

## Public involvement and engagement in primary and emergency care research: the story from PRIME Centre Wales

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### Abstract

#### Background

Policy throughout the United Kingdom promotes involvement of patients and public members in research to benefit patient care and health outcomes. PRIME Centre Wales is a national research centre, developing and coordinating research about primary and emergency care which forms 90% of health service encounters. In this paper, we describe our approach to public involvement and engagement in PRIME Centre Wales (hereafter called PRIME), in particular: how this approach has developed; ways in which public members contribute to PRIME activity; the strengths and limitations of our approach, challenges and future opportunities. PRIME ensures work is relevant to service users, carers, the public and policy makers by incorporating comprehensive patient and public involvement in every phase of our work.

#### Approach

PRIME has policies and processes to enable and promote successful public involvement and engagement across research activities. This ensures public perspectives and patient experiences are integrated throughout research development, implementation and dissemination and in managing and delivering PRIME strategy over a 10 year timescale. A public/patient group called SUPER is a key resource providing wide-ranging perspectives via email and face-to-face discussion. We collect information on processes and experiences to assess value and impact, to guide ongoing involvement and engagement. A funded post provides leadership and support to staff and to public/patient contributors to facilitate collaborations.

#### Discussion

A stable, well-resourced structure has provided the timescales to build strong relationships and embed diverse approaches to public involvement and engagement within PRIME. Researchers and public contributors have committed to collaborations, developed knowledge and skills and sustained relationships. Effective approaches incorporate values and actions which, when operating together, strengthen processes and outcomes of public involvement and engagement.

#### Conclusion

Supportive context, motivation and time are necessary to foster values and practices that enable effective public involvement and engagement. PRIME has embedded public involvement and engagement across research activities and structures. Central is the public/patient group SUPER offering experience-based expertise to add value to the research cycle. This innovative model, aligned with best practice, enhances relevance and quality of primary and emergency care research to benefit patients and the general population.

#### Keywords

public involvement; public engagement; consumer involvement; primary care research; emergency care research

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## Key messages

- A supportive context, resources and stable research environment have enabled PRIME Centre Wales to embed public involvement and engagement throughout the research cycle.
- The SUPER model, incorporating a patient/public panel of diverse individuals, develops strong relationships and effective working practices that enable public involvement and engagement in mixed methods research to benefit patients and the general population.
- More routine use of virtual communication, normalised by the COVID-19 distancing practices, may help address the challenges of including views from different socio-economic groups and balancing genuine public involvement and engagement with meeting short research timescales.

## Background

Public involvement in health and care research is best practice and encouraged in order to ensure research is relevant, accessible and accountable to its end users. Policy throughout the United Kingdom (UK) promotes involvement of patients and public members in research with the aim of ultimately benefiting patient care and health outcomes [1]. Most major research funders require and reward meaningful public involvement in bid development and implementation plans, including as public co-applicants [2, 3]. Some funders provide modest resources to support Public and Patient Involvement (PPI) at pre-application stage, irrespective of the ultimate outcome of the application. The UK Standards for Public Involvement were launched in 2019 [4]. They were designed to improve the quality and consistency of public involvement in research, and aimed to address concerns that public involvement within research processes can be insufficient, inconsistent, or tokenistic [3, 5]. The SUPER public/patient group (Service Users for Primary and Emergency care Research) works with PRIME Centre Wales researchers, as described in this paper. All acknowledge the challenges of involving as diverse a group of patient and public members as possible and have presented at national conferences on their attempts to support meaningful inclusion and involvement [6]. Tokenism can be a difficult challenge to fully rebut. However, the SUPER group and PRIME Centre Wales take the view that the best attempts at inclusion, using a whole range of approaches, improve the situation although they fall short of perfection and this belief underpins our practice.

PRIME Centre Wales is a national research centre focused on developing and coordinating research about primary and emergency care [7]. Over 90% of patient encounters with the National Health Service (NHS) in Wales are through primary and prehospital emergency services [8]. The NHS faces challenges in meeting the increasingly complex healthcare needs of patients, and rising requirements for care. PRIME Centre Wales brings together teams across four Welsh Universities (Cardiff, Swansea, Bangor and University of South Wales), with members of the public and partners from industry, health and social care professionals and third sector.

Together they undertake work addressing pressing health needs and health service delivery challenges. PRIME Centre Wales is funded by Health and Care Research Wales, part of the Welsh Government.

From its outset, public involvement and engagement has been incorporated into the operating structure and research activity of PRIME Centre Wales. The aim is to undertake research and dissemination activities that are of genuine importance to patients and the public. Over time, public contributors have become involved at all levels of its infrastructure and across the research portfolio. Meanwhile, research teams have extended the scope and range of dissemination activities to engage with groups who have a stake in PRIME research (Figure 1).

In this paper, we describe our approach to public involvement and engagement in PRIME Centre Wales (hereafter called PRIME), in particular: how this approach has developed; ways in which public members contribute to PRIME activity; the strengths and limitations of our approach; challenges and future opportunities.

