dynamic, flexible and sensitive. Engagement with services was crucial in recruiting young people and supporting their engagement. The dominant discourses and cultures of</td>
<td>NR²</td>
<td>The flexible and young people-centred model for involvement which emerged from this work provides a template for a different approach.</td>
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¹ N/A - Not applicable
² NR - Not reported
| Byrne (2019), Ireland | **Aim:** To increase the likelihood of developing a feasible, implementable, applicable, and effective intervention. | **Term:** Stakeholder engagement (SE).  
**Definition:** An umbrella term that encompasses activities, including patient and public involvement (PPI) and patient engagement. | **Concepts/Theory:** NR. | **PPI (YP):** 8 members of a young adult panel (18-25yrs) with T1D.  
**PPI (Others):** N/A. | **Developing materials and dissemination.** | **Impact on Research:** Ensured that surveys acceptable to younger adults and dissemination methods increased chances of the surveys reaching young adults.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR. | **Conclusions:** Integrating engagement approach was critical to delivering the final product.  
**Lessons learned:** Engage young people early in the research process and regularly update them on progress. It takes time to build trust and relationships. Engagement requires commitment and flexibility from the research team. Stakeholders should have protected time within research meetings. Abbreviations and technical language should be avoided. Training should be provided to enable participation. Delivering research impact can be a slow process. A neutral local “knowledge broker” can be valuable. | NR. | Future research is needed to develop a solid evidence base for the impact of SE and to estimate where engagement and involvement have the greatest impact. |
| Carroll et al. (2018), New Zealand | **Aim:** To foreground the voices of disabled young people. | **Term:** Advisory group.  
**Definition:** NR.  
**Concepts/Theory:** NR. | **PPI (YP):** Advisory group of young disabled people. No information provided on number or age range.  
**PPI (Others):** N/A. | **Designing data collection tools** | **Impact on Research:** Change in study age range and data collection tools resulting from feedback.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR. | **Conclusions:** Research methods need to be applied flexibly, negotiated and adapted to maximise each young person’s participation.  
**Lessons learned:** A toolbox approach is proving vital to achieving this study’s overarching goal. | NR. | A toolbox approach to canvas the diverse voices of mobility, hearing and vision-impaired young people in NZ increases opportunities for their effective community participation. |
| Chopel et al. (2019), USA | **Aim:** To explore how e-cigarettes marketed and promoted to youth and how these products are perceived by youth in Oakland? | **Term:** Community-based participatory research (CBPR).  
**Definition:** CBPR is action-oriented, equitable, and serves as both an intervention and an investigation. | **PPI (YP):** 5 young people (15-24yrs). Two left before study completion to attend college.  
**PPI (Others):** N/A. | **Developing research questions, designing methods, data collection, analysis, and dissemination.** | **Impact on Research:** Evolution of research aim, influence in terms of methods and introduction of alternative geo-narrative approach.  
**Impact on Young People:** Training in content, research and communication skills. Developed as advocates in | **Conclusions:** Using a CBPR approach ensured flexibility and responsiveness.  
**Lessons learned:** Engaging youth as partners in a CBPR study is complex and requires a lot of forethought, planning, and strategy, as well as flexibility and adaptation. | NR. | Future CBPR studies should incorporate safety planning. A two-part training strategy would enable youth to explore various avenues of change-making and embody the |
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<tr>
<th>Study</th>
<th>Country</th>
<th>Aim</th>
<th>Concept/Theory</th>
<th>Term</th>
<th>PPI (YP)</th>
<th>PPI (Others)</th>
<th>Impact on Research</th>
<th>Impact on Young People</th>
<th>Impact on Policy</th>
<th>Conclusion</th>
<th>Lessons learned</th>
<th>Notes</th>
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<tr>
<td>Coad (2012), England.</td>
<td></td>
<td></td>
<td>Empowerment theory.</td>
<td>Co-Researchers.</td>
<td>Young people (n=4, 15-17yrs; 3 females, 1 male).</td>
<td>N/A.</td>
<td>Young people contributed to campaign that is more inclusive of young people’s views and experiences.</td>
<td>Young people enjoyed being co-researchers and felt comfortable being part of a small peer research group.</td>
<td>Young people contributed to the process.</td>
<td>A key role was limited but YP pushed for increased participation.</td>
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<td>Collin &amp; Swift (2016), Australia.</td>
<td></td>
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<td>Participatory Design methodology.</td>
<td>Participation/Participatory design (PD).</td>
<td>Young people (n=140) involved in participatory research and in 2014; 267 involved in research &amp; design activities.</td>
