

## **Evaluating the extent and impact of young people's involvement in National Institute for Health Research (NIHR) studies: an assessment of feasibility**

Louca-Mai Brady and Jennifer Preston

A report of a project commissioned by the James Lind Initiative

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## **Plain English Summary**

This project, commissioned by the James Lind Initiative, looked at young people's involvement in the design and delivery of research studies adopted by National Institute for Health Research Clinical Research Network: Children (CRN Children). We wanted to find out what information was available on how and when young people are involved in research, and what difference this involvement makes to research and to the young people involved.

We started by looking at the information CRN Children collect on when and how young people are involved in research. We found that most of the information collected was about the stages of research in which people had been involved, but there was hardly any information on who was involved and how. The significant finding is that there is currently no way of finding out which young people were involved in CRN Children studies, whether studies had involved young people rather than their parents, or what difference any involvement may have made.

In Stage 2 of the project we talked to professionals who work in public involvement to get their ideas on how we could answer some of the questions that came out of Stage 1. The people we spoke to thought that it was important for NIHR to ask some new questions about who is involved in research and how, as well as what difference this involvement makes. They suggested we could do this by looking at what people say in funding applications and reports about public involvement, as well as adding new questions about who is involved in research to the forms researchers have to fill in. People also pointed out that most information collected on young people's involvement is written by researchers and that there needs to be more opportunities for young people to have a say on how they have been involved and the difference they think it has made to them and to the research. We have made some recommendations about how these things could happen.

Further research is required to fill some of the information gaps about how and when young people are involved in health research, and what difference this involvement makes to research and to the young people involved. Knowing more about what works in young people's involvement in research would also help understanding of how other groups of people can be involved and how best to measure this.

## Executive Summary

A report on Generation R, a national Young Person's Advisory Group (YPAG) (GenerationR, 2014), identified the need *"to develop a systematic way to measure the impact of [young people's] involvement activities"* (Recommendation 10, GenerationR, 2014). Following previous unsuccessful attempts to address this issue, the James Lind Initiative commissioned this project to investigate the feasibility of measuring young people's involvement in National Institute for Health Research (NIHR) studies.

The project sought to identify data currently collected on the nature and impact of young people's involvement by the NIHR Clinical Research Network: Children (CRN Children), and consider the scope for future data collection across NIHR.

Stage 1 of this work assessed the availability, quality and reliability of existing data in the CRN Children portfolio through analysis of data available through the CRN Central Portfolio Management System (CPMS), the CRN Closed Study Evaluation Survey and the GenerationR YPAGs. A significant finding is that there is currently no way of identifying through existing CRN data collections or via GenerationR YPAGs which studies have involved young people, or indeed whether studies have involved young people in addition to parents, let alone assessing what form that involvement may have taken, who was involved or any impacts of involvement.

Stage 2 involved a qualitative exploration of the issues and questions which had emerged from Stage 1 through conversations with key stakeholders from across NIHR. This work identified a need to better collate, understand and disseminate data on the nature and impact of young people's involvement in research using both existing systems and processes and the possible development of new metrics and measures. We found that NIHR data collection systems currently provide little scope to do more than identify whether or not there has been any public involvement. But there is potential within existing systems and processes to collect comparable data across studies on the nature, impact and influence of public involvement. This includes the suggested addition of a demographic measure on public involvement in the CPMS and the Integrated Research Application System which informs it, and in monitoring information including ResearchFish. NIHR funding applications, monitoring and reports also offer potential for secondary qualitative analysis of 'free text' information on the nature and impact of public involvement. A study recording form developed as part of an evaluation of the GenerationR YPAGs could be used to collect comparable information on the nature and impact of researchers' work with YPAGs. Further research could address many of the issues raised and have wider applicability across NIHR public involvement, as well as generating specific learning on the nature, extent and impact of young people's involvement in research.

## **Recommendations**

### **NIHR data collection**

1. Any reviews or development of public involvement questions in the NIHR Integrated Research Application System, ResearchFish, and the NIHR standard application form and monitoring information should consider the need for the collection and collation of information on who is involved in research and how, as well as on impact.
2. In its work on measuring the impact and developing standards for public involvement following *Going the Extra Mile* the NIHR should consider the need to identify when children and young people, as distinct from adults, are involved in research.
3. Alongside other demographic information, the NIHR should routinely collect information on the ages of those involved as public reviewers, on advisory boards and in other roles, as currently being piloted by the NIHR Central Commissioning Facility.

### **Other recommendations**

4. The GenerationR steering committee should consider whether and how it may be possible to capture and collate data on YPAG activity, including reviving the study monitoring form from the National Children's Bureau evaluation (Wallace and Eustace, 2014).
5. This project should be followed by a more substantive study which explores how, when and where young people are involved in health research in England, and the impact of this involvement on research studies, research bodies and the children and young people involved.
6. Any follow-up to this project or other work to develop measures of the impact of young people's involvement in research should consider how to include the views of the young people involved.

## Acknowledgements

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Last but by no means least we would like to thank all those who provided access to data and support in stage 1 and the stakeholders listed in Appendix 1 who contributed their time, knowledge and considerable expertise in stage 2.

## Glossary

**CCF:** NIHR Central Commissioning Facility. <http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/>

**CPMS:** NIHR CRN Central Portfolio Management System

**CRN Children.** NIHR Clinical Research Network: Children. <http://www.nihr.ac.uk/nihr-in-your-area/children/>

**GenerationR:** a National Young Persons' Advisory Group made up of local YPAGs across the UK. <http://GenerationR.org.uk/>

**HRA:** NHS Health Research Authority. <http://www.hra.nhs.uk/>

**INVOLVE:** NIHR national advisory body for public involvement in NHS, public health and social care research. <http://www.invo.org.uk/>

**IRAS:** Integrated Research Application System. <https://www.myresearchproject.org.uk/>

**NETS/NETSCC:** NIHR Evaluation, Trials and Studies Coordinating Centre. <http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-evaluation-trials-and-studies-coordinating-centre/>

**NIHR:** The National Institute for Health Research. <http://www.nihr.ac.uk/>

**NHS:** National Health Service

**PPI/E:** Patient and public involvement/ and engagement

**YPAG:** Young People's Advisory Group

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# 1. Introduction

## 1.1 Background

The case for young people's<sup>1</sup> participation<sup>2</sup> has been well-documented (e.g. Kirby *et al.*, 2003; Percy-Smith and Thomas, 2010), and it is a popular concept in many healthcare organisations (Percy-Smith, 2007; Weil *et al.*, 2015). The United Nations Convention on the Rights of the Child<sup>3</sup> has established international recognition that all children have a right to the highest possible standards of both healthcare and participation (Alderson, 2014). The understanding that children should be involved in decisions which affect them is reflected in law, guidance, and policy in health services, research and more widely (Franklin and Sloper, 2005).

Public involvement is now an essential element of all publicly-funded health research in the UK (Evans *et al.*, 2014) and there is increasing interest in young people's involvement in the research process (Powell and Smith, 2009). Research that actively involves young people should lead to research, and ultimately services, that better reflect their priorities and concerns (Brady *et al.*, 2012; Fleming and Boeck, 2012) and enhance the opportunity for optimal health outcomes (Jamal *et al.*, 2014). However there is a lack of evidence on the impact of young people's involvement in health research (Bird, Culley and Lakhanpaul, 2013; Wilson *et al.*, 2015), as well as a lack of information on which young people are or are not involved (Brady, 2015; Richards, Clark and Boggis, 2015).