## Our approach: public involvement and engagement in PRIME Centre Wales

### Setting out our approach

PRIME is committed to public involvement and engagement to deliver co-produced and patient-relevant research. The vision drew on research literature which reported that public involvement and engagement increased the quality and relevance of research and its likelihood of making a difference to patient care [1, 9, 10]. Research funders want to increase the quality and impact of the research they fund. Working with patients and public members can build skills and knowledge of researchers including students and early career researchers [2, 11].

In 2015, PRIME set out to involve patients, service users, carers and the wider public in the prioritisation, design, conduct, oversight, interpretation and dissemination of research. PRIME research involves rigorous and innovative study methodologies including original trial designs and use of routine and linked data. PRIME also proposed that public members contribute at forums overseeing delivery and strategic direction of the Centre. Two individuals, with experience of using health services and caring for family members, helped write the document which described this plan. The commitment was also informed by learning among PRIME collaborators. They used their experience of developing and delivering an innovative approach to enable public and patient views to be included across a research portfolio [12]. At a time when public involvement and engagement was reported to be mostly confined to individual research studies, this co-produced model facilitated a group of patients and carers to be involved in framing and delivering research undertaken across a programme of study.

Across PRIME, we have created and developed processes and structures which fundamentally and practically embed public involvement and engagement. This responsive approach has reflected the needs of the PRIME research community. It also acknowledges the growing Welsh and UK-wide profile

Figure 1: PRIME's aim, themes and work packages



and priority placed on public involvement and engagement, now considered an indispensable part of delivering high quality research [1–3].

## Undertaking our approach

In PRIME, public involvement and engagement is standard practice in all research activities and is delivered in the following ways:

### Developing research

PRIME researchers involve and engage with patients and public contributors through consultations, group discussions and research development groups [13, 14]. All PRIME research is required to involve and engage with patient and public contributors since this ensures research proposals reflect public views. Early involvement is key to enabling and ensuring public involvement and engagement throughout the research cycle [2, 15]. It also helps research teams to evidence comprehensive public involvement in: the rationale for, and preparation of, research funding proposals; the plans to undertake and disseminate research, and: how this is supported in a research study. Public contributors are routinely named as research co-applicants. A key resource in developing research proposals is the SUPER group (see case study in box 1). SUPER was established in response to researchers' requests to have an accessible route to consult, collaborate and engage with public members. SUPER provides experience-based input

to all aspects of planning research. SUPER holds regular quarterly meetings which provide an early opportunity for researchers to collaborate on research ideas in development.

### Delivering research

While all PRIME research undertakes public involvement and engagement, this happens in various ways. Different models of public involvement and engagement enable research teams to include experience-based expertise in the way which best suits the interests and availability of public contributors. What they can offer may be affected by health condition, ethnicity and legal status, community context and occupational and family commitments [6, 16–18].

Wherever possible PRIME studies include two public contributors as members of a study's research management group. In this role, they jointly oversee strategic and operational decisions that shape implementation and delivery of studies [19]. Studies also involve public members on independent scrutiny committees and they can establish separate patient groups to ensure their expertise is available to the research team [15, 18]. Public members of research teams have used their experience-based expertise to support specific research tasks such as data collection [16], analysis and interpretation [14, 17] and recruiting patients to a stakeholder meeting [20]. For example, in the PREPARE study, a public panel of seven individuals people meets regularly to advise and support the study team [21].

## Box 1: Case study - the SUPER group

A central element of the PRIME public involvement and engagement approach is the SUPER public and patient panel. It is the only stand-alone forum of public contributors available to PRIME and complements the other involvement routes described above. SUPER was established in response to demands from researchers to have good access to, and strong relationships with, public members and patients who could support the range of PRIME research. A panel was proposed to build on learning shared by co-authors BAE, RHM and JD [12]. Their experience of co-producing the SUCCESS (Service Users with Chronic Conditions Encouraging Sensible Solutions) model to involve and engage people in a programme of research identified the elements that worked best. These included: people meeting online and face-to-face to safely discuss research and also receive mutual support; a facilitator to coordinate activities, provide accessible information and be a link between people and researchers; a supportive research environment where research leaders explicitly valued public input; practical support such as honoraria and accessible opportunities; and access to research activities so members could achieve a sense of purpose [12]. SUPER provided an opportunity to refresh the SUCCESS model and its membership.

SUPER (Service Users for Primary and Emergency care Research) first met in 2016 and was named by a member. All involved have personal and caring experiences of health and care services and also a shared interest in research involvement and engagement. They come from across Wales including rural and urban areas and the less populated regions of north, west and east Wales. Three are parents of young children and a quarter of members are in paid work. The others are retired, mostly from professional roles, because of poor health or age. Several speak Welsh. All are white. Many of them are active in their communities, volunteering in local groups and patient networks. At least a third of members are carers, or have previously cared for loved ones. They were recruited by leaflets distributed to voluntary sector networks and patient groups. Information was also circulated through the Public Involvement Community. This network of people interested in being involved in research is convened and supported by Health and Care Research Wales.

