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Title: Public involvement in research: making sense of the diversity

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Abstract

There are normative and instrumental arguments for public involvement and a multitude of ways in which the public can and do get involved in research. This paper offers a coherent framework for distinguishing between the different motivations and methods for public involvement in research; and the ensuing interactions and potential for impact.

The pivotal point in this framework is the interaction where researchers and others exchange ideas and may influence each other. The appropriate ways for bringing them together depends upon their different motivations and characteristics.

We draw on a rich, cross-disciplinary literature and on our combined ‘hands on’ experience of user involvement in health and social research to explore each element of the framework to consider how to choose between methods or evaluate their impact.

Public involvement in research: making sense of the diversity

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ABSTRACT

There are normative and instrumental arguments for public involvement and a multitude of ways in which the public can and do get involved in research. This paper offers a coherent framework for distinguishing between the different motivations and methods for public involvement in research; and the ensuing interactions and potential for impact.

The pivotal point in this framework is the interaction where researchers and others exchange ideas and may influence each other. The appropriate ways for bringing them together depends upon their different motivations and characteristics.

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INTRODUCTION

Public involvement in research is a stated aim for many UK research funders. There are normative and instrumental arguments for involvement and a multitude of ways in which the public can and do get involved in research. These are increasingly captured by systematic reviews addressing different sectors of the patient and public involvement literature, albeit with relatively little conceptualisation or theoretical development, and few comparative studies.[1, 2] We need to make sense of this diversity if we are to share learning across different areas, choose wisely between different forms of involvement and evaluate their fitness for purpose.

We write as researchers in the UK who have consulted and collaborated with policy makers and the providers and users of public services to make our work more relevant to them. Participating in wider debates about public involvement, we have encountered other reasons for involvement. This paper draws on empirical research and scholarship, and our direct experience, to offer a framework for distinguishing between the different motivations and methods for involvement in research; and the ensuing interactions and potential for impact (Figure 1). We propose this framework primarily as a tool for planning, organising and evaluating involvement of others in research. It is also a way of systematising the vast range of approaches to involvement in research.

Many terms have been used for describing involvement of members of the public in research and there are interesting debates on what these terms reveal.[3] Without the space to go into those in this paper, we use the term ‘involvement’ to describe people’s participation in a shared research task, and ‘engagement’ to describe their intellectual focus on research or researchers. We use the term ‘others’ or ‘outsiders’ when describing academics’ more inclusive approaches to research while recognising the realities of institutional boundaries. These ‘others’ will include, but not be confined to, users or receivers of services, members of the general public, interest groups, practitioners and policy makers. We recognise that there are people who wear two hats, such as service user researchers, or practitioner-researchers.

DRIVERS OF INVOLVEMENT: WHO AND WHY

Why researchers invite involvement

Involvement can be driven by the research community or by people outside of it. The top and bottom rows of Figure 1 indicate that currently, it is researchers who tend to approach others, rather than the other way around. Regardless of whether involvement is initiated by researchers or outsiders, individuals have their own motivations for participating or not. There are enthusiasts and sceptics; and there are people who have accrued considerable experience and others who are just starting. The tasks to be done, the enthusiasm and prior experience are factors that influence the choice of involvement method. In Figure 1 these people and their motivations appear in the upper and lower boxes feeding into 'how people are brought together'.

There are two main reasons for researchers to reach out to outsiders for guidance. Most common is the specialist knowledge others bring from their personal experiences of health and illness.[1] This rationale anticipates involvement leading to more relevant research questions, more ethical recruitment procedures, more acceptable research tools, more study participants, more (or more accurate) data, and research findings that are more likely to have influence. To achieve this researchers seek people who have a particular expertise;[4] people whose personal health, living or working conditions, area of residence or particular interests relate directly to the research.