<td>N/A.</td>
<td>Design, conceptualising, peer research activities, workshops.</td>
<td>Young people contributed to campaign that is more inclusive of young people’s views and experiences.</td>
<td>Young people enjoyed being co-researchers and felt comfortable being part of a small peer research group.</td>
<td>The use of PD could have contributed to the promotion of a collaborative ‘logic of care’ rather than simply an individualised ‘logic of choice’ in the development of online campaigns.</td>
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<td>Cooper et al. (2017), UK</td>
<td></td>
<td></td>
<td>N/A.</td>
<td>PPI.</td>
<td>Young people with arthritis (n=8; 10-14yrs, median 14yrs). Siblings</td>
<td>N/A.</td>
<td>Designing study and presentation of materials.</td>
<td>Influenced decisions on co-primary outcome measures of appearance and infection rates, use of 3-point scale, presentation of patient information.</td>
<td>Young people contributed to the process.</td>
<td>The full NINJA study objectives were modified, and a follow-up regime and content designed to suit this very specific patient population was developed. Solutions offered by children and parents can be incorporated into trial design at an early stage.</td>
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<td>Costello &amp; Doris (2019), Ireland.</td>
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<td></td>
<td>N/A.</td>
<td>PPI.</td>
<td>Young people with arthritis (n=9; 10-14yrs).</td>
<td>N/A.</td>
<td>Co-design at every stage.</td>
<td>The methodological approach was received positively by both researchers and young people.</td>
<td>The interactive nature and involvement of young people was enabled from the outset.</td>
<td>The use of PD could have contributed to the promotion of a collaborative ‘logic of care’ rather than simply an individualised ‘logic of choice’ in the development of online campaigns.</td>
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<tr>
<td>Study</td>
<td>Aim</td>
<td>Term</td>
<td>Definition</td>
<td>Concept/Theory</td>
<td>Sample Size</td>
<td>Impact on Research</td>
<td>Impact on Young People</td>
<td>Impact on Policy</td>
<td>Conclusion</td>
<td>Lessons learned</td>
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<td>Curtin et al. (2007), Australia.</td>
<td>To ensure that research was appropriately designed and that the interests and abilities of the participants were considered.</td>
<td>Participation</td>
<td>Children being consulted on matters that affect them and being given adequate information to be able to form an opinion...making choices...influencing decisions, contributing to understanding and solution of social issues.</td>
<td>Participation</td>
<td>NR.</td>
<td>The young people made excellent suggestions for the wording and layout of the questionnaire.</td>
<td>Needs to feel comfortable to meaningfully engage in PPI to be fully engaged.</td>
<td>NR.</td>
<td>PPI improved the design of materials and tools.</td>
<td>The need for collaborative involvement should be guarded against, as it is not active participation.</td>
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<td>Dovey-Pearce et al. (2019), UK.</td>
<td>To provide a young people's perspective and to oversee the governance and delivery of the Transition programme.</td>
<td>Public Involvement</td>
<td>PPI refers to the roles for service users and members of the public in defining, delivering and disseminating research. Includes activities on a continuum from consultative tasks, through to &quot;partnership working&quot; to service-user- led initiatives (INVOLVE).</td>
<td>Public Involvement</td>
<td>N/A.</td>
<td>Overseeing delivery and governance of the research programme, process evaluation.</td>
<td>Needs to feel comfortable to meaningfully engage in PPI to be fully engaged.</td>
<td>NR.</td>
<td>PPI improved the design of materials and tools.</td>
<td>An agile, reflexive skill set is needed.</td>
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<tr>
<td>Forsyth et al. (2019), UK.</td>
<td>To obtain the views of CYP on service development plans, the design of generic facility and research participant.</td>
<td>CYP</td>
<td>Research carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them.</td>
<td>CYP</td>
<td>N/A.</td>
<td>Informing study design and materials.</td>
<td>Needs to feel comfortable to meaningfully engage in PPI to be fully engaged.</td>
<td>NR.</td>
<td>PPI improved the design of materials and tools.</td>
<td>Agile models of working and the potential skills needed, quickly brings people with varied expertise together.</td>
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<td>Study</td>
<td>Aim</td>
<td>Term</td>
<td>PPI (YP):</td>
<td>Co-researchers involved throughout the study.</td>
<td>Impact on Research:</td>
<td>Impact on Policy:</td>
<td>Conclusions:</td>
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<td>Funk (2012), Canada</td>
<td>To explore feasibility of youth to co-facilitate the focus groups and what role the youth would be able to take in the study.</td>
<td>PPI (YP): Young people (n=6; 19-24yrs; 3 female; 1 identified as having Aboriginal ancestry; 2 had previously injected drugs). PPI (Others): N/A.</td>