SUPER members support PRIME by providing lay perspectives on developing, conducting and disseminating research about primary and emergency care services to strengthen the relevance, quality and dissemination of research on these topics. This happens by working with research teams on specific research projects and by being one of the three forums that advise and oversee PRIME strategy and operation. The group has a strong identity and members have developed effective working relationships. SUPER is chaired by one of its public members who also oversees meeting arrangements and agendas. This means that researchers presenting to the group are explicitly SUPER guests, which reduces likelihood of public contributors being inhibited by researcher status. At each meeting, the Chair establishes an atmosphere of respect and equality by using introductory remarks and ensuring all voices are heard in the discussions. Information circulated to researchers about SUPER states that members offer expertise based on lived experience to complement the academic and clinical perspectives of other research collaborators. SUPER members have access to training through their membership of the Public Involvement Community in Wales and can also seek information and support from the PRIME Patient and Public Involvement Lead.

The group meets quarterly, holding a day-long face-to-face business meeting with refreshment breaks for informal conversation. Members also communicate by email as required. Researchers present early research ideas, more advanced proposals or questions about project implementation and dissemination. These are then discussed in detail. Presenters include MRes (Masters in Research) and PhD students, encouraged to engage with and involve patients and public members as part of their research training.

Using their personal experience and knowledge derived from a wide range of networks they are part of, SUPER comments cover:

- the relevance and priority of the topic area and research question where drafted;
- feasibility of research methods, particularly the ability of patients to provide informed consent and data;
- processes for involving public members or patients in a funded study and budget headings needed to support this.

PRIME staff also present on aspects of PRIME activity and invite input. Examples include: advising on PRIME dissemination and reporting; commenting on Knowledge Implementation Strategy drafts; contributing to PRIME strategy documents and core funding proposals; reviewing annual reports and co-planning Annual Meetings. Two SUPER members attend the PRIME Wales Advisory Board.

SUPER annually reviews its Terms of Reference and guidelines for member and meeting conduct. Some initial members have resigned or reduced involvement, for different personal reasons. Recruitment of new members will refresh the group but is not yet underway. All SUPER activity is coordinated by the PRIME lead for public involvement and engagement. The 19 SUPER members are offered honoraria to acknowledge their contributions and expenses incurred are reimbursed. Comprehensive paperwork is provided in advance of meetings.

In another example, 17 women with rheumatic disease, such as Rheumatoid Arthritis, Lupus, vasculitis and various types of inflammatory arthritis, joined an online group. They advised on research about pregnancy and autoimmune disease, engaging with patients and their future research priorities [18]. These women were pregnant, had young children or were considering starting a family. Often they also experienced chronic pain so understood the concerns of women who have non-obstetric chronic pain complaints during pregnancy. Autoimmune rheumatic diseases can affect women during their childbearing years. This raises many important issues around the information and support that women have in relation to starting a family. This might be about deciding on whether to have children, when the best time is to start a family, what happens if women have difficulties with starting a family, what medications are safe to use during pregnancy and breastfeeding, and how to manage symptoms like pain and fatigue during this time. The online panel is a useful way to involve patients with rare conditions who live across the UK and who go through periods of being very unwell. Many of them aim to be in employment and also have young children. These are all reasons why it is challenging for them to attend day time face-to-face meetings or make a regular commitment to being involved in the project. This online input supplemented the involvement of two individuals during the research development phase and who also helped engage with a wider spread of women.

### Dissemination and implementation

Half of research is not disseminated and most fails to have significant or lasting effect on policy or practice [22–24]. Research which involves and engages with public members and patients is predicted to be *'more likely to be put into practice'* [1]. Much dissemination happens after study completion, when study funding to support public involvement is no longer available. To address this limitation, PRIME studies are beginning to involve public contributors in preparing dissemination and engagement plans or they identify available funding to support involvement for a longer period. PRIME can also support some public involvement and engagement activities through core funds. PRIME research has informed implementation of primary and prehospital emergency services [25]. In PRIME, examples of activities involving and engaging with the public include:

- conference presentations - about specific research studies; public involvement and engagement processes; value added by undertaking public involvement and engagement. Presentations may be given by public contributors, entirely or in part;
- raising research awareness at national or regional events and visitor venues such as the leading cultural festival held annually in Wales (called the National Eisteddfod), stakeholder meetings and tourist attractions;
- public contributors advising on non-academic dissemination;
- public contributors as co-authors on academic publications in peer-reviewed journals, contributing to the drafting and revision of manuscripts [14, 17, 26, 27].

### Informing PRIME strategic direction, delivery and future planning

Strategic direction is guided by three groups. The Wales Advisory Board and the International Advisory Board members are stakeholders with regional, national and international perspectives. Membership of both boards also includes public contributors who have good networks across diverse patient groups. These groups were envisaged at the outset. The third forum is the SUPER group. SUPER's primary role was to contribute to research development and implementation activities. However, PRIME leaders subsequently recognised the contribution SUPER could make to how PRIME operated. They amended the management structure to include and define SUPER's role (Figure 2).