Less often in research is the democratic argument for greater openness of activities supported by the public purse.[1] More transparent governance of public resources is part of public accountability and participatory democracy. This argument can be extended to the rights and responsibilities of citizenship where people are invited to be involved as a member of the general public. A prime example in the UK is the Citizen's Council of NICE which "was established to ensure that the views of those who fund the NHS – the public – are incorporated into the decision-making process".[*]

We have encountered a third reason for researchers to involve the public, which is to leverage resources or build alliances. In biomedicine researchers work with patient organisations who share their mission to develop treatments, raise funds and encourage patients to provide personal data for research.[5]

Whatever the arguments for involvement in research, not all researchers are highly motivated and enthusiastic.[6] The innovators and early adopters were enthusiasts, some of whom, in time, became the experienced veterans who now not only bring their research skills but also cross-cultural skills that facilitate involvement. In contrast, some researchers invite wider involvement because they are required to do so by their employer or funding organisation. They may be uninspired, sceptical of the benefits or simply overworked. In these circumstances involvement may be tokenistic. Implementing involvement large scale requires recruiting capable change agents and investing in a programme of education and support not only for the public, but also for those implementing the policy.

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[*] www.nice.org.uk/aboutnice/howwework/citizenscouncil/citizens_council.jsp

Why others get involved

Outsiders accept researchers' invitations for a range of reasons.[7] Opportunities for personal development such as learning more about the health condition or building their confidence for negotiating with health professionals, may appeal. Some may wish to influence the research for their own personal, family or community interests. They may be driven by an ideology, either for a specific cause, or for active citizenship generally. Sometimes poor experiences of public services inspire people to seek improvements, or good experiences of services may encourage them to give something back. People can feel obliged or inspired to act as advocates on behalf of their peers. Lastly, some accept invitations because they are curious, little is asked of them and there is no inconvenience. A mixture of these rationales is likely to underpin most outsiders' involvement.

This group of 'others' also include enthusiasts and sceptics; the latter may be disinterested, unconvinced or discouraged by 'repetitive consultation fatigue' where they have seen no benefits from their earlier efforts to contribute.[7] Similarly, there are veterans and novices. The veterans may have acquired some useful research skills and experience. They are sometimes dismissed as 'professional users' who are 'unrepresentative', a situation arising from confusions between alternative meanings of 'representative'. Someone who shares common characteristics of the general population and is therefore 'representative', does not necessarily hold the skills required to be a good advocate for that population. A good advocate keeps strong ties with, and is well informed by, their peers, and has the skills to engage with the research community. However, if they privilege their learning from research over their personal, family and community network knowledge, they lose their value as an advocate, having 'gone native'.

Understanding outsiders' reasons for participating and managing their expectations is central to the success of recruiting and retaining people and employing appropriate involvement methods. For instance, involving people who merely tolerate researchers' approaches will require either quick methods or greater persuasion. Similarly, a researcher lacking motivation may be satisfied with tokenistic approaches. Knowing their motivations for involvement will help identify suitable methods as well as training and support needs.

PROCESSES OF INVOLVEMENT

The processes of involvement (the middle row in Figure 1) include how people are brought together, materials and procedures to support their exchange of ideas and how people interact.

a. How people are brought together

It has become common for national research programmes to open their committees and consultations to service users or the wider public, and to require researchers to state how they will involve service users in their work, or justify why not.[8] There are agreed principles for successful involvement,[9] and building reciprocal relationships is a feature of many projects.[10] Increasingly, researchers are gaining experiences of how people can be involved in research using methods from teaching, community participation and qualitative research. Some apply principles from action research, where the involvement of others in decisions for the research is integrated into the research design.[11] This contrasts with other approaches, which aim for greater distance between investigators and their field, for example opinion polls that invite wide consultation, or citizen's juries that facilitate collective deliberation about research agendas but do not necessarily share decision-making.[12]

Analyses of the involvement literature have made sense of this diversity by considering key dimensions that distinguish different methods for involvement.[13] The first distinction is who takes the initiative: researchers or outsiders.[14] Activist groups driven by a political feeling of misrepresentation in society at large will come with a pre-set agenda, whereas those drawn in by researchers' need for experiential expertise may not arrive with strong arguments for certain views. When researchers take the initiative they are faced with an array of strategic decisions: to involve individuals or organised groups; to mount a consultation exercise or to establish a collaborative working relationship; and to facilitate debate amongst similar people who are more likely to achieve consensus for decisions, or between disparate people who can usefully raise a broad range of relevant issues. Involvement may differ across the research project or come at one point only. Operational decisions cover the numbers involved; the forums for debate (face-to-face, written or electronic); formal or informal procedures for decision-making; the number, duration and timing of activities: and the materials, training and other resources made available. These decisions may be guided by theories of democracy, empowerment, or of learning organisations that develop their own internal structures and staff to respond to changing environments.

b) How people interact

Levels of involvement have been illustrated by a hierarchy, or a ladder, starting at no involvement, or tokenism, moving through consultation, and further up to collaboration and the ultimate level where all decisions are made by service users.[15] The image of a ladder has been criticised for assuming a common basis for all outsiders and ignoring the existence of different relevant forms of knowledge and expertise at different stages in the research process.[16, 17] This framework builds on this by aligning ways of working with the wider context, choice of partners, and the motivations described above.