<td>Co-researchers involved throughout the study.</td>
<td>Young people’s realities and interpretation of the findings is based on experience.</td>
<td>Public speaking experience, research skills, and opportunities to network leading to employment opportunities, appreciation of services available and the gaining of confidence to advocate for themselves and others.</td>
<td>The YIP Project was successful in being a highly participatory research project. In a safe and open environment, youth felt comfortable to question and take on initiatives that went beyond the academic researcher’s initial expectations.</td>
<td>To ensure that youth “truly” participate and determine their own level of participation we recommend that future studies include frequent team-building exercises and evaluations.</td>
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<td>Griffiths et al. (2018), UK.</td>
<td>To increase relevance, validity and interpretation, as well as providing research capacity and personal growth.</td>
<td>PPI (YP): Main group - Young people with a long-term health condition (n=4, 16-25yrs). PPI events - (n=39, 14-18yrs). PPI (Others): N/A.</td>
<td>Project management group and two two-day PPI workshops.</td>
<td>Young people influenced research design and interpretation of data.</td>
<td>Young people influenced research design and interpretation of data.</td>
<td>Conclusions:</td>
<td></td>
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<td>Hannon et al. (2018), USA.</td>
<td>To codesign a clinic intervention using shared decision making for addressing diabetes self-care with an adolescent patient and parent advisory board.</td>
<td>PPI (YP): Young people with T1 diabetes (n=6; 12-16yrs, median 14.6; 4 male) who were members of patient advisory group. PPI (Others): Parents.</td>
<td>Establishing desired intervention outcomes, intervention feasibility and acceptability.</td>
<td>Co-created diabetes management plan tool for use in the clinic with teens and their parents.</td>
<td>Co-created diabetes management plan tool for use in the clinic with teens and their parents.</td>
<td>Young people can be effectively engaged and involved in patient-centred research design. Important for patient-centred outcomes research to help people achieve personal goals and address diabetes distress.</td>
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<td>Holmes et al. (2002), Australia.</td>
<td>To have opportunity for non-Aboriginal!</td>
<td>PPI (YP): Young people recruited as peer reviewers</td>
<td>Defining research question and</td>
<td>Use of peers helped to raise awareness of the study in the</td>
<td>Contributed to a positive shift towards research among</td>
<td>Study contributed to a positive shift towards research among</td>
<td>This research model fits with the principles of self-determination</td>
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| Researchers, Aboriginal health workers and young people to contribute together to the study design. | **Definition:** NR  
**Concepts/Theory:** NR.  
**[n=18; 12–25yrs, both sexes].**  
**PPI (Others):** Adult community stakeholders.  
**developing questionnaire.**  
**community, informed understanding of underlying issues and development of questionnaire. It was important that Kooris facilitate the discussions and interpret the results.**  
**Impact on Young People:** Several Koori health workers and young people trained in research and public health skills. They gained confidence and now play important advocacy and management roles.  
**Impact on Policy:** NR.  
**Aboriginal policy makers and staff and increased the capacity.**  
**Lessons learned:** Opportunities for genuine community involvement occur more readily when a study is based in a community organisation. Young Koori researchers played a key role in ongoing negotiation.  
**and offers one possible approach to improving Aboriginal health research practices.** |
|---|---|
| **Hunt et al.** (2015), UK. | **Aim:** To use findings from the consultation to develop the research bid and develop collaborative relationships with the CYP, families and service providers.  
**Term:** Service users, user involvement.  
**Definition:** User involvement includes consultation, collaboration and user-controlled research (Oliver et al., 2008),  
**Concepts/Theory:** NR.  
**PPI (YP):** CYP (n=7; 13-18yrs, 6 male, 1 female; 5 wheelchair users, 6 had physical disabilities),  
**PPI (Others):** Parents, Service professionals.  
**Designing study and study logo.**  
**NR.**  
**Impact on Research:** Consultations proved extremely helpful in shaping the research questions and research design.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR.  
**Conclusion:** Consultations proved extremely helpful in shaping the research questions and research design.  
**Lessons learned:** Important for researchers to gain an understanding of the formal and informal professional networks. Important to build close links with family users.  
**Difficult to determine when consultation efforts have been sufficient. Important to consult with those who receive services and those who might be excluded or currently not accessing.** |
| **Kendal** (2017), UK. | **Aim:** To ensure that support for youth should be informed by youth-led research.  