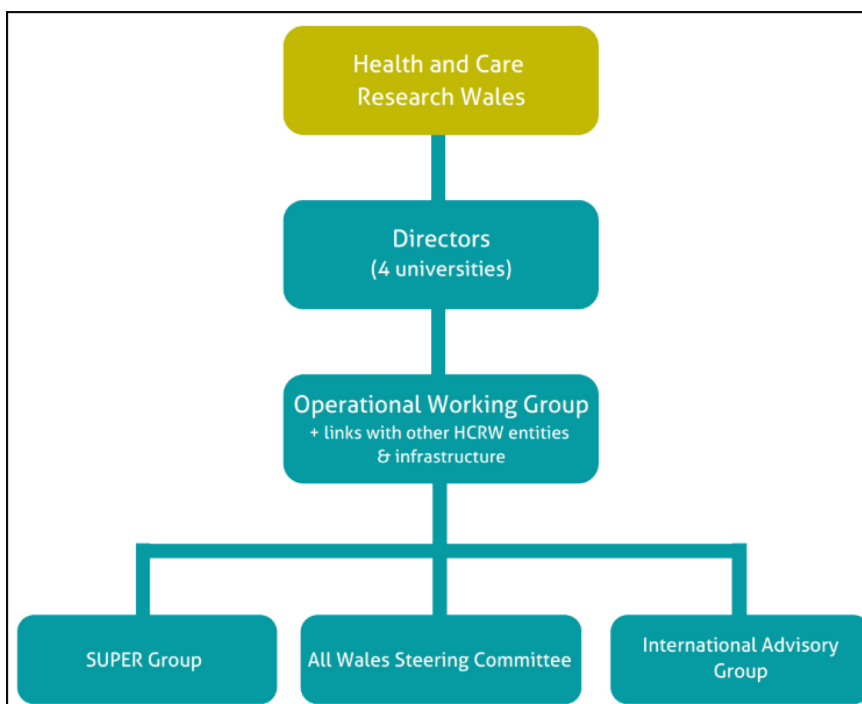
### Leading and facilitating public involvement and engagement

Effective public involvement and engagement, when embedded across research structures and processes, requires coordinated support and leadership [4, 12, 28]. At PRIME's outset, a role was established and resourced – a lead for public involvement and engagement. This ensures a champion and facilitator across all PRIME activities. PRIME directors also support public involvement and engagement, in line with UK-wide policies, research funders' guidelines and research evidence [1, 2, 4, 29]. Directors attend the annual PRIME conference and dinner and SUPER group members always attend these events. Throughout the year, a number of events which are organised by PRIME are attended both by directors of PRIME and SUPER members and relationships between both groups are collaborative and constructive. Directors have ensured funding is available for the development and sustainment of the group. Additionally, resources are also available for expenses and honoraria for patient and public members from the Support Centre of Health and Care Research Wales including expert advice and training. The priority and profile is underpinned by best practice and staff and budget resources, to enable effective collaborations which deliver high quality impactful research. Genuine public involvement at research development stage enables research teams, including public contributors, to thoughtfully consider processes and costs for collaborative approaches. This supports research using rigorous and innovative methodologies to address issues affecting populations who use primary, community and emergency care services. It also ensures teams propose realistic budgets for involvement and engagement within submitted bids that further contribute to sustaining public involvement and engagement across PRIME.

### Assessing value and impact of our approach

Evidence about the difference that public involvement and engagement makes to research is key to understanding how research processes and collaborations are affected [4]. To understand the changes that result from SUPER contributions to PRIME activity, we collect information on processes and experiences. All researchers presenting to SUPER are asked to provide feedback, using a template designed by the group. In this way, they report how the input from public

Figure 2: Organisational structure of PRIME Centre Wales



*This flowchart illustrates how diverse stakeholders (public members, patients, members of industry, health and care professionals, third sector representatives and academic experts) contribute experience and expertise to inform the operation and strategic direction of PRIME Centre Wales.*

and patient contributors has contributed to their research planning and delivery including changes made or discarded and the reasons why. Respondents are encouraged to give constructive comments about merits and limitations of the comments received. They are also asked to reflect on the process of communication and collaboration. Feedback to public contributors also takes place within individual study teams. Examples of value and impact are reported later in this paper. Reviewing involvement processes and impact helps identify elements of tokenism and insufficient or inconsistent approaches to collaborative research [3, 5]. By openly sharing feedback within a constructive, learning-focused atmosphere, a cycle of reflection and improvement is fostered for both researchers and patient and public members.

Seeking 'critical friend' feedback is an important element in developing learning and improvements [29]. SUPER members report that feedback from researchers has several benefits. It helps to develop their reviewing and feedback skills and understand the research process. It also builds confidence by revealing how patient experiences are useful in research and how researchers experience collaborative working. Thus, research and public partners are mutually accountable for their roles in research projects. Value is also evident in the equal status of public contributors within the research process, for example by being named as co-applicants, collaborators and co-authors. Feedback from external reviewers commenting on research proposals is also shared and noted.