In 2014 an independent panel conducted a review of public involvement in the National Institute for Health Research (NIHR), *Breaking Boundaries*, which led to a report entitled *Going the Extra Mile*<sup>4</sup>. The report called for a new vision, mission and set of principles to underpin public involvement in research and for public involvement in the NIHR to be focused on six common goals:

- Opportunities to be involved in research are visible and seized on by the public,
- It is standard practice for the public and professionals to work together,
- The experience of patients, service users and carers is valued,
- Public involvement is a required part of high quality research,
- **Evidence of what works is easily available and can be put into practice** [our emphasis],
- The NIHR has maintained its global presence and influence for working with the public.

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<sup>1</sup> Although this report refers to children's rights the term generally used in this report is 'young people' as most of those currently involved in health research tend to be of secondary school age. Whether more should be done to include younger children in research is a point for discussion, but not the focus of this project.

<sup>2</sup> The term 'participation' is generally used when discussing young people's involvement in policy, practice and service development. However in health research 'participation' refers to "*people tak[ing] part in a research study*" (i.e. as sources of data) and 'involvement' to "*research...carried out 'with' or 'by' members of the public rather than 'to', 'about' or 'for' them*" (INVOLVE, 2016).

<sup>3</sup> <http://www.ohchr.org/EN/ProfessionalInterest/Pages/CRC.aspx>

<sup>4</sup> <http://www.nihr.ac.uk/news/going-the-extra-mile-a-strategic-review-of-public-involvement-in-the-national-institute-for-health-research/2739>

The role of the NIHR Clinical Research Network (CRN) is to provide support for researchers to deliver studies to ‘time and target’ and provide the infrastructure to make research ‘work’ in the NHS. In April 2014, the NIHR CRN underwent significant reorganisation intended to streamline and simplify the processes that support research delivery.

The NIHR CRN encourages researchers to involve the public in the early stages of research development. The CRN provides advice on public involvement and works collaboratively with NIHR partners to ensure continuity for the patients and carers involved, so that they can share their insights and experience to influence the entire study pathway, as illustrated below:



## 1.2 GenerationR

Children and young people’s involvement in the NIHR has predominantly been facilitated through GenerationR, a National Young Persons’ Advisory Group (YPAG) made up of local YPAGs<sup>5</sup> across the UK. In September 2013, GenerationR was inaugurated at a meeting in the Science Museum and a report of this meeting, containing 11 recommendations for future developments, was accepted by the Director General of NIHR, Professor Dame Sally Davies (GenerationR, 2014). The NIHR-funded James Lind Initiative (JLI) undertook to help promote three of the recommendations in the report:

- **Recommendation 9:** Develop an effective communications strategy that showcases involvement activities and sustains the objectives highlighted at GenerationR
- **Recommendation 10:** To develop a systematic way to measure the impact of involvement activities
- **Recommendation 11:** Work with the education sector to promote clinical research education in schools

The project described in this report has some potential relevance to Recommendations 9 and 11, but its main focus is on Recommendation 10: developing a systematic way to measure the impact of involvement activities. It follows an evaluation of the GenerationR YPAGs by the National Children’s Bureau (Wallace and Eustace, 2014). This concluded that the YPAGs had supported the involvement of young people in making input to a significant number of research proposals: over half of the individual research projects in which young people’s involvement was supported in 2013-14, mainly during initial work to inform funding applications (48%) or to inform ethics applications (9%) (Wallace and Eustace, 2014). However the National Children’s Bureau evaluation only focused on studies that had worked with the GenerationR YPAGs, and did not look at studies on the NIHR CRN portfolio, which had involved children and young people in other ways. The evaluation also identified the need to “develop clear streamlined and effective monitoring systems to enable the

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<sup>5</sup> Following the transition to the CRN West Midlands that group was renamed the Young Persons’ Steering Group, but for simplicity we refer to all groups collectively as the *GenerationR* YPAGs.

*gathering of high-quality data and collation of findings across the network*” (Wallace and Eustace, 2014, p.30), echoing Recommendation 10 in the *GenerationR* report.

Following the evaluation and the GenerationR report, the JLI identified two main ways in which young people’s involvement may have desirable impacts: (i) on the knowledge of young people involved (e.g. YPAG members); and (ii) on the studies that have involved young people. Following unsuccessful attempts to measure the impact of involvement activities on the knowledge of YPAG members, the JLI decided to focus on the impact of young people’s involvement on studies in the CRN Children’s portfolio and across NIHR more widely.

### **1.3 Aims**

This project aimed to assess the feasibility of measuring the nature and impact of young people’s involvement on research planning, processes and on the young people involved by:

- Assessing the availability, quality and reliability of existing data on young people’s involvement in CRN Children-adopted studies and the GenerationR YPAGs (see Part 2),
- Comparing the data collected on young people’s involvement by different parts of NIHR;
- Identifying data which could be collected in order to routinely monitor and evaluate young people’s involvement and its impact on NIHR studies.

## 2 Existing data relating to the impact of young people's involvement

Stage 1 of this work assessed the availability, quality and reliability of existing data on young people's involvement in the CRN Children portfolio by analysing data available through the NIHR CRN Central Portfolio Management System (CPMS), the CRN Closed Study Evaluation Survey, and the GenerationR Young People's Advisory Groups (YPAGs).

### 2.2 Assessment of available data on young people's involvement in the NIHR CRN Central Portfolio Management System (CPMS)

To assess the feasibility of evaluating the impact of young people's involvement on studies adopted by the CRN we began by analysing data stored on the CRN CPMS. The CPMS is a national information system which, in August 2016, replaced the CRN's previous Portfolio Database in order to *"build greater insight and deliver more effective support, both locally and nationally, for clinical research in the NHS"*<sup>6</sup>. For this report, data were extracted from 1<sup>st</sup> April 2015 to August 2016. Data include all open studies (i.e. closure date is blank) and closed studies (closure date on or after 1 April 2015).

We found that, as of 1<sup>st</sup> April 2015, there were 563 adopted studies on the CRN Children portfolio. But only 48 studies had completed the Patient and Public Involvement and Engagement (PPIE) activities section. All 48 studies were non-commercial studies (see Appendix 2, Table 1 for more information). More detail was provided in the free text public involvement section but only 13 out of the 48 studies completed this section (see Appendix 2, Figure 3). The 13 completed responses indicated that members of the public were involved in the prioritisation of the research, commissioning the research, and were involved throughout the study. Only one of the 13 responses expanded on who had been involved, and in that case it was a parent. **It was therefore not possible to identify through CPMS data a single study in the CRN Children portfolio which had involved young people.** This does not mean that young people were not involved in any studies, but rather that it was not possible to tell when those involved had been with young people rather than adults.

Up until the 1<sup>st</sup> August 2016 study teams were not required to complete the PPIE section of the Portfolio Database, but the CPMS now includes systematic extraction of data from the Integrated Research Application System (IRAS) application forms. These are used to assess applications for ethics approvals. Since 2009, the IRAS form has included a two-part question (QA14-1) asking researchers about their plans for active public involvement, with a guidance note explaining what 'public involvement' does, and does not cover (see Appendix 2, Figure 3). QA14-1 has both a tick-box list of public involvement activities, and a free-text box asking researchers to describe the involvement they have ticked (similar to questions asked on the old CRN Portfolio Database).

