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Implementing public involvement throughout the research process – experience and learning from the GPs in EDs study

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available from the corresponding author upon reasonable request

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AUTHORS' CONTRIBUTIONS

This paper was conceived by BH and JH. BAE led drafting of the manuscript with detailed input from BH and JH. The manuscript received additional editorial input from AC-S, AC, FD, ME, TH, DP, NAS, HS and AE. All authors read and approved the final manuscript.

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Abstract

Background

Public involvement in health services research is encouraged. Descriptions of public involvement across the whole research cycle of a major study are uncommon and its effects on research conduct is poorly understood.

Aim

To describe how we implemented public involvement, reflect on process and effects in a large-scale multi-site research study and present learning for future involvement practice.

Method

We recorded public involvement roles and activities throughout the study and compared these to our original public involvement plan included in our project proposal. We held a group interview with study co-applicants to explore their experiences, transcribed the recorded discussion and conducted thematic analysis. We synthesised findings to develop recommendations for future practice.

Results

Public contributors' activities went beyond strategic study planning and management to include active involvement in data collection, analysis and dissemination. They attended management, scrutiny, planning and task meetings. They also facilitated public involvement through annual planning and review sessions, conducted a Public Involvement audit and coordinated public and patient input to stakeholder discussions at key study stages.

Group interview respondents said involvement exceeded their expectations. They identified effects such as changes to patient recruitment, terminology clarification and extra dissemination activities. They identified factors enabling effective involvement including: team and leader commitment; named support contact; building relationships and demonstrating equality; public contributors being confident to challenge and flexible to meet researchers' timescales and work patterns. There were challenges matching resources to roles and questions about the risk of over-professionalising public contributors.

Conclusion

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We extended our planned approach to public involvement and identified benefits to the research process which were both specific and general. We identified good practice to support effective public involvement in health services research which study teams should consider in planning and undertaking research.

Public contribution

This paper was co-conceived, co-planned and co-authored by public contributors in order to contribute research evidence, based on their experiences of active involvement in the design, implementation and dissemination of a major health services research study.

Key words

Public and patient involvement, evaluation, research, consumer involvement

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Background

Public involvement across the research cycle is encouraged to improve relevance, quality and accountability of health and care research [1, 2, 3]. Many research funders expect evidence of involvement in developing study proposals and in planning how involvement will occur throughout a funded study [2, 4, 5]. However, there continue to be barriers to developing and undertaking impactful research with patients and public members [6, 7, 8, 9].

Conceptual models of public involvement in research highlight the different levels of involvement from none to full control of research [10, 11]. Involvement and partnership require power to be shared within research teams [12]. Some public contributors report negotiating their influence by using their experience, leading to queries of professionalisation [13]. Others argue that communication skills sensitise research teams to patient experiences, a role which goes beyond simply presenting patients' encounters with health care services [14]

To address concerns about the quality and effectiveness of public involvement processes, several guidelines, standards and value statements have been published, most prominent of which is the UK Standards for Public Involvement [15, 16, 17]. Researchers and policy experts also recommend that public involvement in research is thoroughly assessed, to build an evidence base and inform future practice [15, 18]. The GRIPP 2 reporting checklist is one tool for ensuring public involvement is consistently described in published papers requiring, as a minimum, a summary of public involvement activity [19]. The checklist does not consider quality or effects of reported involvement. Detailed accounts of how public involvement is undertaken within research studies remain limited [20] and usually focus on specific involvement roles [18, 21, 22, 23, 24]. Descriptions of public involvement across the whole research cycle of a major research study are uncommon [25]. More evidence about the context, process and effects of public involvement in research is needed [21, 26]. There are divergent views over the value of, and approaches to, assessing effects of public involvement [27, 28, 29] including defining core features, activities and mechanisms [30, 31] and encouraging feedback and mutual learning [32, 33].

We undertook a large research study (realist evaluation) involving three phases of data collection and analysis over four years. Our study evaluated models of care in which general practitioners work in or alongside Emergency Departments at UK hospitals [34]. Our successful application to the National Institute of Health Research (NIHR) Health Service and Delivery Research (HS&DR) programme (project 15/145/04) included a description of proposed public involvement in delivering the study. Our objectives for public involvement were to ensure our research remained relevant to health service users by including public and patient experiences and perspectives throughout research planning, implementation and dissemination. We also determined that our research should be acceptable,

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understandable and feasible, to be of highest quality. These objectives informed our plan for public involvement. This plan was developed with two public co-applicants who also had extensive input throughout planning the research design.