Whatever the degree of involvement, for outsiders to have an influence on research they must have a channel for expressing their ideas (illustrated on the right hand side of the framework's middle row). Then researchers must understand those ideas, and integrate and retain them within their work. The expression and understanding of ideas on both sides requires communication skills in speaking and listening, or in writing and assimilating the written word as well as an attitude that recognises other people's expertise as of equal value to their own. If everyone recognises other people's expertise as important, this will facilitate team work between people who bring different combinations of traditional expertise (qualifications), competencies and problem solving.[18] Working together requires communicating clearly, engaging fully with new ideas and other people and for someone to facilitate interaction between people from different backgrounds.[19]

The presence of outsiders also provides an element of transparency and accountability to the public, as they act as witnesses to discussions.[†] Health scientists who rarely meet patients may be reminded, merely by the presence of patients or carers, of the ultimate purpose of their own work and so be motivated further.[20] Whilst the presence of an outsider may prompt scientists to think a little differently, it does nothing to bring the outsiders' views to the discussion if they do not speak. Thus involvement methods need to focus on enabling outsiders to contribute to debates and influence decisions.[13]

How people are brought together and how they interact is involvement in action. Again, being clear about the tools used to facilitate this is important for planning involvement, and for evaluation.

IMPACT OF INVOLVEMENT

The ultimate aim of involvement is to have outsiders influence research. This is possible through communication, joint decision-making, or simply representation.[7, 17] The first potential impact is for researchers' and service users' perspectives to be changed. Researchers may become more aware of the lived experiences of the conditions they research, and be alerted to areas previously under-researched, or ignored. Service users and members of the public may in turn gain a new perspective on their situation, and be encouraged to think about the personal experience in relation to a wider picture. Second, impact may be seen on the quality of research, for instance in its focus, design, ethics and conduct.[7, 21] This could be improved, for example, because a user perspective helps with access to the field and research translation so that the community understands its aims, or it could be reduced because people who lack knowledge about research methods gain an influence on how the research should proceed.[17] A third, and less direct, potential impact arises when the findings are more readily used because outsider perspectives increase a study's relevance to policy, practice and personal concerns.

a) Research as a focus of public interest

The top right hand corner of our framework describes the context of public involvement in research, including political and commercial interests. The 'public understanding of science' movement in the 1950s sought to engage people with the findings of research, to encourage an appreciation of its role in society. The intention was to attract political and public support for a science-based economy.[22] From the 1970s academics were challenged by activists calling for research to take into account their concerns; for instance, about a dearth of research about breast cancer, research unacceptable to people living with HIV, and environmental science that ignored the knowledge of farmers.[23, 24]

Now that involvement has broad policy support, outsiders are invited to bring an external perspective to setting and implementing ethical standards for research.[25] Research funders invite people with experiential expertise to join them in identifying gaps in knowledge, setting research agendas, and commissioning and monitoring research projects.[7, 13] For individual projects there are

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[†] www.nice.org.uk/newsroom/publicmeetings/publicmeetings.jsp

opportunities to influence recruitment, data collection and analysis, and how findings are reported.[10, 26]

The external environment in which involvement operates changes slowly and steadily, and is impacted by the political agenda, especially economic policy (through funding streams). This will in turn influence the planning of involvement and therefore its evaluation. It is important to communicate these structures to those involved, since it can restrict or enhance their opportunity for impact.

b) Barriers to impact

Barriers occur in every element of this framework. Failure to start involvement may come from researchers' lack of motivation or their inability to identify appropriate people to involve. Barriers may come from scepticism or lack of interest amongst the people approached. The involvement methods chosen may be inappropriate, or not reach agreed standards, possibly through lack of resources. With insufficient time, training or skilled facilitators, researchers may be unable to explain the task clearly or prompt individual or collective deliberation. Once brought together, participants may be reluctant to express their views, or be poor listeners. Research tasks themselves may not be open to influence by outsiders, and the researchers and those they work with may be resistant to change themselves.

