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COMMENT Open Access

Involving stakeholders with lived and professional experience in a realist review of community mental health crisis services: a commentary



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Abstract

Patient and Public Involvement (PPI) is considered good practice in all health research including literature reviews. Reporting of involvement practice in realist reviews has been inconsistent leaving gaps in understanding of best practice. Realist reviews are theory driven and explain how interventions work, for whom and in which circumstances. PPI in realist reviews provides a link between programme theory and real-world experiences and can be achieved through a 'stakeholder group' bringing lived and professional experience together. This paper discusses experiences of a stakeholder group with seven members with lived experience and eight members with professional experience in a realist review focused on how community mental health crisis services work. A mental health crisis is a time of distress when people need urgent support. Many different agencies can respond to mental health crises, but despite this, people often find it hard to navigate to the right help at the right time. Reflections on involvement in four stakeholder meetings alongside practical examples of involvement activities used during the realist review are discussed. Having two researchers co-lead the stakeholder group from both lived and professional experience perspectives provided a bridge between the different expertise within the stakeholder group. Engagement with a voluntary organisation provided support to lived experience stakeholders, which sustained their involvement over time. Social connectedness was needed to establish trust between stakeholders. This required informal social contact between stakeholders that needed to be planned, especially for online meetings. To maintain the emotional wellbeing of the stakeholders during their involvement, safe spaces for discussion are needed and these are best planned in partnership with the stakeholders. We concluded that consideration of ways to provide opportunity for informal contact in online meetings may improve the experience of the stakeholders. Careful consideration of ways to sustain stakeholders' contribution over time are needed. The emotional impact of involvement should be considered when planning realist reviews. This may include built in flexibility in the involvement to include small expertise specific breakout groups, individual meetings, and should be planned in partnership with the stakeholders.

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Plain English Summary

Involving people with experience of accessing mental health services (PPI) in literature reviews is good practice. We know less about how to do this in 'realist' literature reviews. Realist reviews explain how things work, who they work for, and in what situations. PPI can help researchers to link theory with people's real-life experience. Researchers do this in a 'stakeholder group' that brings people with experience of accessing services together with professionals.

This paper shares experiences of a stakeholder group with seven PPI members and eight professional members. Stakeholders supported a realist review about how community mental health crisis services work. A mental health crisis is a time of distress when people need urgent support. Many different services can help, but people still find it hard to get the right help at the right time.

The researchers thought carefully about the stakeholder group membership to make sure everyone felt able to join in. We have written about how the stakeholders learned together about doing realist reviews and the activities the stakeholders took part in. Due to Covid-19, the stakeholder meetings moved online. Although online meetings worked well, being in a room together was better for the stakeholders to get to know each other. Support from voluntary organisations as well as informal contact with stakeholders between meetings helped people to stay involved over time. Planning safe spaces to talk, could help avoid stakeholders being upset by being involved in realist reviews.

Keywords Mental health crisis, Patient and public involvement (PPI), Realist evidence synthesis, Realist methodology, Stakeholder involvement

Introduction

Patient and Public Involvement (PPI) is widely considered good practice in all health research [1] and is commonly understood as conducting research "with" rather than "on", "to" or "for" patients and the public [2]. Benefits of PPI include democratisation of knowledge, improved research quality, increased impact, and greater take-up of research in service settings [3, 4]. PPI, which includes those who use mental health services, has been driven by user organisations seeking empowerment, self-determination, and an independent voice for those historically marginalised [5].

Realist evidence synthesis is commonly referred to by the term 'realist review' which will be used throughout this paper. Realist reviews differ from other types of review (such as a systematic review) by being theorydriven [6]. This means that realist reviews seek to explain how and why an intervention works (or not) in different circumstances [7] through a process of iterative evidence searching and development of programme theory [8]. Based on philosophical assumptions of scientific realism, realist research seeks to identify "what works, in which circumstances and for whom?" [8]. To answer these questions, realist methods seek to understand the causal interactions between Context, Mechanism and Outcome using the heuristic C+M=O (See Box 1). The relationships between context, mechanism and outcome are conceptualised as programme theory which expresses what an intervention is expected to do and how it is expected to work. The realist methodological approach places emphasis on stakeholder involvement to identify and

describe, from a real-world perspective, the causal links between context, mechanism and outcome [6].