In this paper, we describe how we involved public contributors in our study. We consider how this involvement evolved from the way we envisaged at the study outset, the experiences of all co-applicants collaborating in the research and consider lessons for future practice [19]. This first-hand account of public involvement [22, 24, 26] is co-authored by public and academic co-applicants and conveys multiple perspectives from our collaborative work on this study. Two authors are public contributors (BH, JH), 10 authors are academics, clinicians, policy makers and health service managers. The author group has worked together for six years.

Aim

To describe:

- how we implemented public involvement within our research study
- reflections on the process and effects of public involvement in a large-scale multi-site research study
- learning for future involvement practice

Method

Terminology

We use 'public contributor' to describe the roles of JH and BH who were co-applicants in the GPs in EDs research study and the two other individuals who joined the independent Study Steering Committee. We occasionally distinguish JH and BH as public contributor co-applicants to avoid confusion. We use 'public and patient members' to describe the individuals who attended stakeholder events and contributed to those stages of the research.

Initial public involvement approach

Before planning our research we recruited two public contributors (JH and BH), with experience of using primary and secondary health services, from the Public Involvement Community supported by Health and Care Research Wales (HCRW) [35]. Our involvement plan was developed alongside research design and preparing the funding application. JH and BH joined the research development group. They took part in all discussions about the proposed research. They shared responsibility for authoring plans for public involvement in the study, including reviewing the proposed budget. They drafted the plain English summary. They were named research co-applicants on the outline and full applications.

In our study, we proposed the following approach to public involvement. We committed to continuing our relationship with the two public contributors we named as co-applicants on the study. We intended that they would maintain an equal status among all co-applicants within the research management team with full opportunity to contribute to strategic and operational decisions throughout the research. We also proposed they would join subgroups to: plan data collection; review early findings; co-plan stakeholder events; lead the public strand of our dissemination activities. At their suggestion, we expected them to

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host pre-meetings to brief and support public and patient members attending our two stakeholder events.

In addition, we planned to recruit two different individuals through the HCRW Public Involvement Community [35] to join our Steering Committee as public contributors and providing independent oversight of our study. Finally, we intended to recruit seven public and patient members to attend two stakeholder events alongside equal numbers of other stakeholder groups (table 1).

We calculated a budget (0.5% of total research bid) to provide honoraria and reimburse all expenses. We named an academic co-applicant (BAE) in the funded post of Public Involvement Lead. Her role included liaison with public contributors, ensuring accessible opportunities for their involvement, offering training and support in the event of distress or difficulty. We committed to standards of best practice, such as providing honoraria, accessible information, a named contact person (see Appendix 5 for further examples) [15, 36].

Data collection

To understand how we implemented or diverged from our initial public involvement plan, team members made comprehensive notes throughout our study. We documented public involvement activities in our meeting minutes and any reported effects on study processes. We made a timeline of public involvement activities in our study by compiling a table recording the activity and effects.

To understand experiences and effect of public involvement in the study, we held a group interview (Appendix 1) with co-applicants attending a regular (online) study management meeting during the last six months of the funded study (9/14 participated: six university staff; three clinical/policy experts). Questions were developed and administered by BH, JH and BAE based on a public involvement effects framework [37]. BH and JH responded to questions and comments at the end of the interview. With participants' consent, the discussion was audio-recorded and transcribed using a facility within Zoom software. We encouraged interview respondents to be frank in their answers and invited them to send comments by email to a third party if they felt uncomfortable at any point.

Analysis

JH, BH and BAE reviewed records describing roles and outcomes of public involvement, compared to the original involvement proposal. We undertook thematic analysis of the group discussion informed by the public involvement effects framework [37, 38]. BAE, JH and BH read the transcript, coding text with the underpinning framework and adding any new codes. Through discussion, we generated themes and interpretation, taking a critical stance to test and confirm findings [39, 40, 41].

We then brought together all data about implementation processes, experiences and effects to consider what we had learnt about involvement in our study. We identified what contributed to effective involvement and prepared recommendations for implementing public involvement, based on our findings.