**Term:** Participatory research.  
**Definition:** An approach, orientation, method, design or methodology aimed at co-production of knowledge between researchers and co-researchers (Bergold & Thomas, 2012).  
**Concepts/Theory:** NR.  
**PPI (YP):** Young co-researchers (n=11; 16-18yrs; n=10 in full-time education).  
**PPI (Others):** N/A.  
**Data collection and analysis.**  
**NR.**  
**Impact on Research:** Young person influenced all stages of the study.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR.  
**Conclusions:** Participatory research underpinned all aspects of the project. Young people’s analysis of their data and contribution to the writing up privileged their perspectives.  
**Lessons learned:** Better ratios of researchers to young people could have resulted in more one-to-one working and/or closer support. More time needed for some aspects of study to develop trust.  
**Number of participants was small and were mostly local, female and in full-time education.** |
| **Larkins et al.** (2013), UK. | **Aim:** To explore the impact that living in low income families has on disabled CYP’s rights and to ensure that CYP led focus on which rights were focused on.  
**Term:** Child rights-based approach (CRBA).  
**Definition:** CRBA starts from a commitment to achieving the rights and guiding principles of the relevant UN conventions; it informs children about their rights; it learns from children about infringements of their rights; it  
**PPI (YP):** Disabled young people (n=43, 4-24yrs), Expert group (n=32, severe impairments). Steering group (n=11, ASD or visually impaired; 12-18yrs, 7 male, 4 female).  
**PPI (Others):** Professionals, families.  
**Involved in co-creation throughout the study.**  
**Internal. No specific methodology stated. Evaluation of working with the steering group. Researcher reflections.**  
**Impact on Research:** Young people decided on the themes explored and contributed substantially to the analysis of the findings.  
**Impact on Young People:** Enjoyment, fulfilment and development for CYP. Young people sent thank you cards’ or reported that they really enjoyed the activities, they felt listened to, they helped each other, and they knew more about their rights.  
**Impact on Policy:**  
**Conclusions:** Research illustrates a methodology for participatory research which has been co-created through dialogue and action by disabled CYP. It could be adapted to explore the impact of low income on the rights of other CYP.  
**Lessons learned:** NR.  
**The need to complete the research within four months, stay within budget and comply with University regulations.** |
| Liabo et al. (2018), UK. | **Aim:** To include the priorities and views of the people we research. | **Term:** Service user involvement.  
**Definition:** NR.  
**Concepts/Theory:** Child rights-based approach. | **PPi (YP):** Care leavers: (n=20, 16-24yrs, 12 female, 8 male). From UK (n=3). Unaccompanied asylum seekers from Central and East Africa (n=13). Eastern Europe (n=3) and Central Asia (n=1).  
**PPi (Others):** N/A. | **All stages of review. Young people were trained in reviewing and were involved in every stage of the review, conference attendance and presentation.**  
**NR.**  
**Impact on Research:** Young people influenced review topic, helped avoid stigmatising language, shifted focus to education and support interventions. Influenced researcher’s knowledge, perspectives and ways of writing on looked after young people. Widened range of studies to be included. Influenced inclusion and exclusion criteria and search terms. Helped highlight hidden judgements and improved review transparency.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR. | **Conclusions:** Young people’s input challenged existing stereotyping and acted as a counterbalance to the researcher bias. Involvement in the screening process led to achieving target. Involvement makes research more relevant and enhances transparency. If involvement is truly participatory, it will always influence the research.  
**Lessons learned:** Involvement is a give and take relationship based on ongoing deliberations, decision making and discussions. Involvement brings people together to discuss topics of importance: outcomes are reached through dialogue, joint learning and deliberation.  
**Potentially influenced by power relations. Systematic reviewing quite technical this may have presented barriers to young people involvement.**  
**NR.** |
| Lightfoot & Sloper (2003), UK. | **Aim:** To identify factors which can support involvement in ways which young patients find appropriate, and to prepare practical guidelines for NHS staff. | **Term:** Involvement work.  
**Definition:** Service user involvement in research, is the inclusion of experience-based experts in knowledge production, is key to developing useful, relevant and valid research (Collins & Evans, 2002).  
**Concepts/Theory:** NR. | **PPi (YP):** No age stated.  
**PPi (Others):** N/A. | **Designing recruitment materials, data collection tools, dissemination**  
**NR.**  
**Impact on Research:** NR.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR. | **Conclusions:** Young people may have particular needs and value ways of working which are not readily accommodated within adult-centred strategies.  