Whilst systematic review methods have benefitted from development of stakeholder involvement frameworks [9], the involvement of stakeholders in realist reviews has received less attention [10, 11]. The terminology used to describe such involvement has been varied, including for example 'stakeholder group', 'advisory panel' [11] but patients or the public have not been consistently involved [12] with some involving only professionals [13]. A systematic review of stakeholder involvement in realist reviews identified that 40% of included studies involved people with lived experience (patients, carers or family) as stakeholders [11]. There are two reported approaches to the composition of stakeholder groups in realist reviews [11]; a mixed membership of those with professional and lived experience in a single group [14] and two separate groups for those with lived experience and professionals [15]. The reporting of stakeholder involvement in realist reviews has also been inconsistent [11] leaving gaps in understanding of best practice regarding recruitment, the nature of the involvement, and its impact [11] with particular concern about the visibility of PPI contributions [12].

This paper focuses on reporting stakeholder engagement within a realist review that aimed to explain how, for whom and in what circumstances different community mental health crisis services work [16]. Mental health crises have been conceptualised as times of great distress [17, 18]; onset or relapse of a mental health condition [19]; serious disruption to usual daily life [20, 21]; or the point when someone can no longer manage alone, and outside intervention is needed [22]. As well

<u>CONTEXT (C)</u>- the background to or situation around an intervention or programme. Contexts include for example organisational structure, politics or cultural norms. Aspects of these contexts may enable mechanisms, while other contexts may inhibit mechanisms.

MECHANISM (M)- Mechanisms describe how the resources within a programme (for example 24-hour telephone helplines) influence the reasoning and responses of people involved in the programme (for example feel secure in the knowledge that help is available). Mechanisms are often hidden and are sensitive to the context.

<u>OUTCOME (O)-</u> This refers to the intended, unintended or unexpected programme outcomes.

Outcomes are generated when there is an interaction between the mechanism and the context.

<u>PROGRAMME THEORY-</u> An explanatory formulae providing an account of how, why and under what circumstances interventions work (or don't work). They explain the relationship between context, mechanism and outcome.

Box 1 Definition of realist concepts

as impacting the person experiencing the crisis, families, social networks, or employers may be affected [23]. Because crises are experienced by individuals in different ways, support is accessed from different agencies including mental health crisis services [24], the voluntary sector [25], the police [26], and ambulance services [27]. Despite availability of crisis responses from multiple agencies [28], people have continued to report difficulty navigating to the right help at the right time [29], too often leaving people unsupported and vulnerable [25].

The realist review was delivered in two phases in line with the realist and meta-narrative evidence syntheses: evolving standards (RAMESES) [6]. Firstly, a scoping search identified initial programme theories (IPTs) from n=45 documents. Secondly, the IPTs were tested through iterative searching of published research and grey literature resulting in inclusion of n=77 documents and primary data from n=20 individual interviews with a range of professionals and people with lived experience [16]. An expert stakeholder group brought lived and professional experience together in a single group [14] to create a space for working generatively across different expertise [30] to support the delivery of the realist review. This paper critically reflects on the delivery and contribution of the Expert Stakeholder Group (ESG).

Overview of involvement

Before the review was designed and funded, PPI was undertaken through NHS public meetings, individual consultations in the voluntary sector and a group consultation with eight people with recent experience of accessing crisis services for themselves or a person they care about. These consultations shaped the focus and design of the review funding application.

During the 26-month project there were four ESG meetings, each timed to take place at key stages of the review to maximise the impact of involvement (shown in Fig. 1). Involvement is reported according to the GRIPP2 guidance for reporting patient and public involvement [31]. The first ESG meeting was held face-to-face and focused on introductions, providing an overview of the review design and realist methods and a range of participatory activities to elicit views and perspectives on the review scope.