Reporting

We present our account of public involvement in three parts: 1) the organisational structure through which we implemented involvement; 2) involvement processes and their effects on conduct of the study; 3) reflections by team members on the experience of public involvement and how they felt it affected the study.

We selected quotations from our group interview to be illustrative and typical of respondents' comments unless otherwise stated. Quotations are identified by numbers 01 to 09.

Ethics

Permission from a research ethics committee was not required but the authors followed best practice in informing respondents, gaining consent, managing and reporting data.

Results

1: Implementing involvement

- Public involvement throughout this study was more extensive and detailed than envisaged
- Numbers of public and patient individuals involved increased from 11 (planned) to 19 (actual)

We convened five forums and ensured public involvement at all stages (table 1).

- i. Research management group: all co-applicants (including two public contributors) plus research staff met every one-two months, taking all strategic and implementation decisions. This was in our original plan.
- ii. Study Steering Committee: two independent public contributors plus methodological, clinical and policy specialists met every six months, providing oversight and advice to the research team. This was in our original plan.
- iii. We had planned for public involvement in four sub-groups. In the study, six sub-groups were convened. New tasks included undertaking the rapid realist review and reviewing interview data.
- iv. Stakeholder workshops – proposed role, to support public members at the events, was extended. Additional roles included: recruiting public members; co-planning the agenda and room layout to address public needs; facilitating discussion groups; co-presenting.
- v. We convened annual Public Involvement Team meetings. This regular forum was not originally planned. The Public Involvement lead coordinated these meetings and attended with the two public contributor co-applicants. At the meetings, the team planned and reviewed the role and operation of public involvement in the study; identified and accessed support and training, including any issues causing distress or difficulty for individuals; identified opportunities to extend public involvement in the study. Briefing sessions were identified and provided but no formal training was requested by public contributors. Members co-authored a Role Description document which they updated annually and reported to the research management group (Appendix 2).

2: Processes of involvement

- Joint working at all stages of delivering the research enabled public views to be included in discussions and decisions, from preparing the ethics application through to dissemination
- Public contributors extended the opportunities for involvement in this study, enabling public and patient views to be more fully included

2.1 Study management, delivery, dissemination and scrutiny

Role

Public contributors were involved at all stages of the research cycle, from developing the research proposal to reporting and dissemination (table 1). Public involvement in the three phases of the study is shown in Figure 1. Public contributors' activities included:

- reviewing all participant information and data collection tools and processes which were submitted for Research Ethics Committee approval
- planning and participating in activities within each study phase: the rapid review of evidence; a survey of hospitals; selection of case study sites; case study data collection and analysis; overall management and scrutiny [42-46]
- planning and delivering the two stakeholder events, including developing materials for workshops during each day; facilitating some of the round-table discussions and presenting the workshop sessions alongside researchers [47]
- dissemination activities including: reports to the study funders; producing a range of accessible written and oral outputs during the study; preparing lay summaries of all academic papers (see [GPs in EDs \(primecentre.wales\)](#)); co-authoring publications [45, 46, 48] and planning for dissemination at study end
- scrutiny through the Study Steering Committee.

Effects on delivering the research

In many instances, the contributions made by public contributors were in team meetings where their views were sought and heard, playing a part in debate and collective decision-making. In these situations, it was not generally possible to determine whose opinion or contribution caused, or was the consequence of, which decision. In other instances, we could describe the role and outcomes of public involvement in the study. In table 2, we summarise public involvement at all stages of the study and any effects of public contributions by JH and BH. In appendix 3 (boxes 3.1-3.4), we provide a detailed account of four of those involvement episodes.

2.2 Developing public involvement in the study

Role

Public contributors played an active role in the process of planning and implementing public involvement throughout the study. They decided how the involvement processes, summarised in the research application, were undertaken in practice. They held discussions at Public Involvement team meetings and undertook an annual Public Involvement review which initiated additional activities to extend the role of public contributors and strengthen the practice.