Since 8<sup>th</sup> August 2016, 74 study submissions from all 30 CRN Specialty Groups had been recorded on the CPMS and included data extracted from IRAS (Appendix 2, Figure 4). Only one of these studies was from CRN Children and in that instance the researchers had responded that no involvement activities had occurred or were envisaged. As the system was only set up and released on the 8<sup>th</sup>

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<sup>6</sup> <http://www.nihr.ac.uk/research-and-impact/nihr-clinical-research-network-portfolio/>

August 2016, not all data sets were complete and some records were in draft, so there could be more children's studies which were not easily identifiable. But again **we were not able to identify through CPMS data extracted from IRAS application forms any studies involving young people.**

Unlike data previously held on the CRN Portfolio, IRAS applications encourage researchers to complete the free text section of the public involvement section. A study by INVOLVE (Tarpey and Bite, 2014) noted that extracting data from IRAS submissions offers the possibility of producing baseline information on the extent and nature of public involvement in a more systematic way, and that there are merits of recording free-text data to explain plans, or otherwise, for public involvement. However, the study report also noted that data included in IRAS applications are often misleading and many researchers (40% in 2012):

*"...seemed to misunderstand what the [IRAS] question on involvement was asking. Whilst they also ticked at least one of the involvement boxes, their free-text responses described plans for engagement and not public involvement. They explained, for example, how they were going to recruit patients to participate in their research or how they would disseminate their study findings to research participants and to colleagues." (Tarpey and Bite, 2014, p.10)*

Of the 74 studies we identified on CPMS which included data extracted from IRAS, only six mentioned in detail who they had involved or planned to involve (parents, carers, etc.). Others referred to accessing patient groups, patient associations, public involvement groups, service users, focus groups, and charities without detailing who they planned to involve.

### **2.3 Assessment of available data on young people's involvement from the CRN Closed Study Evaluation Survey**

Following work undertaken by the former NIHR Mental Health Research Network (Ashcroft, 2013) and the Primary Care Research Network (Johns, Crossfield and Wibley, 2014), the NIHR CRN requested that research teams provide feedback at the point of study closure (when a study is no longer recruiting). The survey captured feedback from study teams on their experience of working with the CRN and included two questions about public involvement in the research process, and researchers' perceptions of impact of this involvement.

Between November 2014 and March 2016 (no data exists after March 2016 due to changes within the system), 103 Closed Study Evaluation Surveys were completed. The data collected covered all 30 specialties, and we identified four surveys completed by CRN Children-adopted studies. However, there are some gaps in the data (due to unanswered questions) so, in principle, more data should be available. Three of the four CRN Children studies indicated that there had been public involvement at different stages of study development and delivery, and one did not report any public involvement activities (Appendix 2, Figure 6).

The Closed Study Evaluation Survey asked researchers if any improvements were made as a result of the public involvement undertaken. Unlike CPMS this offered researchers the opportunity to highlight perceptions of the impact of public involvement on research quality and performance and includes the four children's studies that completed the survey (Appendix 2, Figure 7). However we found that, **although the Closed Study Evaluation Survey data indicates a positive impact of involvement on the quality of information, recruitment procedures and credibility of the research,**

**the limited data available does not allow any robust assessment of impact. As with CPMS it was also not possible to identify which studies, if any, had involved young people rather than adults.**

## **2.4 Assessment of available data collected via GenerationR YPAGs**

As previously mentioned, GenerationR is a National Young Person's Advisory Group (YPAG) made up of 5 local YPAGs across England. Four of the groups were originally set up and supported by the former NIHR Medicines for Children Research Network. The Mental Health YPAG, which was supported by the former NIHR Mental Health Research Network, joined the National group early in 2014. As of 1<sup>st</sup> April 2014, the NIHR CRN has undergone a major reorganization. This meant that YPAGs ended up being supported and sponsored by different NIHR or NHS organisations (Appendix 2, Table 2). Therefore prioritisation of the types of studies the YPAGs are involved in, and the stages of research in which they are involved, are now determined by the remit of the organisation sponsoring each group. The Nottingham YPAG, for example, is required to prioritize research studies that come through Nottingham University Hospital NHS Trust, which will not necessarily be adopted by the CRN.

The reorganisation of the CRN has changed the way the YPAG facilitators work, and has made collaboration to share learning, resources, and showcase good practices more difficult. This has led to differences in the ways that facilitators monitor and evaluate the impact of their groups and where they report their findings. At the time of the NCB evaluation (Wallace and Eustace, 2014), the majority of groups were recording equivalent and comparable information using similar tools, coordinated centrally via the MCRN Coordinating Centre. But **the NIHR CRN reorganization means that YPAG data collection now varies by group and is not collated centrally** (Appendix 2, Table 3). The study recording form developed with the National Children's Bureau (Appendix 3) details the studies in which YPAGs have been involved and level of public involvement required or undertaken for each study. This form was reported by informants to have been a helpful tool for recording data on the nature and impact of young people's involvement, but at the time of this project was only being used by one group. Four of the groups (Bristol, West-Midlands, Nottingham and Mental Health YPAGs) highlighted that they recorded study details and level of YPAG involvement mainly through annual plans, progress reports, and annual surveys sent to researchers. The level of detail in each of these reports varies and it was unclear from our initial scoping which systems were used to keep track of such details. These issues are explored further in Section 3 of this report.

## **2.5 Stage 1: conclusions**

The work leading to this first section of the report aimed to assess the availability, quality and reliability of existing data on young people's involvement in the CRN Children portfolio through analysis of data available via the NIHR CRN Central Portfolio Management System (CPMS), the CRN Closed Study Evaluation Survey, and the GenerationR YPAGs.

Accessing data from the CRN CPMS was not straightforward as only certain personnel within the CRN network have permission to access these data. Similarly the Study Closure Evaluation Survey is held and can only be accessed by the divisional portfolio team and is not routinely collected. But since 1<sup>st</sup> August 2016 CPMS now includes systematic extraction of data (including public involvement activities) from the Integrated Research Application System (IRAS) application forms, data from which can potentially be accessed through routes other than CPMS. The key finding is that currently

nowhere in IRAS or the CPMS are researchers asked to include information on who has been involved, so it is not currently possible to assess if any young people had even been involved in the design and delivery of research studies.

The CRN Closed Study Evaluation Survey suggested that it might be possible to assess retrospectively the level of public involvement at different stages of the research process and what improvements (if any) are made as a result of the public involvement activities undertaken. However, due to the limited number of surveys completed, it is difficult to assess how useful the data are and how they could be used. A more detailed statistical analysis of the surveys would require encouraging all researchers to complete the form, and a question that addressed 'who' was involved would need to be added. As with CPMS it was also not possible to identify which studies, if any, had involved young people rather than adults, or whether or not researchers accessed YPAGs.

Following the reorganisation of the CRN and changes in sponsorship of GenerationR YPAGs, each group now uses different techniques to monitor, evaluate and report group activities. Often this is done in isolation, fitting around busy workloads and managing different expectations for reporting to those sponsoring individual YPAGs.

In summary, from this initial work it appears that there is currently no way of identifying through existing CRN data collection systems which studies have involved young people, the ways in which they have been involved, and what impact any involvement may have had. Furthermore, several questions remain about systems and processes of recording young people's activities on studies not on the CRN portfolio, and at different stages of the research cycle. Stage 2 of this project therefore explored how we might assess the nature and impact of young people's involvement on research planning, processes and the young people involved.

## **3 Scope for developing ways to measure the nature and impact of young people's involvement in NIHR research**

### **3.1 Qualitative exploration**

Stage 1, discussed in the preceding section, assessed the availability, quality and reliability of existing data on young people's involvement held by CRN Children and the GenerationR YPAGs.

In Stage 2 we undertook a qualitative exploration through telephone and face-to-face conversations with key stakeholders (see Appendix 1). These semi-structured conversations explored informants' views on monitoring and evaluation systems used to record involvement activities, the feasibility of systematically collecting and collating data on the nature and impact of young people's involvement, and the key opportunities and challenges to doing so.

Conversations were digitally recorded, with consent, to ensure accuracy and analysed in NVivo using a Framework approach. This is an analytic tool for thematic analysis which enables data to be systematically summarized and analysed by case, issue and theme (Ritchie *et al.* 2014).