Three subsequent ESG meetings took place via videocall due to restrictions related to Covid-19. During the second meeting, the prioritised initial programme theories (IPTs) developed using data from published research, were discussed with the aim of bringing together knowledge from the published evidence with real-world experience [32]. The third meeting explored causal relationships between context, mechanism, and outcome (see Box 1) [6, 33]. In the fourth and final meeting, the ESG considered different contexts for providing crisis care and

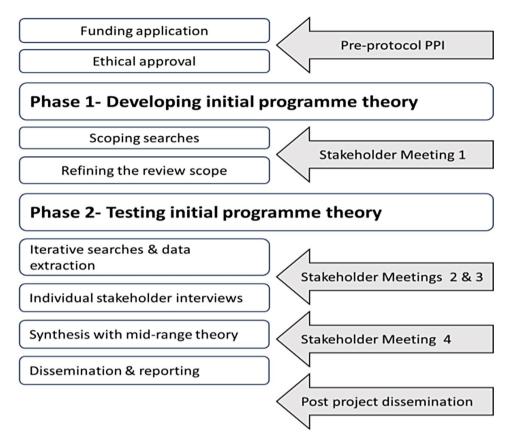


Fig. 1 The review design showing expert stakeholder group contribution

hypothesised if these would trigger different mechanisms and outcomes.

The funder required dissemination, and their guidance on involvement advises that as far as possible, this should involve public contributors [34]. This paper constitutes a key part of the dissemination strategy through reflecting critically on the approach taken to involvement and has been led by the co-chairs of the ESG with authorship from lived experience and professional ESG members. The reflections presented here are based on the feedback from ESG members received both verbally and in writing throughout the realist review.

Leadership of the expert stakeholder group

The research team included a researcher with lived experience of accessing and providing peer support within crisis services. A second researcher in the team brought academic expertise in research involvement and engagement. Together, these researchers co-led recruitment to, chairing of an Expert Stakeholder Group (ESG) and dissemination of stakeholder involvement [35].

A joint leadership approach provided opportunity for mutual support that modelled the intended collaborative approach within the ESG [36, 37]. The inclusion of people with lived experience in the research team and the ESG

may also have helped overcome power imbalances by acting as a bridge between lived experience contributors, health professionals and researchers [38]. The co-chairs attended ESG meetings as well as research team meetings and were able to advocate for the lived experience and professional perspectives during key stages of the review delivery to ensure issues of importance to the ESG were addressed by the research team. To ensure bi-directional communication, the co-chairs of the ESG also supported the development and dissemination of bi-monthly plain English summaries of progress to ESG members. These summaries provided a mechanism through which the research team could illustrate how the ESG had informed the delivery of the review.

The co-chairs of the ESG also maintained contact with individual ESG members between meetings via telephone and email, and this was particularly valued during the restrictions due to Covid-19. This informal contact also provided opportunities for the researchers to develop rapport and trust with the ESG members, deal with any practical issues related to online meetings or remuneration as well as allowing for between-meeting information sharing [37]. Whilst these conversations evaluated positively, their content is difficult to capture, yet the importance of this informal work cannot be underestimated as

we believe it may have mitigated the impact of a lack of social connectedness between ESG members during the Covid-19 pandemic restrictions [36, 39]. For future projects, innovative ways to capture these between-meeting processes may include the use of field notes or reflections from stakeholders. It is also useful to consider, when designing a realist review that adequate time and remuneration, with a degree of flexibility, has been planned for between meeting activity for both the research team and the stakeholders.

Membership of the expert stakeholder group

An ESG with 15 members (Table 1) brought together lived and professional expertise to the realist review [7]. Lived experience ESG members were approached through NHS, voluntary sector and user/carer networks in England. Professionals were identified through the NHS, commissioning groups, universities and policy agencies. The ESG was intended to constitute half of the members with lived experience. Seven people with lived experience of accessing crisis services for themselves or as a carer/family member, joined the ESG and six sustained their involvement throughout. Of the eight ESG members who were approached for their professional expertise, a majority shared that they also had lived experience.