Effects on processes of public involvement

Public involvement in the study was more extensive than proposed in the research proposal and funding application. The Funder described it as '*a fine example of embedding PPI throughout the course of the research*' after receiving routine study reports. Activities which were extra to those proposed in the original study proposal included:

- planning and managing PPI input through annual review meetings and regular contact between the PPI coordinator and public contributors
- collecting data on effects of public involvement during the study
- conducting an audit of public involvement, against the UK standards for public involvement [15]
- monthly research updates from the core team, at the request of public contributors, to keep wider team members abreast of study progress

In table 3 we summarise instances where public contributors amended processes of involvement in the study. In appendix 4 (boxes 4.1-4.4), we detail four case-studies

3: Research team members' experiences of involvement

- Research co-applicants said public involvement had exceeded their expectations and reported positive feelings including pride and self-worth arising from the experience
- Public involvement enabled changes to study processes, such as patient recruitment and dissemination but also presented challenges when expectations exceeded resources
- Respondents identified factors they considered to have facilitated involvement in the study

Nine people participated: six university staff (chief investigator, researchers, administrator); three clinical/policy experts. The two public contributors addressed discussion points at the end.

Expectations and experience

All respondents reflected that public involvement had outgrown their early expectations with more opportunities created to include public contributors than first proposed. Compared to other research projects, they found these public contributors to be more actively involved in study management and delivery.

even when our expectations have risen (with) changing general expectations about what is effective patient and public involvement and with the national standards...there has been more than expected contribution (05)

They believed this resulted in strong team working, with public contributors collaborating equally alongside other stakeholders in discussions and decision-making throughout the study.

seamless, it didn't feel like something separate...part of the study (06)

I was impressed at how much involvement there was in all the different stages of the project. So, it certainly wasn't just like in a tick box (09)

One respondent gave a different view, uncertain whether public members fulfilled all expectations and roles because they hadn't been challenging enough and believed they were in danger of becoming too integrated within the study team.

Are you becoming professional researchers? Or are you still genuinely spokespeople for public and patients... that's your job isn't it? (08)

Effects - what difference did it make?

Respondents identified a number of roles and activities affecting the research study. These included: supporting patient recruitment; reviewing qualitative data; planning and co-delivering stakeholder conferences; clarifying language and messages in dissemination.

to sense check what we were doing, to challenge us about our methods, to think about how we were going to recruit patients, really great feedback (on what) we

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presented in our initial findings, helping with stakeholder events. We couldn't have done that without the PPI team, to have had such good recruitment and to have got such a diverse group to attend for stakeholder events (03)

Respondents recalled several instances where public input changed a discussion or decision. One recalled how a public contributor had 'rescued us' (07) during complicated discussions about terminology, to suggest a simpler descriptive phrase which was then used in all outputs. Another respondent altered data presentation after a public contributor said the findings were not easily understood. Some respondents felt public contributors in the team shifted researchers' awareness to focus on patient experience alongside statistical hospital data.

Participants also reported changes to their view of the research.

to have PPI there is a constant and useful reminding of the wider context in which this study sits, that's always helpful...it's not just a statistical project with the few bits added on, it's a much wider thing, much more important thing (02)

Several remembered instances where presence and input from public members reminded team members that the research was for patients' benefits. One respondent said he now advocated for public involvement in other studies he was working on because he valued this effect on team outlook.

you've kept the focus on what really matters, actually what's relevant to this project, and it's better service delivery, you kept us on track with that... it started me questioning it (PPI) in other areas (07)

While some effects appeared intangible, respondents suggested that these were interlinked with concrete changes and that effects were revealed in a chain of small events which led to things being done differently. This respondent recalled team discussion about low recruitment numbers and that ideas from multiple perspectives convinced the lead researchers to try a different approach.

To me, one of the most concrete ones was the issue about recruitment of patients in the ED for interviews, and different strategies, including the incentives. That was generated from the PPI contributors, actually including the Study Steering Committee PPI members. But then I think it was strongly supported. The initiative to bring that in was led by the PPI contributors, and gave us the confidence to then put that to the ethics committee (05)

Motivation and fulfilment

Respondents' comments during the interview suggested feelings of pride for the effective way that public contributors had been involved in the research, in contrast to their other experiences. They spoke warmly of how meetings had felt cooperative: the sense of shared endeavour was strengthened because everyone was contributing in different but equally valuable ways. That public involvement exceeded expectations – 'extra value' (07) - was considered a benefit, respondents reported.