### **3.2 Current data collection**

#### ***3.2.1 The overall picture***

Although informants were aware of some innovative, inclusive and diverse involvement of young people across NIHR networks and programmes such knowledge was reported to be largely anecdotal. A general view was that comprehensive and comparable data on the nature, extent and impact of public involvement in the NIHR was lacking:

*"I think at the moment we don't actually know what data we are collecting [on public involvement]....and what we're using that information for".*

(Senior Research Manager, NETSCC).

The lack of an NIHR-wide approach to the collection of monitoring and evaluating data on public involvement was felt to have resulted in fairly unsophisticated measures focused largely on process (i.e. tick boxes which focus on the stages at which researchers plan to have public involvement). This echoes the finding from our initial investigations, as outlined in section 2, that there is currently no baseline for assessing the nature and impact of young people's involvement in research planning, processes or indeed for identifying which studies have involved young people rather than adults. These issues have relevance for public involvement generally, but examining them through the lens of young people's involvement offers an opportunity to highlight issues specific to the involvement of young people and to consider the wider systems, structures and processes within which young people's involvement is located.

Informants agreed with our assessment in Part 2 that Integrated Research Application System (IRAS), data on public involvement discussed in section 2.2 currently gives a very limited picture of public involvement activity, with little scope to do more than identify whether or not there has been, or are plans for, any public involvement. Informants nevertheless identified scope within existing systems and processes, particularly IRAS, the NIHR standard application form and monitoring information, and also GenerationR records. These are summarized at the end of this report (Table 1, p.15). There was little awareness among our informants of the Closed Study Evaluation Survey but it was felt that this may nonetheless suggest ways in which the nature and impact of young people's involvement could be captured across CRNs and NIHR more widely:

*“The message about children's involvement is getting out there, so I suppose the next level up from that is that we need to identify who's out there and what they're doing [to involve young people] as well as how we embed [young people's involvement] so those people who perhaps don't want to do it understand why they should”. (YPAG Coordinator)*

### **3.2.2 IRAS**

Variable understanding of public involvement was felt by informants to affect the quality and comparability of information on public involvement in IRAS applications. The result being that applicants often do not provide any or sufficient details of their plans for public involvement, echoing the lack of free text information we found in our analysis of the CPMS data. There was also said to be a lack of consistency on how plans for involvement are assessed by NHS Research Ethics Committees (RECs). RECs have also reported to the Health Research Authority (HRA) that free text information from Qa14-1 is often not particularly helpful as researchers do not provide any or sufficient detail of their plans for involvement. It was felt that information in IRAS forms and therefore CPMS tends to focus on what is required to ‘tick the REC box’ (e.g. public involvement in the design stage), rather than including detail on the nature and potential impact of involvement.

Informants from the Somers Clinical Research Facility and GenerationR YPAGs told us that they do not currently access IRAS data to monitor which studies involved young people. But they thought there could be potential benefits to doing so, for example being able to say that 'xx amount of studies have used our YPAG'. However, as discussed in Section 2, IRAS data does not currently capture information on which studies have involved young people, let alone whether this was through YPAGs or in some other way and...:

*“If we wait to identify studies from IRAS forms it is almost too late. It's better to have processes in place to identify studies with plans or potential for PPI at an earlier stage, in order that PPI is as good as it can be...throughout the study”. (YPAG Coordinator)*

The YPAGs also did not consistently collect information on the stage of the research at which researchers consult the YPAGs (the main data collection points for IRAS) which would make it hard to cross-reference YPAG and IRAS data. The NIHR Central Commissioning Facility (CCF) and Evaluation, Trials and Studies Coordinating Centre (NETSCC) also said that they do not draw directly on IRAS data in monitoring public involvement in studies funded through their programmes, although they do monitor whether funded applications have ethics approval.

There was a general sense among informants that CPMS and IRAS may be the wrong place to look for detailed information on the nature and extent of public involvement. But they were felt to offer an important opportunity to systematically identify which studies are involving young people. The public involvement questions in IRAS are currently under review by the HRA, with input from INVOLVE and others, which provides the opportunity to consider the addition of a demographic question on public involvement. Informants suggested that the review of IRAS is also only one element in a more stringent set of tools and prompts needed to systematically measure the impact of public involvement across NIHR. There was a suggestion that there is an overall need to develop systematic measures of the impact of involvement in routine NIHR practice.

### ***3.2.3 Information from applications, plans and reporting***

Informants thought that secondary analysis of qualitative information in applications and monitoring information could provide more detailed material on the nature and impact of young people's involvement than CPMS and IRAS. Both CCF and NETSCC collect some demographic information on some patients and the public involved in their own work (e.g. public board members) through a voluntary equal opportunities form. CCF collects information on the age of their public reviewers but NETSCC does not currently do so. The NIHR standard funding application form does not currently ask for information on the ages of members of the public they are or will be working with, and monitoring information does not currently include any systematically collected information on who is involved (e.g. age) and how. It is focused more on what those involved have done and how this relates to public involvement milestones. The CCF have a research management system that collects monitoring reports centrally, but said that the primary purpose of monitoring reports is for programme managers to review studies individually, and that they do not routinely analyse across reports. However they identified potential for secondary analysis of free text information in applications and reports, and in researchers' responses to reviewer comments on involvement plans.

The CCF PPI team has mapped PPI data collection in order to develop thinking on this issue with colleagues across all NIHR coordinating centres.<sup>7</sup> Initial searches have enabled them to identify information in free text responses in public involvement sections of applications, and in plain English summaries on the number of applications which had young people as participants and whether these studies had involved, or planned to involve, young people. Although the primary purpose of data collection in the CCF is to inform the commissioning and monitoring of research, a secondary use could include making this information available to external researchers:

*"...to be able to come along and use some of our public involvement data in order to increase our knowledge and understanding of PPI in research as part of the development of this area".* (CCF PPI team member)

Because reporting on the nature and impact of public involvement has in the past been poor, researchers are increasingly being asked in NIHR progress reports to describe any positive and negative effects of involvement rather than just listing public involvement activity. This does not currently include any systematically collected information on who was involved (e.g. age) and how, but it has the potential to do so. Study protocols can also be a source of information, as can reports in the NIHR Journals Library, which requires reports on public involvement. Such monitoring information could be another source of qualitative data for secondary analysis on young people's involvement in practice. A similar approach was used in the RAPPORT study (Wilson et al. 2015), a realist evaluation which found that patient and public involvement can improve recruitment of patients to research studies and shaping research questions. It also identified factors that make good patient and public involvement more likely, including having dedicated input from the research team (Wilson et al. 2015). RAPPORT also identified a lack of evidence on the nature and impact of young people's participation in health research.

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<sup>7</sup> <http://www.nihr.ac.uk/about-us/how-we-are-managed/managing-centres/nihr-central-commissioning-facility/ccf-pi/ccf-pi-data.htm>

### **3.2.4 YPAG data collection**

All the GenerationR YPAGs said that they collected some basic demographic information on the young people with whom they worked through application forms (age, gender etc.) but the ways in which this information was collected and collated varied across groups (see Appendix 2, Table 3). There was also variation in how the YPAGs collected feedback from researchers:

*"We do always ask researchers for feedback. Sometimes we get it sometimes we don't".*  
(Coordinator, Bristol YPAG)

*"We don't currently use a researcher feedback form but when we work with researchers we send them a follow up email...trying to get feedback and then feed that back to the group".* (Coordinator, London YPAG)

The focus of this data collection was often to give feedback to researchers from young people or vice versa, and to improve practice and development within each group, rather than sharing information across the wider GenerationR network. Information collected also tended to focus on short-term impact (e.g. what researchers did as a result of coming to a YPAG meeting) rather than longer-term assessment of impact over the life of a study. Furthermore, not all researchers who came to YPAG meetings responded to requests for feedback. Despite only one of the YPAGs using the study recording form which came out of National Children's Bureau evaluation (Wallace and Eustace, 2014; see Appendix 3), most were aware of the document and all agreed that it could be useful and probably should be used more widely. The difficulty had been that the form came out around the time the NIHR CRN was being restructured, so its implementation got lost.