Whilst the membership is reported according to the primary reason for approaching ESG members in Table 1, each individual stakeholder brought a totality of experience not limited by definitions of lived or professional experience. Despite this, we acknowledge that there can be difficulties with reconciling different viewpoints, and with possible power imbalances between those who use health services and those who provide them [40, 41]. This can be particularly evident in mental health due to ongoing social exclusion and stigmatisation [37, 42]. The research team aspired to all experience and knowledge carrying equal weight making it imperative that

Table 1 Membership of the expert stakeholder group (ESG) by primary role/expertise

ESG Primary Role/Expertise ^a	Number of Individuals
Carer	1
Commissioner	1 ^b
Psychiatrist	1
Mental health nurse	1
Mental health policy	1
Mental health social worker	1
NHS crisis services manager	1
Peer support worker	1
Lived experience of accessing crisis services	6 ^c
Voluntary sector crisis service manager	1
Total membership of ESG	15 ^d

 $[^]a$ Some members reported more than one type of expertise; b two commissioners provided cover, only 1 attended each meeting; C reduced to 5; d reduced to 14

consideration was given to not only how the ESG meetings were conducted but also to the ESG membership. However, group composition alone cannot be assumed to guarantee meaningful engagement or equity between members as the values of the researchers and the group members also play a significant role [3, 43]. Thus, the activities undertaken in the first ESG meeting were vital to ensure that members were aware of each other's backgrounds and experiences and had received the same information regarding the review methods and aims to help to 'level the playing field'.

To meet the realist review aim, it was important that ESG members had current experience and knowledge of community mental health crisis services and that between them, represented (as far as practicable) the range of people, professions, and agencies accessed during mental health crises. It was equally important that the ESG membership reflected the different values about, and definitions of, mental health crises to facilitate engagement and ownership and avoid particular voices being marginalised [16, 19, 21, 25]. An example of how this worked from the stakeholder's perspective, was through engagement with the voluntary sector at an *organisational level*, the review team generated a sense of, often marginalised people, being acknowledged and taken seriously.

There is a critical narrative in some literature that the "usual suspects" become involved [44] (p. 476) creating barriers to engagement with people from diverse backgrounds. With this in mind, some of the lived experience stakeholders were identified in partnership with a survivor led crisis mental health voluntary organisation focused on services for people with black and minority ethnic backgrounds who had recent experience of mental health crisis, to increase the likelihood of a diversity of perspectives [44, 45]. A manager from the voluntary sector organisation provided initial engagement and additional time to ensure that lived experience stakeholders understood what was required of them and, for those already engaged with their organisation, additional support during their membership of the ESG. As lived experience ESG members may have had recent experience of mental health crises, this additional support enabled their safe and sustained participation.

Our experience suggests that working closely with mental health voluntary organisations in this way, could protect studies from attrition of PPI members identified in previous research as a barrier to sustained engagement [15]. In the context of a review focused on mental health crisis, involvement of those with recent experience of crises had to provide requisite support to individuals involved but equally sustain the integrity of the involvement should individuals be unable to contribute over time. Further, one of the lived experience authors fed

back that without the support of the voluntary organisation, they would never have become involved or even known about the research. They added that they were very anxious about joining the ESG and the support of the voluntary sector service enabled them to sustain their involvement, despite their initial fears.

For future research, working in partnership with a crisis mental health voluntary organisation early in the development of the study design provides an opportunity to agree and fully resource a package of support for lived experience stakeholders. This may better enable continuous engagement without burdening individuals, yet also provide a more inclusive approach, potentially widening participation through greater 'reach' within the communities important to the relevance and impact of the review. We also believe that funding a voluntary organisation to support involvement through a devolved budget may also provide more seamless ways to remunerate those involved, especially considering ESG feedback regarding payment via higher education institutes which was described as inconvenient and bureaucratic.