**Lessons learned:** Involvement work has the potential to result in positive outcomes for the personal development of young patients and professional development of staff.  
**Characteristics of sample limit generalisability. Three groups of patients were not represented: younger children; those with severe impairments; and those from minority ethnic populations.**  
**Further research with underrepresented groups may yield useful findings.**  
**NR.** |
| Locock et al. (2019), UK. | **Aim:** To understand to what extent service users might become involved in the development of trigger films and to consider how this might bring new insights to the process. | **Term:** PPI.  
**Definition:** Research is conducted with or by users, rather than to, for or about them.  
**Concepts/Theory:** Experience based co-design. | **PPi (YP):** Young people (n=6, 19–23yrs) with lived experience of depression or stroke.  
**PPi (Others):** Carers. | **Analysing interview transcripts and developing film.**  
**NR.**  
**Impact on Research:** Researchers discovered they were too attached to process, concerned with methods and that analysis means close immersion in large amounts of text. Users preferred conversational engagement in the analytic process.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR. | **Conclusions:** The contribution to analysis can add a valuable layer to the process, ensuring the priorities of service users are firmly at the forefront. Reflections on the process led researchers to consider widening the definition of ‘analysis’ to include early conversation and guidance on  
**Commence involvement in analysis as early as possible in process.**  
**NR.** |
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<th>Source</th>
<th>Aim</th>
<th>Term</th>
<th>PPI (YP)</th>
<th>Engagement in event</th>
<th>Impact on Research</th>
<th>Impact on Young People</th>
<th>Impact on Policy</th>
<th>Conclusions</th>
<th>Lessons learned</th>
<th>Sample</th>
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<td>Manning et al. (2018), England.</td>
<td>To identify and prioritise future research for CYP PICU survivors.</td>
<td>Consultation and PPI.</td>
<td>Young people n=24; 8 CYP aged 7–15 years (n=3 PICU survivors, n=2 PICU survivor siblings; n=3 other health experience). One young person (13yrs) helped to facilitate event.</td>
<td>NR</td>
<td>Identified priorities for future research and services.</td>
<td>NR</td>
<td>NR</td>
<td>Evidence of the value of meaningful PPI in the development of research priorities and health care services to ensure they are appropriate, relevant and acceptable.</td>
<td>It is important to include young people as some of their priorities differed to those of adults.</td>
<td>NR</td>
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<td>McLaughlin (2015), UK.</td>
<td>NR</td>
<td>PPI (YP): Young people n=14, 11–18yrs, roughly even split of female and male, experience of health conditions. PPI (Others): Parents, carers in FRAG.</td>
<td>Developing engagement materials.</td>
<td>NR</td>
<td>Input of young people invaluable in shaping thinking; thoughtful, incisive comments helped us modify aspects of our approach.</td>
<td>Feedback from YRA group suggests they found experience valuable &quot;each of us loves being part of it… glad to give our own opinions for the better use and hope that they have influenced the way research is done&quot;.</td>
<td>NR</td>
<td>Clear evidence that involving CYP brings wide benefits; positive outcomes for young people, more tightly focused projects and outputs that are relevant to CYP, families and carers.</td>
<td>Need adequate time to undertake planning and preparation of research and participation activities. Need staff to support small group working. Important to plan sessions thoroughly and including a mixture of activities. Need time for informal discussion and for making adaptations.</td>
<td>NR</td>
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<td>Mitchell et al. (2018), England.</td>
<td>To co-produce the recommendations</td>
<td>PPI (YP): Young people (12-22yrs) from various</td>
<td>Co-production activities planned for</td>
<td>NR</td>
<td>Input of participants in VIDERS project using mixed methods evaluation indicated project was highly successful with co-researchers and co-producers being influential. Recruitment, training and support were effective, well planned and positively received. Young people’s own life experiences helped to shape study and ensure a real resonance.</td>
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<td>Allow more time when bidding for participatory projects so young people may act as co-researchers. Train all personnel and participants in the different concepts and models. Allow sufficient time and funding for participation and go beyond the “usual suspects”. Invite participation in all aspects of the work and listen to all views.</td>
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<td>Mitchell et al. (2019), UK.</td>
<td><strong>Aim</strong>: To describe the approach to PPI with CYP for research in paediatric palliative care.</td>