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they contributed as equal members in that team... more than I was expecting but that was a good thing (03)

They celebrated how public involvement was integrated within study delivery.

it's just not one thing, it's not just PPI involvement, it is of multi-dimensional contribution (08)

Public contributors acknowledged how their sense of worth within the study team increased through involvement. This also nurtured their motivation and enthusiasm, further building the team bond and sense of shared purpose. Their sense of self-worth was also enhanced by the respect given to their contributions and the atmosphere of mutual respect within the team.

you've demonstrated that you have been open to us, developing the role. I think we have felt listened to and respected (PPI 02)

we were able to make suggestions, and they were welcomed and incorporated, where possible, and we were given real and not token roles (PPI 01)

What made it work?

Respondents identified factors which enabled perceived effective public involvement in the study:

- Commitment across the co-applicant team to public involvement, led from the Chief Investigator
- Having a university staff member to lead public involvement and to support individuals in their role
- Providing public contributors with support and training in the skills required to undertake the role
- Including public contributors as co-applicants, equal at meetings and visible alongside other team members, which made them integral to conducting and delivering the research
- Having regular face-to-face meetings (and online from 2020) building up a relationship within the team so that people felt they could work together
- Public contributors being able to work to researcher deadlines, flexible and prompt in responding to requests for input
- Public contributors being confident enough to articulate their views including challenging other team members

Challenges

Managing study resources within budget and timescales while also meeting rising interest in and expectations of public involvement was a challenge for researchers. Tight deadlines, staff availability and fixed costs meant research staff struggled to work with public contributors as frequently as, or when, they wished.

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expectations and resources, there weren't resources to provide the level of involvement for yourselves that we want, and the national standards advocate (05)

One respondent questioned whether public contributors had been too closely aligned with the research team. The effective relationships and sustained involvement was *'sucking you into our ways, in our language, and our enjoyment of research'* jeopardising their role as *'genuinely spokespeople for public and patients'* (08). Respondents also discussed the challenge of recruiting diverse public contributors.

Public contributors responded by describing the balancing act of maintaining an outside perspective but gaining the communication and research skills to effectively contribute to the collaboration.

finding the right place, that is not too involved, but that learns enough about a project to make informed contributions (PPI 02)

Experience of illness and accessing care remained a defining part of their identity, *'we've been to A&E, we've been to the GPs'* (PPI 02) but they also needed other skills to voice their contributions within research teams, they said.

the more of this sort of work you do, the better you get it actually challenging researchers, because it takes a lot of confidence to do that, when you start off you're not very confident (PPI 01)

Discussion

Summary of findings

In this study, we had a structured approach to involving public contributors which enabled them to have roles in project delivery and dissemination and in how public involvement was undertaken. Public contributors were actively involved throughout the study, taking on more research roles than was envisaged when the study was designed. This enabled changes to study processes, such as patient recruitment and dissemination. It made research co-applicants more aware of patient views and outcomes when reporting results. They identified factors which facilitated this positive public involvement but also challenges when expectations exceeded resources.

Strengths and limitations

Data capture and analysis of public involvement in this study was led by the public contributors. This insider-approach has been used by researchers and public contributors in other studies describing and reflecting on experience of public involvement in research [49, 50, 51] and is encouraged for generating informed assessment of complex factors [15, 16, 19, 52, 53, 54, 55, 56]. Nevertheless, we sought to minimise the risk of bias from potential conflict of interest, while capturing relevant data to address our study aim, in line with existing evidence. Our study records provided prospective data to capture real-time information and minimise recall bias. We used a public involvement effects framework to structure data collection and analysis [37]. We encouraged interview respondents to be

frank in their answers and invited them to send comments by email to a third party if they felt uncomfortable expressing views verbally. One respondent did challenge the meeting consensus on some occasions and others did identify challenges. No emailed views were received.

Comparison with existing literature

Best research practice is to involve public contributors in developing research from the earliest feasible stage and plan their involvement in the funded study [57]. We believed we had a robust and coherent plan which avoided tokenism [58]. Co-applicants believed this expanded due to team dynamics, the supportive environment and the skills of those involved. Even though team members had mixed experiences and expectations of what public contributors' roles would be, there was consensus that it should be, and was, integral to the project. Having a structure and intention for involvement meant we could respond to opportunities which deepened and widened the contributions that public members made. Commitment across the team and visible support from the Chief Investigator and senior staff underpinned our flexibility and opportunism. Support from the Public Involvement Lead boosted involvement of public contributors. Despite the increase in public involvement, there continue to be few reports of such integrated involvement in decision-making throughout a research study [59, 60].