Learning together

Although, the ESG members represented a range of research experience, none had previous experience of realist review. Providing research methods knowledge from the outset has been recommended in evaluations of PPI [38] and in realist research [32]. Because the ESG members would contribute throughout the review (rather than as one-off research participants), the research team felt their contribution would be optimised by providing

them with information about realist methods [10]. Feedback from ESG members suggested that the brief methods training was helpful and that the use of pictorial metaphors to explain complex methodology worked well. The lived experience stakeholders wanted more information about the methods throughout the review and on reflection, the review team believe that the methods could have been revisited to provide a clearer rationale for the activities being undertaken in each of the stakeholder meetings.

To explain the realist methods to the ESG, teaching materials using an analogy and visual image of a wilted plant was developed by the lived experience researcher (Fig. 2). Using text alongside visual imagery has been recommended for optimising comprehension of lay members in realist research [32]. Through this analogy, the context around the plant was described (for example temperature). Watering of the plant was used to describe realist mechanism in that the water is a resource, to which the plant may (or may not) respond by transporting the water via its root and vein system. To produce the *outcome* of a healthy plant, the impact of the context around the plant on the plant's response to watering was discussed. This analogy was also used to give examples of mid-range theories (that bring together related concepts to explain phenomena somewhere between a working hypothesis or programme theory and all-encompassing grand theory) [46] that may explain how and why plants are healthy or unhealthy (for example, theories of weather). A methodological limitation of using a plant to illustrate realist mechanisms is that plants lack human

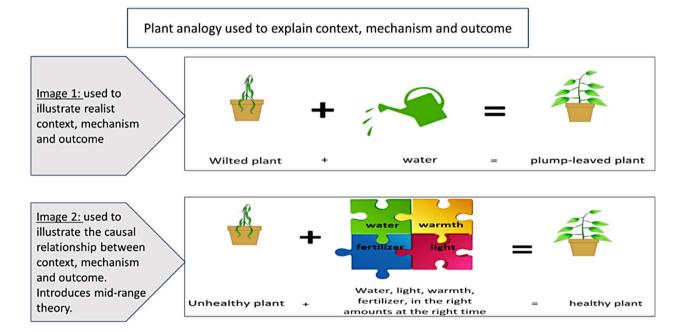


Fig. 2 Plant analogy used to explain context, mechanism and outcome

complexity and are not sentient. To overcome this, examples from other healthcare realist studies were provided to link the analogy back to the complexity of human and health services research.

Working together-building a working alliance

Crucially, the first meeting set the tone of the relationship between the research team and between the ESG members [3]. The first meeting began with an informal lunch, which we feel is an important aspect of demonstrating that people's time is valued. Prior to undertaking any engagement activities, full round table introductions were made, allowing people time to explain their role and experience. The considerable time spent in the first meeting to understand members' expectations of involvement [11] was valued by ESG members who described feeling supported and clear about their role. This first meeting was described by stakeholders as breaking down barriers and establishing a rapport needed to enable a frank and honest discussion.

Although ethical approval is not consistently sought for stakeholder involvement in realist reviews [10], because some stakeholders may have been considered vulnerable (from a research ethics perspective) related to their individual circumstances and their higher risk of harm by taking part, ethical approval was obtained from the UK Integrated Research Application System (IRAS). A 'process approach' to informed consent involved ESG members meeting individually with one of the ESG cochairs to provide or review consent before each meeting. In doing this, consent was conceptualised as subject to change over time [44].

In light of the range of experiences embodied in the individual members of the ESG, the approach taken to group work within the ESG meetings was intended to avoid assigning labels to ESG member experience but rather to allow individuals to self-select the breakout groups they felt best equipped to contribute to. Importantly this recognised that some ESG members brought both lived and professional experience. This resulted in most breakout groups representing mixed expertise and enabled contribution from the totality of their experience. Whilst this promoted personal choice, and may have avoided unnecessary labelling, particularly of those with lived experience, it may have unintentionally inhibited some of the professional ESG members with a clinical background in crisis services, rendering them unable to fully express themselves [36]. In feedback from ESG members, this was attributed to a sense of guilt when listening to reports of poor crisis care received; a phenomenon conceptualised as the 'emotional labour' of co-production [42]. Equally, this approach risked obscuring the impact of lived experience, as identified in previous realist reviews [12]. This points to a need for opportunities for stakeholders to have safe spaces for discussion in expertise specific groups [15] and time for exploration of relational aspects of involvement [36], alongside collective discussions [47].