<td><strong>Term</strong>: PPI. <strong>Definition</strong>: PPI is the active involvement of patients and members of the public in the design and process of research. <strong>Concepts/Theory</strong>: NR.</td>
<td><strong>PPI (YP)</strong>: CYP (12-20yrs) from existing advisory groups. <strong>PPI Population (Other)</strong>: N/A.</td>
<td>Designing research, dissemination, impact.</td>
<td><strong>Impact on Research</strong>: Changing the terminology. This influenced further research by team into language use in palliative care. <strong>Impact on Young People</strong>: Opportunities to engage in activities although no direct feedback from young people provided. <strong>Impact on Policy</strong>: NR.</td>
<td><strong>Conclusions</strong>: The importance of incorporating PPI with CYP is well recognised. However, there is little guidance about how best to conduct such activity. <strong>Lessons learned</strong>: NR.</td>
<td>The framework that emerged is applicable in numerous contexts and could be used to identify and address ethical concerns preemptively, minimising the risk of harm to CYP while maximising the value of their contribution. More could be done to ensure equitable access to involvement opportunities as well as consistent or standardised training in the conduct of PPI for researchers.</td>
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<td>Morton et al. (2017), England.</td>
<td><strong>Aim</strong>: To provide a means of engaging multiple stakeholders in the prioritisation of school environment focused interventions to promote physical activity.</td>
<td><strong>Term</strong>: Public involvement. <strong>Definition</strong>: Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE). <strong>Concepts/Theory</strong>: NR.</td>
<td><strong>PPI (YP)</strong>: Young people (n=37, 12–17yrs). <strong>PPI Population (Other)</strong>: Education and public health professionals.</td>
<td>Priority setting.</td>
<td><strong>Impact on Research</strong>: NR. <strong>Impact on Young People</strong>: NR. <strong>Impact on Policy</strong>: NR.</td>
<td><strong>Conclusions</strong>: From the outset, the boundaries between ‘public involvement’ and ‘research’ were blurred. Although guidelines relating to public involvement and research ethics exist, we could not find information relating to the use of public involvement data in research publications. <strong>Lessons learned</strong>: NR.</td>
<td>Guidelines needed relating to the use of public involvement data in research publications.</td>
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<td>Office of the Children’s Commissioner (2014), England.</td>
<td><strong>Aim</strong>: To help ensure that CYP’s views and voices were at the centre of the research process.</td>
<td><strong>Term</strong>: Young researchers. <strong>Definition</strong>: NR. <strong>Concepts/Theory</strong>: Participatory design.</td>
<td><strong>PPI (YP)</strong>: Young disabled people (n=4). <strong>PPI Population (Other)</strong>: N/A.</td>
<td>Designing research, materials, data collection, analysis, report writing.</td>
<td><strong>Impact on Research</strong>: Voices of CYPs were at the centre of the research process. Young researchers widened age range of target population, helped develop information sheets, ensured focus groups were accessible and engaging, identified games and activities to facilitate discussion. Supported</td>
<td><strong>Conclusions</strong>: There are major obstacles and barriers which prevent disabled CYP realising their rights. <strong>Lessons learned</strong>: NR.</td>
<td>NR.</td>
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| **O'Hara et al. (2017), Ireland.** | **Aim:** To form a PPI panel of young adults with T1D who would actively be involved in co-designing all aspects of the intervention.  
**Term:** PPI.  
**Definition:** Research carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them (INVOLVE).  
**Concepts/Theory:** NR.  
**PPI (YP):** Young people n=8. 18-25yrs, 3 male, 5 female).  
**PPI Population (Other):** N/A.  
**Designing materials and data collection tools, dissemination of findings, co-applicant on grant.** | **Impact on Research:** Funding awarded to study and YAP were first PPI panel to be recognised as official collaborators by the HRB.  
**Impact on Young People:** Some YAP members asked the clinical research team to write letters of recommendation, help them with their CV and assist them entering academic competitions.  
**Impact on Policy:** NR.  
**Conclusions:** It is feasible and beneficial to include a PPI panel of young adults in health research. PPI research raises important issues related to the provision of patient care and involvement in research of those receiving care. Open dialogue and responsiveness to issues enabled the research team to recognise and address these issues. The study encountered common challenges in forming and progressing its PPI panel. The majority of barriers were successfully overcome.  
**Lessons learned:** Forming the YAP required buy-in from both panel members and the rest of the research team. Expectations need to be managed. Avoid jargon.  
**The YAP consisted of only eight members and as such was not a representative group. Inadequate budget to pay members for their time.** | **Impact on Young People:** NR.  