In line with best practice, SUPER reviewed PRIME public involvement and engagement against the UK Public Involvement Standards [4] after participating as a test site (a so-called Freestyle Project) for implementation of the Standards. This has given timely, valuable insight into actions to enhance PRIME PPI against the Standards' six Key

Principles including 'Working Together', 'Communication' and 'Governance'. Current and future PPI in PRIME will use the Standards to guide on-going learning and improvement. Opportunities identified to strengthen SUPER's role include: widening member diversity, creating more flexible routes for involvement and enhancing mutual support; increasing formal information exchange between SUPER members to strengthen awareness and knowledge of other public perspectives; improving communication with PRIME researchers, including opportunities to strengthen public involvement and engagement in individual studies; and evaluating involvement from patient and public perspectives, to ensure improvement as experience widens.

## Discussion

Despite guidance, support and modest resources to encourage public involvement and engagement in health and care research [1, 2, 4, 9], this best practice approach is not consistently followed when designing, undertaking and disseminating research. Building on existing evidence and practice, PRIME Centre Wales has prioritised meaningful public involvement. It does this by integrating collaborative approaches across its research development, implementation and dissemination activities. It has sought to incorporate the hallmarks of good involvement which have been recognised in the UK Standards for Public Involvement [4]. A framework of involvement, at strategic and research levels, provides a structure within which flexible, mutually valued relationships have established. These have enabled productive collaborations. Yet amidst good practice, challenges remain: for researchers managing large workloads with limited

resources in tight timescales; and for public contributors asked to provide diverse and authentic voices, but also to enter the research world. PRIME has sought to ensure public perspectives and patient experiences are incorporated across the research cycle and in managing and delivering PRIME strategy. It also recognises this can improve further.

## Strengths and limitations

Public involvement and engagement within PRIME has broadened and deepened as the research centre has developed effective relationships between collaborators from academic, health service and public arenas. This has highlighted how far our approach aligns with evidence on what is 'good' involvement [30]. The range of involvement approaches across all research stages and activities has enabled public involvement and engagement to be integrated within the work of PRIME. This reflects reports that different models of involvement support diverse individuals and a wider range of public perspectives. They can be tailored to the experiences of public contributors and the formats which best suit their opportunities and skills [31]. In the literature, public contributors report barriers to involvement in research. These include physical, cultural, environmental, financial and attitudinal factors, which hinder their opportunity to be present and to contribute to research. SUPER contains many of the values and approaches which are known to characterise effective involvement and engagement [6, 12, 16]. SUPER brings together a range of people who all share an equal opportunity to contribute to PRIME research, proportional to individual interests and availability. PRIME staff report that these contributions and the commitment made by individuals are valued and respected, for complementing the available academic and clinical expertise. Communication systems and collaborative meetings ensure open communication and build capacity. The approach is purposeful, since there are clear terms of reference and a transparent organisational structure, where routes for public involvement and engagement are illustrated. There is also practical support and social interaction over shared lunches. These features align with the characteristics of 'good' public involvement [10, 30].

Well-developed relationships, based on mutual respect and trust, are recognised to facilitate involvement processes and bridge knowledge-sharing between public members, the academic community and other research stakeholders [4, 9, 10]. Involvement models can enable power and decision-making to be shared when planning and co-producing healthcare, but this requires commitment [9]. PRIME's approach to public involvement and engagement has benefited from the stability provided by a well-resourced and well-managed research infrastructure. PRIME has won continued funding from Welsh Government for a second period until 2025. This provides the timescale and stable environment to build relationships and share responsibility while delivering relevant and high quality research. It enables researchers and public contributors to commit to collaborations, to develop knowledge and skills to work in partnership and to sustain and grow this over time [30, 32]. Public involvement and engagement require investment in both motivation and time to achieve successful collaboration.

The purpose and value of public involvement and engagement within PRIME is understood by all who collaborate in the research centre [10]. A future period of funding certainty will support PRIME to further strengthen involvement and engagement activities. While the range of perspectives provided by public contributors within PRIME is broad, there remain limitations in the diversity across geographic, cultural and economic experiences. This limitation is extensively discussed by practitioners and researchers but is also recognised to be more complex and nuanced than simply rotating individuals or ensuring pre-defined categories are filled [32]. Distances, research timescales and working arrangements can impede genuine access across Wales. SUPER is currently considering ways of widening access through use of social media and video conferencing, which may address this in part, at least in terms of geographic location and the challenges of travel when unwell, dealing with disabilities, or needing to fulfil caring responsibilities.