Variation in the experience of involvement may also relate to the need for later ESG meetings to be conducted online due to COVID-19 pandemic restrictions. Experience of contributing online was varied, some felt that it was hard to make sure that everyone had equal space to speak whilst others felt that online meetings provided a supportive space for discussion and collective group working. As videocall meetings were less familiar at the start of the pandemic and the ESG had not met for some time due to delays caused by the pandemic, it was important that the terms of reference were revisited and the ESG members were updated on progress [15]. Given the potentially sensitive topic of the research, it was especially important to highlight ways to seek support from the research team remotely [15, 36]. Whilst the online meetings were described in the feedback as practical, cost-effective, and well organised, barriers to engagement in online meetings were related to a lack of social connectedness. Informal organic conversation as part of involvement practice have been identified as important mechanisms in enabling open dialogue [36]. The informal social and interpersonal contact between ESG members that occurred naturally during the face-to-face meeting, did not happen during the online meetings suggesting a need to purposefully plan informal social conversation as part of online stakeholder meetings. Despite the challenges faced through the pandemic, the use of videocall breakout rooms proved invaluable to sustaining involvement of ESG members [39].

Working together- the work and impact of the stakeholders

Our reflections on the impact of involving stakeholders can be best articulated in two ways, firstly the impact on specific methodological steps of a realist review and secondly providing more comprehensive input across the review to align it to the real-world perspectives of those providing and receiving crisis care.

During the first face-to-face in person meeting, to initiate 'the work' of the ESG, vignettes (example shown in Additional file 1) developed from the IPTs, were shared and discussed in small groups [48]. The vignettes stimulated discussion and supported the ESG members to explore the architecture of community crisis services from different perspectives. ESG members then discussed and prioritised IPTs using a 'Diamond-9' prioritisation process. The Diamond-9 ranking activity was used to enable the stakeholders to rank the IPTs from highest to lowest priority [49, 50]. To achieve this, brief descriptors of eleven IPTs were printed onto individual

cards along with blank cards to facilitate new ideas from ESG deliberations. The ESG members, in four groups of mixed expertise, worked together to prioritise, reject, or amalgamate any of the IPTs using a card sort process by placing the cards on the Diamond-9 template (shown in Fig. 3). This early step in the work of the ESG contributed to defining the scope of the realist review [6].

The second ESG meeting took place online and facilitated discussion of on the veracity of three prioritised IPTs from the first meeting, enabling ESG members to provide clarification of meaning and provide important nuanced contextual detail from real-world perspectives [12]. The third ESG meeting focused on seeking depth and detail related to causal relationships between context, mechanism, and outcome. To enable this, rounds of break out activities, each with a question for discussion (shown in Additional file 2). The fourth and final ESG meeting focused on theory consolidation through discussion of programme theories presented in the form of pen portraits [51] (an example is shown in Additional file 3). The pen portraits were developed from the programme theories to provide an accessible exemplar of how community crisis services work in three important contexts. The ESG members moved between online breakout groups to consider if there were different contexts from those illustrated in the pen portraits, that may change the mechanisms required to achieve optimal outcomes.

Despite ESG members having a critical role in defining the scope of the review, their feedback regarding their wider experiences of making decisions about how the research was conducted, were mixed. Some ESG members believed they had steered the direction of the research whereas others described their influence as less consistent across the project, describing later contributions as more consultative than generative. This ESG experience resonates with the findings of a systematic review of stakeholder engagement, where involvement was less commonly reported during some stages of realist reviews including for example the selection and appraisal of the evidence [11].