YPAG Coordinators and other informants thought that it was feasible to systematically measure the impact of young people's involvement across YPAGs and the wider GenerationR network, and that it would be really helpful to compare across as well as within the YPAGs. The challenge was doing so in a way that worked across different organisational remits, and with limited capacity and resources:

*"The problem is that we're so busy doing everything [to plan, organise and follow up YPAG meetings] but we do need to do more to record impact...and pull together information in annual reports again".*  
(Coordinator, West Midlands YPAG)

But without dedicated funding for GenerationR the opportunities for rolling out the study recording form, and coordinating and collating data collection across the YPAGs, were considered to be very limited.

### **3.2.5 Stage 2: conclusions**

Informants were clear that there is a need to collate, understand and disseminate data on the nature and impact of young people's involvement in research more efficiently. Informants felt that developing such measures is possible, particularly given both the increasing interest in young people's involvement in research and increasing interest by the commercial sector in public involvement in research.

## **3.3 Next steps**

Addressing some of the challenges discussed above would require strong leadership by NIHR to overcome tensions between the data institutions such as research centres want to collect, and the need identified by this report for more comprehensive and comparable data on the nature, extent and impact of involvement:

*"We [NIHR] should be looking at this [PPI] and tracking...the degree to which people are being...enabled to be influential, as well as the 'reach' of PPI to different sectors of the population".*  
(National Director for Patients and the Public in Research)

### 3.3.1 Building on existing systems

The reviews of IRAS and the NIHR standard application form offer opportunities to collect information on who is involved and how, as well as the stages of research in which patients and the public will be involved. But informants suggested that the direction of travel is to reduce rather than increase the data collection burden for NIHR studies. However, the findings of this project make a case for including some basic demographic information on who researchers plan to involve, including age groups. Informants also identified a need for greater examination of whether questions being asked about public involvement in NIHR are 'fit for purpose'. It was also felt by informants that the systems discussed above do not generally provide opportunities for members of the public involved in research to provide their own perspectives on the process and impact of involvement.

There are also ongoing discussions in NIHR about integrating information about public involvement throughout the standard application form rather than in a separate section. But this could make the proposed secondary analysis of qualitative data more difficult, and some informants expressed concerns that this could mean that public involvement gets lost:

*"Having that information [from the PPI section of application forms] enables me to have a quick summary of what that public involvement might be and how the YPAG might inform it".*

(Coordinator, Nottingham YPAG).

NETSCC pointed out that, although there is not currently an agreed critical appraisal tool for reviewers to assess public involvement, there are currently ongoing discussions on developing such tools for use across the NIHR. There is follow up through monitoring and final reporting processes of whether what is said in funding and ethics applications happens in practice, but it is not yet known how successful this is in following up on the translation of plans into activity and impact.

Our informants identified the need for further information on how individual NIHR elements and initiatives monitor and evaluate public involvement, including who is involved and how. INVOLVE informants reported that past attempts to gather systematic information on and map public involvement activity across the NIHR have been patchy and met with limited success. However, in addition to the opportunities within existing systems already discussed, ResearchFish<sup>8</sup> was mentioned as offering potential opportunities. ResearchFish is an external online system used by the NIHR since 2012, which requires award holders, on an annual basis, to submit data about their research outputs, outcomes and impacts. Questions on public involvement have been asked of all award holders since 2016. These focus on the stages at which there has been public involvement and researchers' perceptions of the benefits of involvement. But there is scope for further analysis of free text responses, and again, consideration of the addition of a demographic question on who is involved would be helpful.

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<sup>8</sup> <https://www.ResearchFish.net/>

### ***3.3.2 Developing new metrics and measures***

There is scope, as outlined in Table 1 (p.15), for existing NIHR systems to be used to identify studies that plan to involve young people (through an additional question in IRAS) and some information on who has been involved and how (through secondary analysis of applications and monitoring data and via GenerationR). But a further suggestion which emerged from this consultation was the idea of developing of a simple and manageable NIHR-wide mandatory measure or metric on the nature, impact and influence of public involvement. Possibilities suggested included measures based on the INVOLVE values and principles framework.<sup>9</sup> The Public Involvement Impact Assessment Framework (PiiAF),<sup>10</sup> a resource to help researchers assess the impacts of involving members of the public in their research, was also considered to have potential. However, it was also pointed out that uptake and use of PiiAF has been limited thus far and it has tended to be used on an adhoc basis as it was more relevant to some studies than others. Although some people have found it very useful for individual studies, in its current form our informants felt that it was probably too complicated and time-consuming to provide comparable data across studies. The GRIPP (Guidance for Reporting Involvement of Patients and Public) checklist was also mentioned (Staniszewska et al. 2011). NETSCC are implementing the short-form GRIPP 2 checklist (Royal College of Nursing Research Institute, 2017), when this is available, as part of the editorial process, and also to encourage more studies that have a significant public involvement component, to use the long-form GRIPP 2 checklist. Our informants identified the need to do more to identify what needs to be measured and to consider how any data collected would be used to improve practice, before developing and rolling out any public involvement tools. Any work on measuring the impact of young people's involvement in research needs to draw on the growing literature on the impact of public involvement, as well as linking into NIHR initiatives. For example, Health and Care Research Wales and NIHR Public Involvement Standards Development project<sup>11</sup> are seeking to address some of these issues and improve the quality and consistency of public involvement in research by developing a set of national standards to inform the systematic gathering and reporting of public involvement data across the NIHR.

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<sup>9</sup> <http://www.invo.org.uk/posttypepublication/public-involvement-in-researchvalues-and-principles-framework/>

<sup>10</sup> <http://piiاف.org.uk/>

<sup>11</sup> <https://sites.google.com/nihr.ac.uk/pi-standards/home>

## 4 Conclusions and recommendations

An NIHR goal, as set out in *Going the Extra Mile* (NIHR, 2015), is that “evidence of what works [in public involvement should be]... easily available and can be put into practice”. This project sought to assess the feasibility of measuring the nature and impact of young people’s involvement on research planning, processes and on the young people involved. We found that NIHR data collection systems currently provide little scope to do more than identify whether or not there has been any public involvement. There was no way of finding out which CRN Children-adopted studies had involved young people, or indeed whether studies had involved young people in addition to parents, let alone assessing what form that involvement may have taken, who was involved or any impacts of involvement. However, as summarised in Table 1 (p.15), there is scope within existing systems and processes to begin to address this. There is also potential for the development of simple and manageable measures to collect comparable data across studies on the nature, impact and influence of public involvement. But further consideration is needed on how such information could best be systematically collected, collated and made available for monitoring and evaluation.

Although there may be specific details that need to be recorded when looking at impact of young people’s involvement (e.g. age), our informants pointed out that there is not any intrinsic difference between the contributions made and the measurement of impact for young people’s or adults’ involvement. Therefore many of the findings in this report also have generic applicability. Attempts to measure the impact of involvement have only had partial success so far, so any attempts to do this for young people through any follow-up to this project could have both wider benefits and wider implications.

### 4.1 Recommendations

#### NIHR data collection

1. Any reviews or development of public involvement questions in IRAS, ResearchFish, and the NIHR standard application form and monitoring information should consider the need for the collection and collation of information on who is involved in research and how, as well as on impact.
2. In its work on measuring the impact and developing standards for public involvement following *Going the Extra Mile* the NIHR should consider the need to identify when children and young people, as distinct from adults, are involved in research.
3. Alongside other demographic information, the NIHR should routinely collect information on the ages of those involved as public reviewers, on advisory boards and in other roles, as currently being piloted by the CCF.