## Challenges and how addressed

The challenges of delivering proposals and funded studies to deadlines can result in overreliance on particular individuals who are more accessible and familiar to research teams. While good, established relationships strengthen collaborative working, exclusive arrangements can make it harder for other individuals to be involved in research. Having a panel of 19 public members and patients in SUPER is one way to share opportunities for involvement, particularly when very short funder deadlines conflict with desire for adequate involvement. Roles can be proportional to interest and ability. Face-to-face contact in meetings and email discussions provide different forums to suit mixed abilities. Meetings also allow longer and more considered debate while email enables timely, deadline-focused input as required by circumstances [30]. Ways to involve and engage people will always depend on the context and requirements at the time [29]. By working in a large group, in person and virtually, the SUPER structure enables PRIME to address known challenges of the research environment. The model provides some flexibility for public contributors and researchers by providing a range of opportunities to collaborate in person and virtually, both at pre-arranged times and *ad hoc*, as circumstances determine.

Another challenge may be the largely stable membership of SUPER. From the start, members recognised they needed processes to bring in new individuals with other perspectives and experiences, to widen and refresh its contributions. Members agreed a system whereby a third of the membership was replaced each year, after an initial three years tenure. While around a fifth of inaugural meeting attendees have ceased their involvement, the approach to recruiting new individuals remains unresolved. Active members agree that a renewing membership is needed to sustain the group over time. But they also recognise that effective working relationships have been created, trust has been built between individuals and skills match the demands of the role. Like the SUCCESS model [12] from which SUPER developed, the group has reached a point where it needs to refresh membership without losing the benefits of members' experience and effective co-working. Bringing in other people risks altering the dynamics and compromising the collaborative atmosphere. The shared

emotion and experiences of group activity should be recognised [30]. Liabo notes that researchers value members with long experience of involvement but recognises this can exclude others from being involved and engaged. Solutions include expanding without immediately losing longstanding members and pairing new and experienced members [30].

Public involvement and engagement has typically been associated with qualitative research. Here, patient perspectives are considered more easily incorporated into research development and implementation [9]. This has led to calls for more practice in, and evidence about, the processes and effects of public involvement and engagement incorporating other research methods and settings [9, 33]. The challenge is to communicate the human interest contained within research data about a study population which may appear distant from patient experience. There is limited evidence of public involvement in quantitative research methods using routine data and complex statistical analysis [10]. However, PRIME undertakes many robust and complex research studies using mixed methods [18, 34] which include public and patient contributors in their planning and delivery. Factors that support their involvement include:

- genuine partnerships fostered by trust and mutual respect, where different expertise and contributions are recognised to add value;
- regular two-way communication and information sharing, including access to a named contact, so all research collaborators are kept updated with study progress, feel informed and able to question and comment throughout;
- scheduled sessions to collectively discuss methods and results in accessible formats and also plan dissemination to different audiences;
- considerable mathematical and statistical knowledge and skills among some of the SUPER membership.

## Examples of public involvement making a difference

### Gaining public input to population studies

Recognising public and patient attitudes to using and linking routinely collected health services data helped design and deliver a randomised step-wedge trial reporting data from 230,099 participants using general practice [19]. Public members of the Research Management Group joined discussions about how to present trial design information and seek consent to linking data. Their contributions provided insight into public understanding and perceptions about population data science amongst the 90% who use primary and emergency services. As one of the public contributors reflected: *'I considered this research to be advantageous to service users and I was pleased to be part of its development. I was able to pose questions and ask for explanations as part of the team... As a service user with chronic conditions, I am aware of the problems with access to health services especially primary services, for example GP (general practice) surgeries'* [19].

### Supporting a research proposal

SUPER members were asked to comment on a fellowship application about studying relationships between patients, carers and clinicians providing treatment. There was a short deadline and all members were emailed the details. Six feedback comments on the lay summary, methods and the proposed approach to involvement and engagement. The researcher amended the proposal to reflect the feedback, particularly on the lay summary and involvement/engagement plan. She won the award and reported back to SUPER *'My application was successful, and this will have been achieved because of your support and input'*. SUPER members subsequently joined the public involvement panel which holds six-monthly meetings rotating between study sites.

### Future plans

PRIME is committed to maintaining, extending and deepening public involvement and engagement in the work of the research centre. The COVID-19 pandemic has changed the nature of interactions as virtual meetings replace all face-to-face contacts. This presents an opportunity to level access to research involvement. Public members, who previously phoned into meetings because of access challenges (or chose not to contribute because of the difficulties of interacting remotely) are now equal amongst all research partners who have to contribute online. Swift take-up of video-conferencing technology for many aspects of daily life has equalised dynamics in meetings. The technology can be extra-demanding of energy and relies on clear protocols to enable all to contribute. Future meetings will not exclusively rely on virtual interaction but seek a blend of in-person and online contact. However, online opportunities may make it quicker and more equitable in facilitating public involvement and engagement in research. For research teams faced with short deadlines, particularly relating to urgent public health issues such as COVID 19, virtual contact may support more flexible and agile involvement approaches and timescales.

## Conclusion

PRIME is committed to public involvement and engagement to deliver co-produced research. A supportive context, motivation and time are necessary to foster the values and practices which enable effective public involvement and engagement. PRIME has set out to mainstream public involvement and engagement across its research activities and structures. The heart of its approach is the public/patient group SUPER which offers experience-based expertise to add value to the research cycle. This innovative model, aligned with best practice, has demonstrated ability to enhance the relevance and quality of primary and emergency care research with the potential to benefit patients and the general population.