USING THE FRAMEWORK

We propose this framework as a tool for designing both involvement activities and their evaluation.

When designing involvement activities, the framework can act as template for constructing a causal pathway to make use of different perspectives. It prompts thinking about who could bring valuable experience to the task, their likely skills and motivation and, consequently, the commitment they might make, the language they might use and the support they might appreciate.

When designing evaluations of involvement, data collection and analysis can focus on each element of the framework: about those eligible for involvement, those approached, and those who ultimately participated; about procedures for supporting involvement, the barriers and facilitators; whether the design and implementation of involvement met agreed standards;[9] about how people with different perspectives interacted or how they felt discouraged from interacting; and data about the origin and influence of contributions, whether people's ideas were expressed and understood, and subsequently integrated and retained in the final research product. The extent to which involvement improves or reduces the quality of the research needs to be considered, as well as whether researchers and members of the public have themselves changed as a result of the collaboration. Evaluating these intermediate steps is particularly important in a field with a history of tokenism.

How data are collected for evaluation depends upon the nature and stage of the involvement. Interviews and questionnaires are useful for understanding motivation, how people judge the process and whether they have felt they had an influence, or were influenced by others. Where the exchange of ideas is through the written word, document analysis can trace the origin and influence of contributions.[27] Where the interaction is face-to-face there is need for observation. Evaluating involvement can be challenging, particularly where interpersonal dynamics are complex and possibly imbued with emotion and drama.[28] Structured non-participant observations have provided limited quantitative analysis of research discussions.[27] Far more can be learnt by in-depth ethnographic study.[29] When a researcher collaborated with a group of young people with experience of residential and foster care to conduct a systematic review, this framework was applied to analyse and illustrate the main processes of their involvement and its impact.[30] In this example, young people worked with the researcher to decide the topic and question for the review, and were involved in all stages including protocol writing, and searching, screening and appraisal of studies (figure 2). Impacts were apparent on the research and on those who were involved throughout the research.

CONCLUSION

There is a growing literature about public involvement in health and social care research. Though dispersed through multiple journals, books and standalone reports, this literature is increasingly brought together by systematic reviews,[1, 7, 10, 11, 13, 21, 31] and a checklist has been proposed for better reporting of impact.[32] Better planning, reporting and evaluating of involvement may result from considering the dimensions of the framework: participants and their motivations; principles, procedures and resources for involvement; techniques for facilitating discussion and decisions; the resulting interpersonal exchanges; and potential impact.

In some ways, however, the debate needs to move on. Recent initiatives have aimed explicitly to support the involvement of service providers as well as service users, thereby recognising their specialist knowledge.[33] Although our framework acknowledges input from service providers (in the bottom left hand cell of our figure) a more integrated approach would focus on how drivers, processes, barriers and impact both differ and interact between all those involved in research, whether as users or providers of services, or as funders of research or those tasked with implementing the findings. In addition, further work is needed on inequalities in involvement and how existing structures aimed at facilitating equal opportunities might in fact continue the exclusion of groups who are already alienated by organisational structures and service approaches.