#### Other recommendations

4. The **GenerationR steering committee** should consider whether and how it may be possible to capture and collate data on YPAG activity, including reviving the study recording form from the NCB evaluation.
5. This project should be followed by a more substantive study which explores how, when and where young people are involved in health research in England, and the impact of this involvement on research studies, research bodies and the children and young people involved.
6. Any follow-up to this project or other work to develop measures of the impact of young people’s involvement in research should consider how to include the views of the young people involved.

**Table 1: Summary of current CYP PPI data collection**

<b>Data source</b>	<b>Current scope</b>	<b>Key issues</b>	<b>Potential</b>
<b>IRAS</b>	Comprehensive. Identifies whether or not there has been, or are plans for, any public involvement	No information of who is involved and how  Variable understanding of PPI question and limited free text information  Focus on involvement at the design stage	IRAS Qa14-1 review could consider the addition of demographic question(s), including whether those involved are YP or adults
<b>CRN Closed Study Evaluation Survey</b>	Question on researchers' perceptions of impact of involvement, as well as stages in which public were involved	No longer collecting data and small, self-selecting sample  No information on who was involved	If revived and implemented systematically, with addition of demographic question, offers opportunity for collection of data on impact of involvement
<b>Information from NIHR funding applications, monitoring and reports</b>	NIHR research management systems collect application and monitoring reports centrally  Study protocols and reports are publicly available online	Currently no demographic question on public involvement in the NIHR standard application form  The resources required to support in-depth qualitative analysis of a large volume of material	Qualitative secondary analysis of funding applications, protocols, monitoring information and reports could provide a rich source of material on the nature and impact of young people's involvement
<b>GenerationR Study Recording form</b>	Details the studies with which YPAGs have been involved and the nature and impact of YPAG involvement	Form currently only being used by one YPAG	GenerationR Study Recording form could be used by all YPAGs and potentially across the wider GenR network
<b>ResearchFish</b>	Requires all NIHR award holders to submit data about research outputs, outcomes and impacts, including PPI	PPI information only collected since 2016  No question on who has been involved in PPI	Potential for qualitative analysis of free text responses and addition of a demographic question on who is involved
<b>New metrics or measures</b>	Potential for new PPI measure based on GRIPP2, PiiAF and/or INVOLVE values and principles framework, including questions on who is involved and how	Uptake and use of existing tools has been limited & used within rather than across studies  Need to consider of data collection burden, and how any data collected would be used to improve PPI practice and rolled out	Any measure or metric on the nature, impact and influence of PPI needs to link into work on development of national PPI standards

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## Appendix 1: Authors and contributors

This project was led by **Dr Louca-Mai Brady**, on behalf of the James Lind Initiative. Louca-Mai recently completed a PhD on young people's participation in health services and research (Brady, 2017), alongside work as an independent research consultant and facilitator. Recent work has included supporting young people's involvement in an NIHR Health Technology Assessment Programme study (Watson *et al.*, 2017), advising NIHR bodies on the involvement of young people in research, and training young evaluators of health services. Prior to her doctoral studies Louca-Mai was a Senior Research Officer at the National Children's Bureau Research Centre, when she led the Centre's work on the involvement of young people in research. Louca-Mai was also a member of the NIHR INVOLVE advisory group from 2007-2016, where in recent years she contributed to the development of guidance on social media for public involvement and the involvement of children and young people in research.

**Jenny Preston**, who led Stage 1 of this work, is the Patient and Public Involvement and Engagement (PPIE) Priority Lead, NIHR Clinical Research Network (CRN) and Patient and Public Involvement Manager for the NIHR Alder Hey CRN. Jenny joined the NIHR CRN in 2005 as a full-time Consumer Liaison Officer for what was the Medicines for Children Research Network (MCRN). For 10 years Jenny's main role was to develop and implement a strategy for involving young people, parents and carers in all aspects of the MCRN and Clinical Research Facility to ensure the inclusion of a lay perspective in the design and delivery of paediatric research. Jenny set up and currently supports the *GenerationR* National Young Persons' Advisory Group. Jenny has also been a co-investigator on several PPI impact projects including one that explored optimising PPI in clinical trials called the EPIC study (Gamble *et al.*, 2015).

### Informants consulted in Stage 2

- Simon Denegri, NIHR National Director for Patients and the Public in Research
- Dr Jim Elliott, Public Involvement Lead, NHS Health Research Authority (HRA)
- Martin Lodemore, Senior Public Involvement Advisor and Kate Sonpal, Senior Public Involvement Manager, NIHR INVOLVE Coordinating Centre
- Dr Doreen Tembo, Senior Research Manager (Public Involvement), NIHR Evaluation, Trials and Studies Coordinating Centre (NETSCC)
- Dr William Van't Hoff, Director of the NIHR Somers Clinical Research Facility (CRF) and Clinical Director for NHS Engagement
- Members of the NIHR Central Commissioning Facility (CCF) Patient and Public Involvement team including Philippa Yeeles, Director of Involvement and Engagement
- *GenerationR* YPAG Coordinators in West Midlands, Bristol, Nottingham and London<sup>12</sup>

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<sup>12</sup> Jennifer Preston, Coordinator of the Liverpool YPAG is a co-author of this report and was therefore involved throughout. The Coordinator of the CRN: Mental Health YPAG was very recently in post at the time of this project and was therefore not included.

## Appendix 2: Tables and Figures

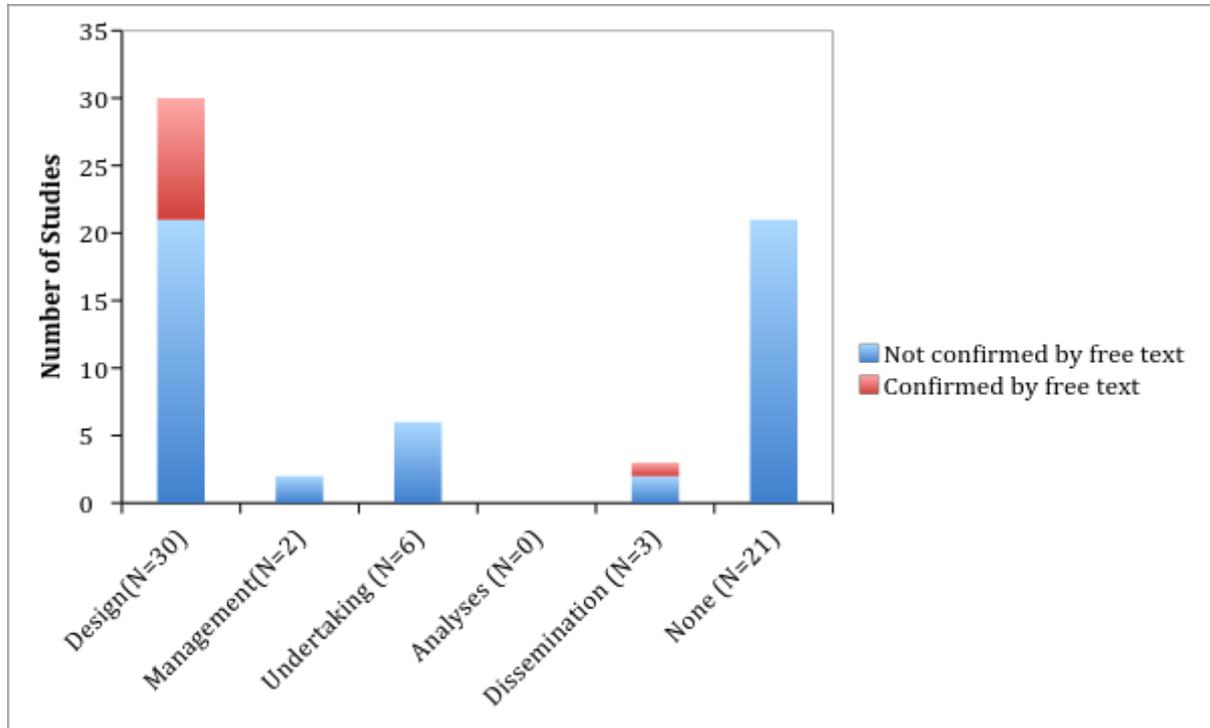
**Table 1: Summary of studies adopted by NIHR CRN Children during 04/2015-08/2016**

This table should be read horizontally. It provides a summary of the number of studies, study design, study status, study type, and PPIE activities submitted on to the CPMS within the project time period above.