Although the ESG did not impact on the selection, appraisal or data extraction processes, they played an iterative and significant role in the development of programme theories. The ESG impacted on the research team's understanding of key concepts and how these operated in real-world contexts thus deepening understanding of causal links. Their contribution also impacted on the development of pen portraits used to illustrate how the programme theories operate in relation to specific contexts. Discussions with the ESG provided meaningful challenge to assumptions about how things work or don't work from diverse perspectives. This provided a critical perspective on the limitations of the review and supported articulation of gaps in the evidence.

Conclusions

This paper provides a novel insight into the processes and activities adopted to involve people with lived and professional experience in a realist review of community mental health crisis services. The stakeholders evaluated their involvement in the realist review positively but also suggested areas for improvement. The adoption of a coleadership approach provided value in modelling involvement values but also in providing a bridge between the study team and the different expertise embodied in the stakeholder group. We recommend that realist reviews consider adopting this approach to involvement and ensure that adequate resources have been assigned to allow flexibility in the involvement events and between-meeting support that the stakeholders valued.

The decision to have a single stakeholder group with lived and professional experience within it, provided a platform for generative working that was valued by the stakeholders. Whilst this facilitated people contributing from the totality of their experience, it also limited our ability to report the specific impact of lived experience on the review. The stakeholders suggested that to overcome the limitations of a mixed stakeholder group, safe spaces for discussion are needed to bring people with similar experiences together in smaller break out groups

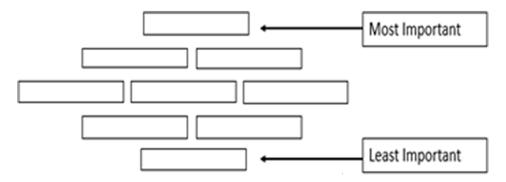


Fig. 3 Diamond-9 template and card sort. A form of card sort activity used to rank the importance of IPTs. Cards with IPTs on them are discussed in groups and placed on the template shown below according to their perceived importance to meeting the aims of the realist review

alongside opportunities for one-to-one meetings with the involvement leads.

The support of a voluntary organisation within the field of the realist review can provide additional support for lived experience stakeholders and enable safe and sustained engagement across the review timeline without burdening individuals. We found that the diversity of lived experience improved with their support as they are more able to reach the communities they work with. Providing realist methodological information was valued. The use of pictorial metaphors for complex realist concepts worked well but may require development to better represent the complexity of human behaviour to explain realist mechanisms. The delivery of realist methods information should be delivered throughout the review aligned to the steps being undertaken by the stakeholder group.

Our work included a range of practical activities to involve the stakeholders meaningfully in the steps of a realist review, it would be helpful for more researchers to share their approaches to build an understanding of best practice. The activities used here were largely received positively and provided the link between theory and real-world experience although some activities were felt to be more consultative than generative, especially later in the review.

Abbreviations

PPI Patient and Public Involvement ESG Expert Stakeholder Group

GRIPP2 Guidance for Reporting Involvement of Patients and the Public 2

NHS The National Health Service IPTs Initial Programme Theories

NIHR The National Institute for Health and Care Research

Supplementary Information

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Supplementary Material 1

Supplementary Material 2

Supplementary Material 3

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Author contributions

All authors contributed to or led aspects of the study as part of the research team or as expert stakeholders. MA, JT, HG, ET, YK & NC developed and edited the manuscript and provided critical feedback on the plain English summary.

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Data availability

No datasets were generated or analysed during the current study.

Declarations

Ethical approval and consent to participate

Ethical approval was obtained from the UK Integrated Research Application System (IRAS) Reference: IRAS261486 and Committee Ref: 19/YH/0347. Written or recorded verbal consent was obtained from all stakeholders involved in the activity discussed in this paper.

Consent for publication

Participants and stakeholders involved in the review provided consent for anonymised publication and were given a participant information sheet that included information about confidentiality, personal data management and anonymity. All authors have seen the final version of the paper and have consented to its submission for publication. They have all also consented to be named authors in the stated order.

Competing interests

The authors declare no competing interests.

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