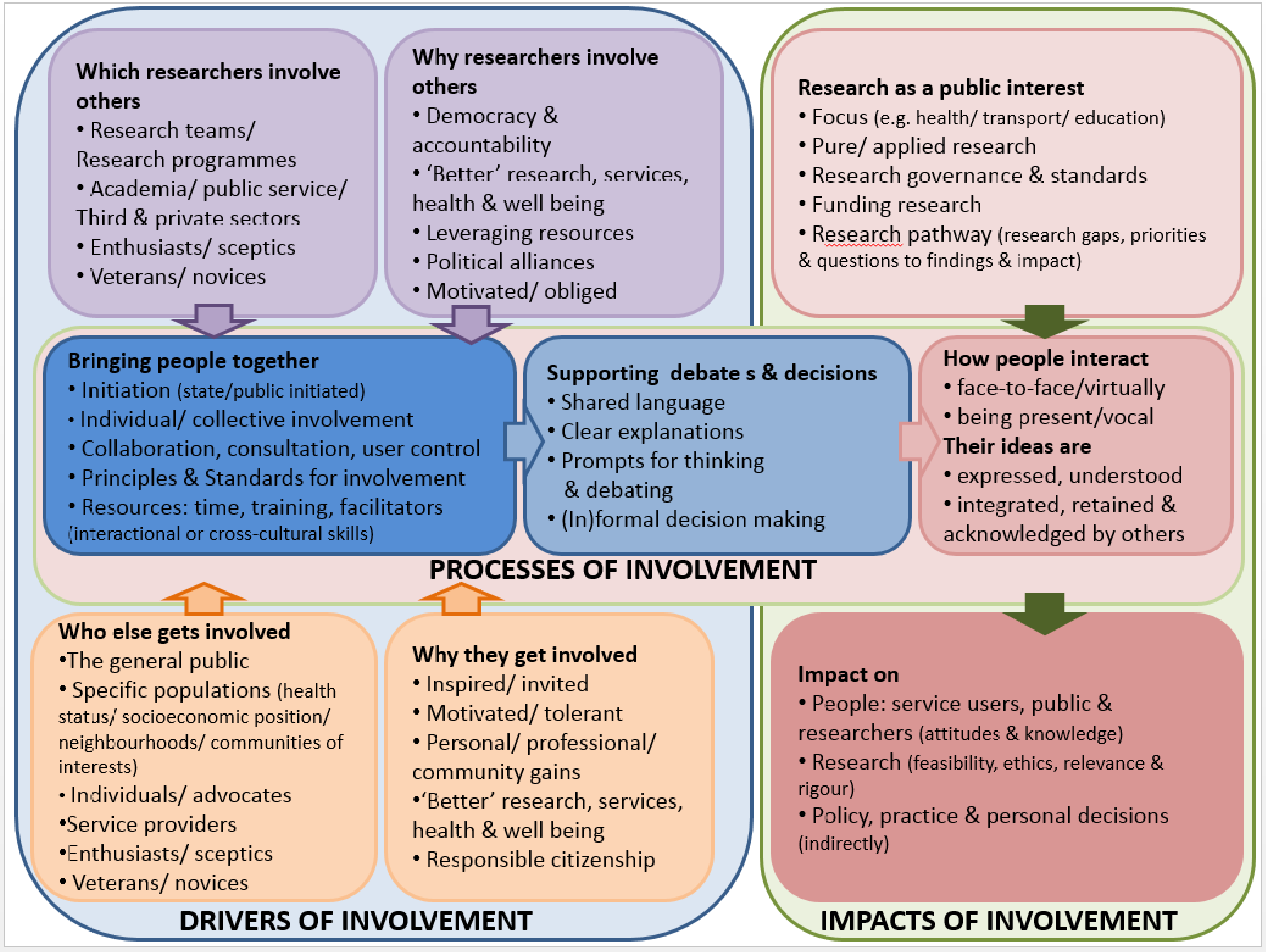
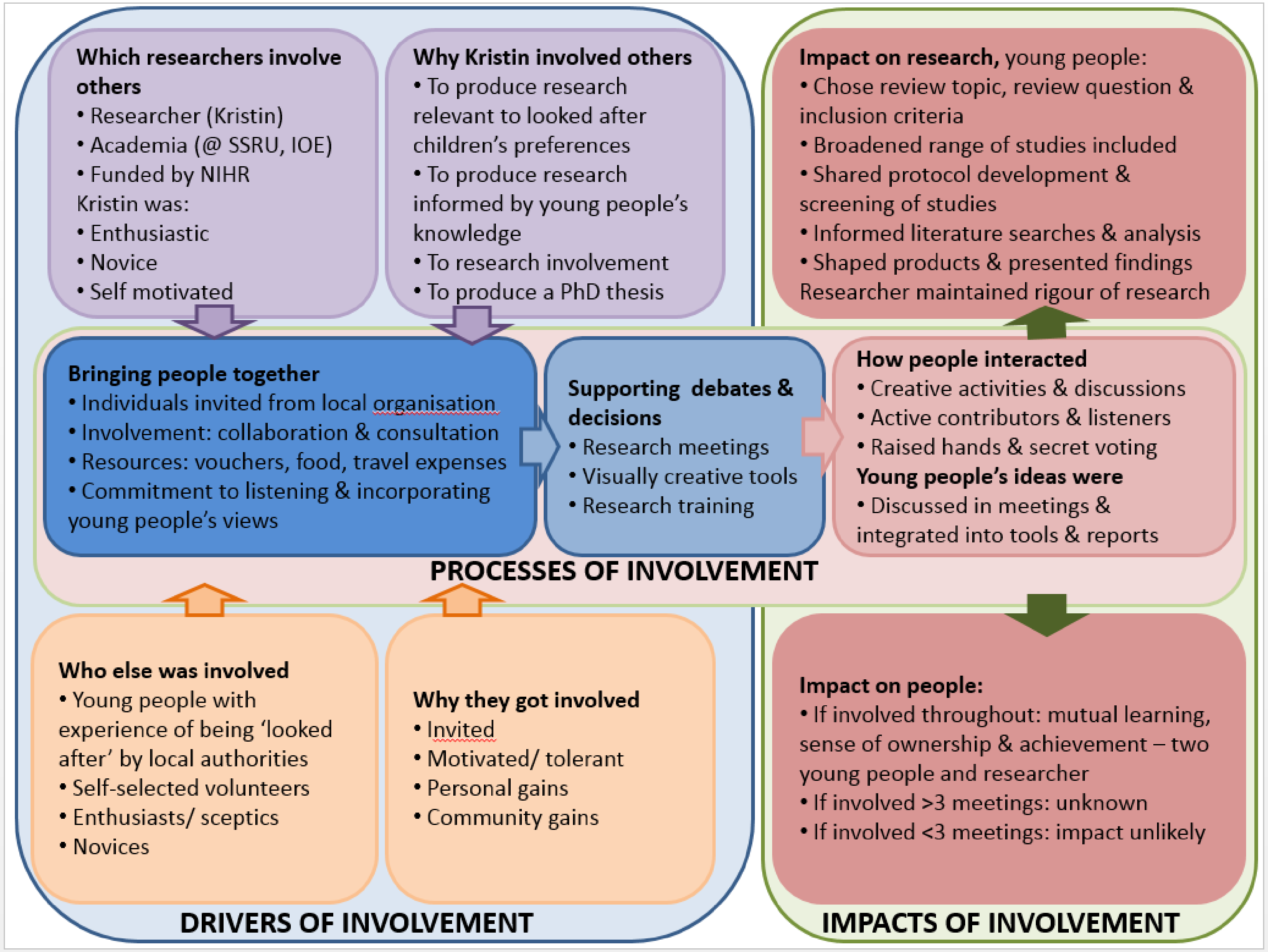