This placed more pressure on team resources to respond to additional involvement, despite having a well-costed proposal including a PPI budget. Funders need to acknowledge the cost of genuine public involvement and accept these may result in bigger research budgets [15, 36]. Otherwise, research teams risk cutting other costs which are necessary to delivery high quality and timely research, in order to appear competitive in the contested research application process, risking tokenistic involvement.

Extending public involvement in our study generated questions over whether these public contributors risked being too integrated within the research team and losing their outsider status. The notion that public contributors become too professional has been reported previously but this view is not shared by the individuals who become involved in research [61, 62, 63]. Researchers and user-researchers report that experience differs from professionalism; the role requires skills which develop with practice and can be passed between contributors [64, 65, 66]. That this interpretation persists may suggest that trust continues to be shaky among the research community; and that individuals remain uncertain about the process and robustness of involvement. It may also reflect the practical challenges of delivering work to deadlines and with competing priorities, so that the requirement to involve public members and respond to their views becomes too demanding [63].

The public contributors in our study said remained very conscious of their different skills and perspectives, including their health and care experiences [67]. There is a long-standing debate on who should be a public contributor [68]. The current emphasis on including less-heard voices overlaps these issues. People new to public involvement must gain enough knowledge and skills to make their voices heard. Power is recognised to rest with the research community and with it the responsibility to empower people and facilitate communication and interaction [61, 63]. To overcome the competing demands on

researchers, a Public Involvement Coordinator within a team can support patients and public members to be effective in their role [15]. We included someone in this role within our team from the outset of project development. The role was considered by all partners to be critical to our positive experience, as this paper describes. Other barriers, which contribute to power imbalance and damage involvement processes and outcomes, were not identified by respondents in this study. These can include devaluing people, tokenism, controlling or minimising information flows, all compromising clarity of role and partnership interaction [18, 69]. Our prospective plan, subsequently extended by consensus and implemented with open discussion, provides an approach to building involvement through a research project.

Our account is a rare example of the story of public involvement in a research study which describes the actual activities our contributors undertook [26, 63]. With systematic record keeping and comprehensive meeting minutes, we were able to record specific changes because public contributors were involved in our study. We showed they affected patient recruitment, interpretation and dissemination of findings. They also affected the context for discussions, providing new information or reassurance to support decision-making and changing the awareness of research, clinical and policy study members so that the study gained a stronger focus on patient outcomes as it progressed [70]. The interrelationship between tangible and intangible effects suggests the importance of integrating public members in a team so that they are part of ongoing discussions and decisions [61]. The challenges of recording effects are well reported [49, 50] but can be overcome.

Implications for practice

Our study shows there are some actions which support effective public involvement in health services research. Based on lessons from our experience, we make the following recommendations to support research teams to plan and undertake public involvement in large scale research studies. These recommendations may also be helpful for research teams when evaluating processes and effects of public involvement.

- Ensure public involvement is embedded from the earliest stage to allow influence in project design and implementation and to demonstrate equality within partnership from the outset
- Agree a team commitment to public involvement and document this through meeting documents and minutes
- Appoint a Public Involvement Coordinator, funded by the study budget, with the skills and responsibility to lead public involvement and support public individuals in their role
- Provide access to relevant and timely support and training so public members have the skills and confidence to undertake their role
- Integrate public involvement in study delivery by including public members as equal members within research management structures and processes
- Make public involvement a standing item on meeting agendas to ensure public contributors have an opportunity to raise issues above contributions made to other discussions
- Build a relationship within the research team to establish trust for collaborative working

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- Clarify structures and ways of working so public members and researchers have clear and realistic roles and expectations
- Review public involvement structures and processes during the study so that new opportunities can be identified and taken and additional support needs can be met
- Instigate simple data-gathering of public involvement processes and outcomes and report these so that experiences can inform the emerging evidence base

Conclusion

Public involvement in health services research is growing but remains inconsistent and poorly reported. Using the skills, commitment and resources in our team, we extended our planned approach to public involvement in our research study. We identified benefits to the research process which were both specific and general. These led to changes in patient recruitment, data interpretation and dissemination, but also refocused the study to include more information on patient outcomes. Study co-applicants reported positive experiences but also identified challenges, including matching rising expectations to available study resources. We identified good practice to support effective public involvement in health services research which study teams should consider in planning and undertaking research.

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