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## Statement of conflicts of interest

The authors have no conflicts of interest.

## Ethics statement

Research ethics permission is not required for this article about the involvement of members of public in research, in line with Health Research Authority guidance. All research studies undertaken within PRIME Centre Wales obtain ethical permission. Public involvement is considered to improve the ethical standard of research (<https://www.hra.nhs.uk/planning-and-improving-research/best-practice/public-involvement/what-do-i-need-to-do/>).

## References

1. Department of Health. 2006 Best research for best health: a new national health research strategy. London, Dept of Health. [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/568772/dh\\_4127152\\_v2.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/568772/dh_4127152_v2.pdf) (accessed 02.09.2020)
2. National Institute of Health Research. 2020. <https://www.nihr.ac.uk/researchers/apply-for-funding/how-to-apply-for-project-funding/make-a-strong-application.htm> (accessed 29.05.2020)
3. National Institute of Health Research. 2015. Going the extra mile: Improving the nation's health and wellbeing through public involvement in research. <https://www.nihr.ac.uk/documents/about-us/our-contribution-to-research/how-we-involve-patients-carers-and-the-public/Going-the-Extra-Mile.pdf> (accessed 29.05.2020)
4. UK Standards for Public Involvement 2019. <https://sites.google.com/nihr.ac.uk/pi-standards/home> (accessed 29.05.2020)
5. Ocloo J, Matthews R. From tokenism to empowerment: progressing patient and public involvement in healthcare improvement *BMJ Quality & Safety* 2016;25:626-632. <http://doi.org/10.1136/bmjqs-2015-004839>
6. Evans B, Brown A, Fitzgibbon J, Griffiths L, Khanom A, Manning C, McCutchan G, Moyo S, Smits S. 2018 Hearing Everyone's Voice: Widening opportunities to be involved in research. [https://www.healthandcarereseach.gov.wales/uploads/AMshowcase4\\_Bridie\\_Evans.pdf](https://www.healthandcarereseach.gov.wales/uploads/AMshowcase4_Bridie_Evans.pdf) (accessed 29.05.2020)
7. PRIME Centre Wales. <http://www.primecentre.wales> (accessed 02.09.2020)
8. Welsh Government, NHS Wales. 2015 Our plan for a primary care service for Wales up to March 2018. <https://gov.wales/docs/dhss/publications/151106plannedprimarycareen.pdf> (accessed 14.3.19)
9. Staley K. Exploring impact: public involvement in NHS, public health and social care research. INVOLVE. 2009. [http://www.invo.org.uk/wp-content/uploads/2011/11/Involve\\_Exploring\\_Impactfinal28.10.09.pdf](http://www.invo.org.uk/wp-content/uploads/2011/11/Involve_Exploring_Impactfinal28.10.09.pdf) (accessed 1 May 2015)
10. Aitken M, Tully MP, Porteous C, Denegri S, Cunningham-Burley S, Banner N. et al. Consensus Statement on Public Involvement and Engagement with Data Intensive Health Research. *International Journal of Population Data Science* (2019) 4:1: <https://doi.org/10.23889/ijpds.v4i1.586>
11. Nasser M, Clarke M, Chalmers I, Brurberg KG, Nykvist H, Lund H, et al. What are funders doing to minimise waste in research? *Lancet* 2017;389:1006–7. [https://doi.org/10.1016/S0140-6736\(17\)30657-8](https://doi.org/10.1016/S0140-6736(17)30657-8)
12. Evans B, Porter A, Snooks H, et al. A co-produced method to involve service users in research: the SUCCESS model. *BMC Medical Research Methodology* 2019;19(34) <https://doi.org/10.1186/s12874-019-0671-6>
13. Wallace C, Kenkre J. (2015) A Consensus for the Priorities for Public Health in Wales. *Public Health Wales*. <https://doi.org/10.13140%2FRG.2.2.35338.06080>
14. Evans BA, Brown A, Bulger J, et al. Paramedics' experiences of administering fascia iliaca compartment block to patients in South Wales with suspected hip fracture at the scene of injury: results of focus groups *BMJ Open* 2019;9:e026073. <https://doi.org/10.1136/bmjopen-2018-026073>
15. Bulger JK, Brown A, Evans BA, Fegan G, Ford S, Guy K, et al. Rapid analgesia for prehospital hip disruption (RAPID): protocol for feasibility study of randomised controlled trial. *Pilot Feasibility Study* 2017;3:8. <https://doi.org/10.1186/s40814-019-0454-1>
16. Khanom A, Alanazyl W, Ellis L, Evans BA, Fagan L, Glendenning A, et al. 2019 The Health Experiences of Asylum Seekers and Refugees in Wales. *Public Health Wales*.
17. McCutchan G, Hiscock J, Hood K, et al. Engaging high-risk groups in early lung cancer diagnosis: a qualitative study of symptom presentation and intervention preferences among the UK's most deprived communities *BMJ Open* 2019;9:e025902. <http://doi.org/10.1136/bmjopen-2018-025902>
18. Phillips R, Edwards A, Grant A, Choy E, Taylor A, Williams D, Bowen D, Pell B, Sanders J. STAR Family Study. <http://www.primecentre.wales/star-family-study.php> (accessed 29.05.2020)
19. Snooks H, Bailey-Jones K, Burge-Jones D, Dale J, Davies J, Evans B, et al. Predictive risk stratification model: a randomised stepped-wedge trial in primary care (PRISMATIC) *Health Services and Delivery Research* Volume: 6 Issue: 1 (Published 19-Jan-2018). <https://doi.org/10.3310/hsdr06010>