Study design	Study Count	PPIE	%
Interventional	272	17	6.30%
Observational	273	29	10.60%
Both	18	2	11.10%
<b>Total</b>	<b>563</b>	<b>48</b>	<b>8.50%</b>
Study status			
Closed	141	12	8.50%
Open	307	34	11.10%
In Setup	79	2	2.50%
Suspended	19	0	0.00%
Withdrawn	17	0	0.00%
<b>Total</b>	<b>563</b>	<b>48</b>	
Study type			
Commercial	206	0	0.00%
Non commercial	357	48	13.40%
<b>Total</b>	<b>563</b>	<b>48</b>	

**Figure 2: Degree of public involvement and whether confirmed by free text in CPMS**

This figure shows responses related to the degree of public involvement and whether confirmed by free text (study teams could tick as many stages of research as applicable, so these data are presented as absolute numbers rather than percentages).





**Figure 4: Breakdown of public involvement activities in IRAS submissions and whether confirmed by free text**

This Figure shows a breakdown of PPIE responses to all 74 submissions and whether confirmed by free text (applicants could tick as many stages of research as applicable; therefore this data is presented as absolute numbers rather than percentages).

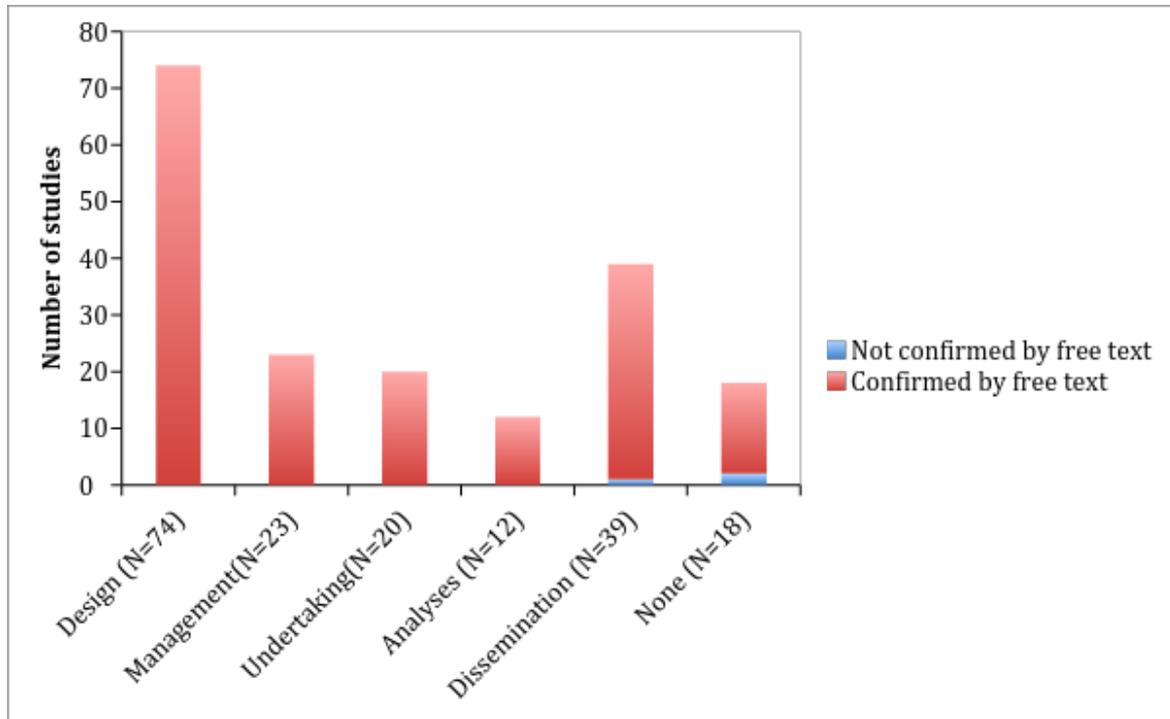


Figure 5: Public involvement interventions in study development and delivery (CRN Children Closed Study Evaluation Surveys)

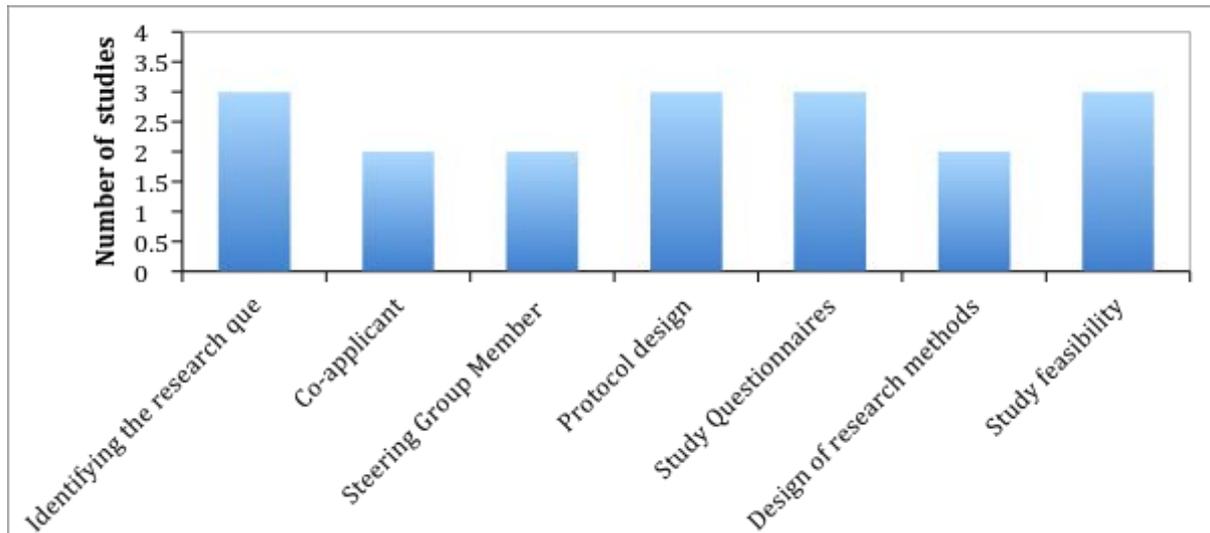


Figure 6: Public involvement interventions during research delivery/recruitment phase (CRN Children Closed Study Evaluation Surveys)