Figure 1: Framework for designing and evaluating involvement in research

Figure 2: Framework for designing and evaluating involvement in research: care leaver involvement in conducting a systematic review



Which researchers involve others
- Researcher (Kristin)
- Academia (@ SSRU, IOE)
- Funded by NIHR

Kristin was:
- Enthusiastic
- Novice
- Self motivated

Why Kristin involved others
- To produce research relevant to looked after children's preferences
- To produce research informed by young people's knowledge
- To research involvement
- To produce a PhD thesis

Bringing people together
- Individuals invited from local organisation
- Involvement: collaboration & consultation
- Resources: vouchers, food, travel expenses
- Commitment to listening & incorporating young people's views

Supporting debates & decisions
- Research meetings
- Visually creative tools
- Research training

How people interacted
- Creative activities & discussions
- Active contributors & listeners
- Raised hands & secret voting

Young people's ideas were
- Discussed in meetings & integrated into tools & reports

PROCESSES OF INVOLVEMENT

Who else was involved
- Young people with experience of being 'looked after' by local authorities
- Self-selected volunteers
- Enthusiasts/ sceptics
- Novices

Why they got involved
- Invited
- Motivated/ tolerant
- Personal gains
- Community gains

DRIVERS OF INVOLVEMENT

Impact on research, young people:
- Chose review topic, review question & inclusion criteria
- Broadened range of studies included
- Shared protocol development & screening of studies
- Informed literature searches & analysis
- Shaped products & presented findings

Researcher maintained rigour of research

Impact on people:
- If involved throughout: mutual learning, sense of ownership & achievement – two young people and researcher
- If involved >3 meetings: unknown
- If involved <3 meetings: impact unlikely

IMPACTS OF INVOLVEMENT

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