**Impact on Policy:** NR.  
**Conclusions:** Only one reviewer attended both workshops so young people’s ideas filtered through this individual. Limited opportunity to question the young people about their ideas. Researchers did not have direct access to the raw data. Methods of involvement inevitably influenced the ideas elicited. Young people were older than the children in the studies, did not have a specialist interest which may have influenced their perceptions or limited their ability to empathise. May have been more involvement activities for systematic reviews need to be designed with the review stage, purpose and group being involved in mind. |
| **Oliver et al. (2015), UK.** | **Aim:** To elicit young people’s reviews in relation to the review topics and draft findings in two configurative systematic reviews.  
**Term:** Public involvement.  
**Definition:** Outsiders influence research (Oliver et al, 2014).  
**Concepts/Theory:** NR.  
**PPI (YP):** Young people (n=approx. 24 across 2 groups, 12-17yrs).  
**PPI Population (Other):** N/A.  
**Commenting on themes and final findings of the review.** | **Impact on Research:** Young people identified important and/or missing themes from the synthesis resulting in studies and coding being revisited by researchers. Implications for research were developed by considering both priority areas for young people and explanations from the literature.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR.  
**Conclusions:** The review processes and products differed as a result of involving young people. Both systematic reviews became more relevant to young people.  
**Lessons learned:** With more time for workshop preparation, a more considered approach could have been taken. There were advantages to having such an engaged, research and public health-literate group of young people to work with on the reviews.  
**Lessons learned:** With more time for workshop preparation, a more considered approach could have been taken. There were advantages to having such an engaged, research and public health-literate group of young people to work with on the reviews. | **Impact on Research:** NR.  
**Impact on Young People:** NR.  
**Impact on Policy:** NR.  
**Conclusions:** Impact on Young People:** NR.  
**Impact on Policy:** NR.  
**Conclusions:** It is feasible and beneficial to include a PPI panel of young adults in health research. PPI research raises important issues related to the provision of patient care and involvement in research of those receiving care. Open dialogue and responsiveness to issues enabled the research team to recognise and address these issues. The study encountered common challenges in forming and progressing its PPI panel. The majority of barriers were successfully overcome.  
**Lessons learned:** Forming the YAP required buy-in from both panel members and the rest of the research team. Expectations need to be managed. Avoid jargon.  
**The YAP consisted of only eight members and as such was not a representative group. Inadequate budget to pay members for their time.** |
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<tr>
<th>Study</th>
<th>Aim</th>
<th>Term</th>
<th>PPI (YP)</th>
<th>Impact on Research</th>
<th>Impact on Policy</th>
<th>Conclusion</th>
<th>Outcome measurement needs to be as relevant and sensitive to CYP’s experiences.</th>
<th>Researchers need to be reflective during the selection process and the running of the sessions, ensuring that different interests and voices are represented.</th>
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<td>Pavarini (2019), UK.</td>
<td>Aim: To develop a group where CYP are involved in shaping research.</td>
<td>Term: Co-production. Definition: Researchers, practitioners and the public work together, sharing power and responsibility from the start to the end of the project, including the generation of knowledge. (Hickey et al., 2018). Concepts/Theory: Co-production model.</td>
<td>PPI (YP): Young people (n=30, 15-18yrs) from wide range of backgrounds and schools. PPI Population (Other): N/A</td>
<td>Impact on Research: Young people shifted research focus to one which they deemed more relevant to their daily lives. Developed peer-led interviews as a comfortable, engaging method giving young people greater sense of agency. Developed digital games to be used as engaging tools to collect data. Implemented more effective recruitment strategies, leveraging online platforms. Impact on Young People: Participation helped the young people gain both technical (research methods) and soft skills (confidence, teamwork).</td>
<td>Impact on Policy: N/A.</td>
<td>Conclusions: Adopting an open and reflective perspective can increase researchers’ capacity to engage young people in ways that are meaningful, democratic and inclusive. Lessons learned: Important to have on-going evaluations on the impact of the group and reflections upon whether the group is mutually beneficial, and genuinely empowering for young people.</td>
<td>NR.</td>
<td>Researchers need to be reflective during the selection process and the running of the sessions, ensuring that different interests and voices are represented.</td>
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<td>Perry &amp; Carpenter (2016), UK.</td>
<td>Aim: To explore young people’s views of appropriate outcome measures of the effectiveness of therapy and to develop a novel user-generated questionnaire.</td>