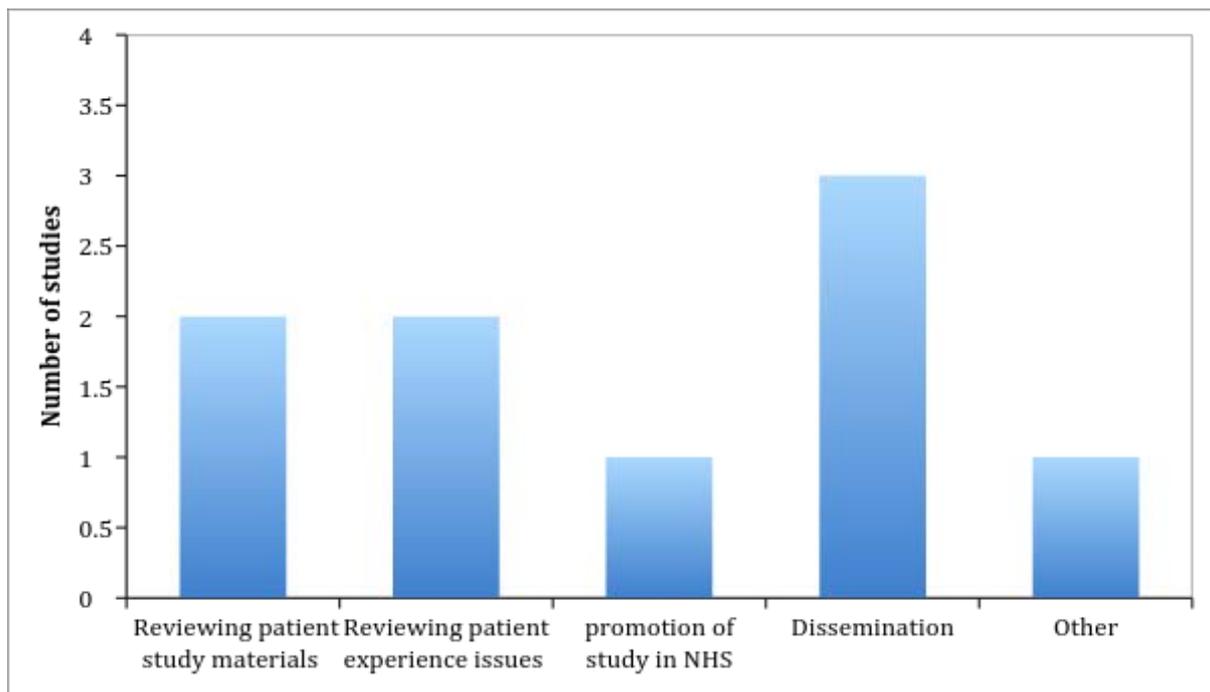
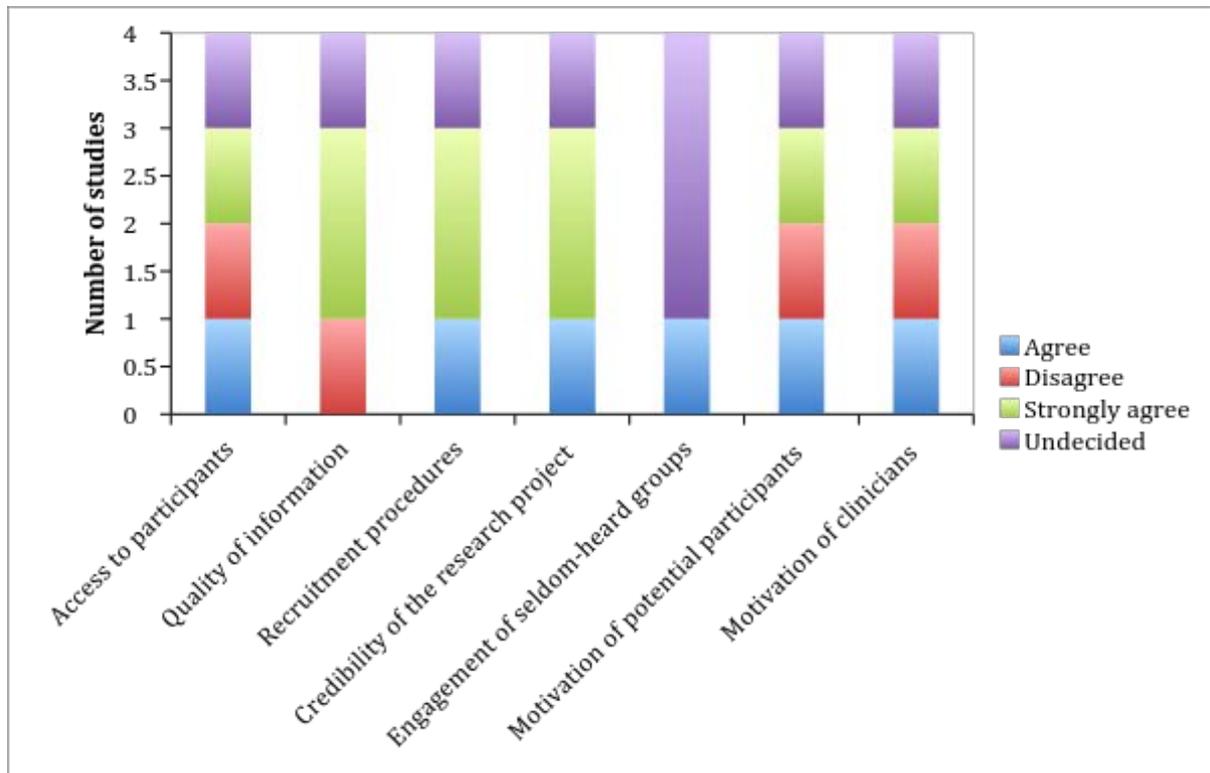


Figure 7: Perceived impact of public involvement on research quality and performance (CRN Children Closed Study Evaluation Surveys)



**Table 2 GenerationR YPAGs: remit and sponsors**

Name of YPAG	Remit of the Group	Sponsor
Liverpool YPAG	To inform the design, development and delivery of research.	The group is funded by the NIHR Alder Hey Clinical Research Facility (CRF)
CRN: West-Midlands Young Persons' Steering Group	To inform the design, development and delivery of research.	The group is funded by the NIHR CRN: West-Midlands
Bristol YPAG	To inform the design, development and delivery of research.	The group is funded by Bristol Health Partners
Nottingham YPAG	To support and work in partnership with researchers in the delivery of health research and across the research lifecycle.	The group is funded by Nottingham University Hospitals NHS Trust, Research and Innovation.
London YPAG	To help researchers to understand more about what it's like for young people to take part in studies so that they can design studies that better meet the needs of young people.	The group is funded by the NIHR Biomedical Research Centre at Great Ormond Street Hospital for Children NHS Foundation Trust and University College London
Mental Health YPAG	To provide advice and support to researchers working on mental health studies/projects.	The group is funded by NIHR CRN: Mental Health

**Table 2: Tools used by GenerationR YPAGs to monitor and evaluate group activities**

Group	Study recording form	Researcher agreement form	Researcher feedback form	YPAG evaluation	Annual Reports	Other (blogs, etc)
Liverpool	X	X	X	X	X	X
West-Midlands	-	-	X	X	X	X
Bristol	-	X	X	X	X	X
Nottingham	-	X	X	X	X	X
London	-	-	-	X	-	X
Mental Health	-	-	X	X	-	X

X means a tool is used to record this

- means a tool isn't in place or information wasn't available at the time of collecting this data.

### Appendix: 3: YPAG Study Recording Form

Study data	Field required
Date approached	
PPI lead	
Name of researcher/investigator	
Contact details	
Name of study	
Protocol Number (If Industry Study)	
Type of study	
Stage of study	
Has this study been through a CSG?	
Where did you hear about <i>GenerationR</i> Young Persons' Advisory Group?	
<b>PPI Activity</b>	
Type of activity (review of protocol, patient information sheet design etc.)	
Background to Study	
Deadline for activities to take place	
Can the researcher attend the next young person's meeting?	
<b>Outcome of activity (To be completed by PPI Manager)</b>	
Month activity actually took place	
Is this a one off consultation or on-going?	
What was the main outcome of the activity?	
<b>Evaluation of the activity (To be completed by PPI Manager)</b>	
Did you evaluate the activity?	
After activity has taken place	
Have you received feedback from the researcher	