20. Price D, Edwards M, Carson-Stevens A, Cooper A, Davies F, Evans B, et al. Challenges of recruiting emergency department patients to a qualitative study: a thematic analysis of researchers' experiences. *BMC Med Res Methodol* 20, 151 (2020). <https://doi.org/10.1186/s12874-020-01039-2>
21. Gobat NH, Gal M, Francis NA, et al. Key stakeholder perceptions about consent to participate in acute illness research: a rapid, systematic review to inform epi/pandemic research preparedness. *Trials* 16, 591 (2015). <https://doi.org/10.1186/s13063-015-1110-6>
22. Beckett K, Farr M, Kothari A, et al. Embracing complexity and uncertainty to create impact: exploring the processes and transformative potential of co-produced research through development of a social impact model. *Health Res Policy Sys* 16, 118 (2018). <https://doi.org/10.1186/s12961-018-0375-0>
23. Glasziou P and Chalmers I. Research waste is still a scandal. *BMJ* 2018;363:k4645. <https://doi.org/10.1136/bmj.k4645>
24. Chalmers I and Glasziou P. Avoidable waste in the production and reporting of research evidence. *The Lancet* 2009; 374:9683 86-89. [https://doi.org/10.1016/S0140-6736\(09\)60329-9](https://doi.org/10.1016/S0140-6736(09)60329-9)
25. Snooks HA, Kingston MR, Anthony RE, Russell IT. New models of emergency prehospital care that avoid unnecessary conveyance to emergency department: translation of research evidence into practice? *Scientific World Journal* 2013; <https://doi.org/10.1155%2F2013%2F182102>
26. Williams D, Edwards A, Wood F, et al. Ability of observer and self-report measures to capture shared decision-making in clinical practice in the UK: a mixed-methods study *BMJ Open* 2019;9:e029485. <https://doi.org/10.1136/bmjopen-2019-029485>
27. Owen-Jones E, Lowe R, Lown M, et al. Protocol for a double-blind placebo-controlled trial to evaluate the efficacy of probiotics in reducing antibiotics for infection in care home residents: the Probiotics to Reduce Infections iN CarE home reSidentS (PRINCESS) trial *BMJ Open* 2019;9:e027513. <https://doi.org/10.1136%2Fbmjopen-2018-027513>
28. Shippee ND, Domecq Garces JP, Lopez P, Wang Z, Elraiyah TA, Nabhan M, et al. Patient and service user engagement in research: a systematic review and synthesized framework. *Health Expect.* 2013;18:1151-66. <https://doi.org/10.1111/hex.12090>
29. Baines R and Regan de Bere S. Optimizing patient and public involvement (PPI): identifying its "essential" and "desirable" principles using a systematic review and modified Delphi methodology. *Health Expectations.* 2018;21:327-35. <https://doi.org/10.1111/hex.12618>
30. Liabo K, Boddy K, Bortoli S, et al. Public involvement in health research: what does 'good' look like in practice?. *Res Involv Engagem* 6, 11 (2020). <https://doi.org/10.1186/s40900-020-0183-x>
31. Devonport TJ, Nicholls W, Johnston LH, Gutteridge R, Watt A. It's not just 'What' you do, it's also the 'Way' that you do it: patient and public involvement in the development of health research. *Int J Qual Health Care.* 2018;30(2):152-6. <https://doi.org/10.1093/intqhc/mzx177>
32. Wilson P, Mathie E, Keenan J, McNeilly E, Goodman C, Howe A, et al. ReseArch with Patient and Public invOlvement: a RealisT evaluation the RAPPORT study. *Health Serv Deliv Res* 2015;3(38). <https://doi.org/10.3310/hsdr03380>
33. Burton H, Adams M, Bunton R, Schröder-Bäck P. Developing Stakeholder Involvement for Introducing Public Health Genomics into Public Policy. *Public Health Genomics* 2009;12:11-19. <https://doi.org/10.1159/000153426>
34. Koniotou M, Evans BA, Chatters R, Fothergill R, Garnsworthy C, Gaze S, Halter M, Mason S, Peconi J, Porter A, Siriwardena AN, Toghil A, Snooks H. Involving older people in a multi-centre randomised trial of a complex intervention in pre-hospital emergency care: implementation of a collaborative model. *BMC Trials* 2015;16:298. <https://doi.org/10.1186%2Fs13063-015-0821-z>