<td>Term: Co-researchers and co-participants. Definition: Research “with” rather than “on” young people (Reason and Bradbury Huang, 2005). Concepts/Theory: Action research or cooperative enquiry.</td>
<td>PPI (YP): Consultation group (10-18yrs). Pilot, young people (n=8, 10-17yrs, 4 male, 4 female, all white). PPI Population (Other): N/A.</td>
<td>Impact on Research: Young people developed and designed a new questionnaire (outcome measure) to capture experience/benefits of therapy; items included verbatim wording of their comments on therapy. Impact on Young People: NR. Impact on Policy: NR.</td>
<td>N/A.</td>
<td>Conclusions: It is important to consider which voices are privileged and which voices are silenced. Healthcare providers consulting young people need to &quot;listen and respond&quot;. Lessons learned: Importance of CYP being as involved as possible in the research process.</td>
<td>N/A.</td>
<td>Outcome measurement needs to be as relevant and sensitive to CYP’s experiences. Treating young people as co-researchers is recommended to anyone working in the field of CYP’s mental health.</td>
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<td>RCPCH (2012), UK.</td>
<td>Aim: To undertake consultations with parents and carers and CYP themselves, to derive the issues important to this group and to design and test a survey with the target user group.</td>
<td>Term: Patient participation. Definition: NR. Concepts/Theory: NR.</td>
<td>PPI (YP): CYP in focus groups (5-18yrs). PPI Population (Other): Parents and carers of 0-8yr olds</td>
<td>Impact on Research: Young people identified and ranked the important domains of healthcare which influenced weighting of the survey questions, topics and domains. Identified key domains they were concerned. Cognitive testing highlighted the need for separate versions of the survey. Impact on Young People: NR. Impact on Policy: NR.</td>
<td>N/A.</td>
<td>Conclusions: This collaborative project was able to develop a robust tool to measure the experience of paediatric patients; this incorporated children’s views. Lessons learned: NR.</td>
<td>NR.</td>
<td>Researchers need to be reflective during the selection process and the running of the sessions, ensuring that different interests and voices are represented.</td>
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<td><a href="#">Sheridan et al. (2019), UK.</a></td>
<td>To seek input, inform decision-making and review study documentation and tools.</td>
<td>PPI</td>
<td>Responsive &amp; managerial public involvement approach</td>
<td>Young people (n=3, 19-24 yrs, 2 female, 1 male) with long-term health conditions. Plus members of the Liverpool GenerationR Young People’s Advisory Group.</td>
<td>NR</td>
<td>NR</td>
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<td><a href="#">Snodin et al. (2017), England.</a></td>
<td>To ensure that the language and content of the CYP’s study documents were appropriate and accessible and would promote recruitment and assent/consent.</td>
<td>PPI</td>
<td>Consultation</td>
<td>Young people (n=7, 5-12yrs) with wide range of health experiences.</td>
<td>Research design.</td>
<td>NR</td>
<td>Impact on Research: Young people helped refine focus and objectives of study, rejected some proposed methods of data collection but supported others, ensured study documentation relevant and accessible and influenced terminology used to describe clinical holding that would be accessible for children.</td>
<td>Impact on Policy: NR.</td>
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<td><a href="#">Taylor et al., 2015 UK</a></td>
<td>To involve young people in naming and branding the study which may then contribute to successful participation and retention.</td>
<td>PPI</td>
<td>active inclusion of patients, carers, service users, and stakeholders and may be defined as research being carried out ‘with’ or ‘by’ members of the public rather than ‘to’, ‘about’ or ‘for’ them.</td>
<td>Young people (n=9, 17-26yrs) with cancer. Plus (n= approx. 200) at teenage cancer conference.</td>
<td>Naming and branding of study.</td>
<td>Impact on Research: Young people changed name and branding of study; although impact not known it is hypothesised this may have positively influenced acceptability of the study resulting in higher acceptance rates. Anecdotally, young people and healthcare professionals responded favourably to change.</td>
<td>Impact on Policy: NR.</td>
<td>Impact on Policy: NR.</td>
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| Walsh et al. (2018), Ireland. | **Aim:** To increase the likelihood of developing a feasible, implementable, applicable and effective intervention | **Term:** PPI, Stakeholder, **Definition:** PPI occurs “when individuals meaningfully and actively collaborate in the governance, priority setting, and conduct of research, as well as in summarising, distributing, sharing, and applying its resulting knowledge” (de Wit et al., 2013). **Concepts/Theory:** user-centred design development | **PPI (YP):** Young people (n=8, 18-25yrs). **PPI (Others):** N/A. | Contributing to systematic review, development of materials and data collection tools, organising committee for symposium, co-applicant on grant. | NR. | NR. | NR. | NR. | NR. | NR. | NR. | Engaging with key stakeholders is recommended as best practice for effective intervention development.