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Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network.

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ABSTRACT

Objectives: To identify the roles public contributors undertake in the patient and public involvement (PPI) programme at a health network.

Design: A longitudinal case study with three embedded units (projects) involving public contributors. Interviews (n=24), observations (n=27), and documentary data collection occurred over 16 months.

Setting: The West of England Academic Health Science Network (WEAHSN), one of 15 regional AHSNs in England.

Participants: Interviews were conducted with public contributors (n=5) and professionals (n=19) who were staff from the WEAHSN, its member organisations, and its partners.

Findings: Public contributors established their legitimacy by utilising nine distinct roles: 1) lived experience, as a patient or carer; 2) occupational knowledge, offering job-related expertise; 3) occupational skills, offering aptitude developed through employment; 4) patient advocate, promoting the interests of patients; 5) keeper of the public purse, encouraging wise spending; 6) intuitive public, piloting materials suitable for the general public; 7) fresh-eyed reviewer, critiquing materials; 8) critical friend, critiquing progress and proposing new initiatives; and 9) boundary spanner, urging professionals to work across organisations. Individual public contributors occupied many, but not all, of the roles.

Conclusions: Lived experience is only one of nine distinct public contributor roles. The WEAHSN provided a benign context for the study because in a health network public contributors are one of many parties seeking to establish legitimacy through finding valuable roles. The nine roles can be organised into a typology according to whether the basis for legitimacy lies in: the public contributor's knowledge, skills and experience; citizenship through the aspiration to achieve a broad public good; or being an outsider. The typology shows how public contributors can be involved in work where lived experience appears to lack relevance: strategic decision-making; research unconnected to particular conditions; or acute service delivery.

Key words: Patient and public involvement, roles, legitimacy, network organisations.

ARTICLE SUMMARY

Strengths and limitations of this study

- Adopts an embedded case study design enabling the detailed study of how PPI functions
- Adopts maximum variation sampling to gather data from three WEAHSN projects, each using a different approach to PPI
- Extends the previous literature on public contributor roles using corroborating data collected from interviews, observation and documents.
- Emphasises depth of understanding in a single network, which limits generalisability.

INTRODUCTION

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Patient and public involvement (PPI) initiatives in health are underpinned by government aspiration[1], funder requirements[2], journal reporting[3], and have a growing international presence[4]. While the requirement for PPI from government or funders provides public contributors with external legitimacy[5], they must establish their own internal legitimacy[6]. Internal legitimacy hinges on finding a valuable role. Current PPI literature in research and services focuses on public contributors offering their lived experience of health conditions and is associated with changing outcome measures, improving the quality of research and increasing participant enrolment and retention[7-9].

Public contributors can experience challenges to the legitimacy of their lived experience. Some professionals do not believe in the value of experiential knowledge[10], or consider it legitimate only when public contributors are either representative [11] of or connected to their particular patient group[12]. However, there is no guarantee that public contributors will identify with a patient group, nor do groups necessarily share a broad set of interests[13]. PPI places public contributors in a legitimacy double bind where the involvement admits a few individuals whom professionals are able to denigrate as 'unrepresentative' when they speak for a group, and as 'anecdotal' when they offer their own stories[14].

Identifying PPI solely with lived experience presents difficulties. One is the limit placed on the ambition of public contributors[15,16] and the government[1] to see the public involved in decision making at all levels of the English national health service (NHS). To be involved at the higher levels public contributors need to take on more strategic roles in determining health care agendas and directions. In strategic roles, direct lived experience inevitably becomes less and less relevant to the work at hand. There are difficulties for organisations too. PPI based on lived experience tends to work better in areas such as rheumatology where professionals and public contributors can build long-term relationships[17]. Health delivery organisations serving acute rather than chronic conditions, and those working in fields such as implementation[18] and antimicrobial medicines[4] research all report challenges to involving public contributors on the basis of their lived experience.

The nature of the involving organisation is important as PPI is held to be highly context-specific[8, 17]. The WEAHSN worked directly in neither health research nor health services, so lived experience appeared to lack relevance in many areas of their work. We characterised the WEAHSN not just as a network, but as a mandated network administrative organisation (NAO)[6, 19, 20], created by government to administer a formal, membership-based network of independent organisations to meet specific objectives. Thinking of the WEAHSN as an NAO allowed us to consider which elements of the context were instrumental to the findings and to generalise beyond the immediate case.

Previous studies reporting on PPI roles beyond lived experience either examined the involving organisation's work[18] and anticipated the public's potential contribution or captured only the public contributors' perceptions about the roles they undertook[21]. This paper addresses a gap in the literature by collecting corroborating observation, interview and documentary data concerning public contributor roles. We define involvement as healthcare projects being carried out 'with' or 'by' patients and the public[22]; and we present findings showing the range of roles public contributors

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undertook when lived experience appeared to be of limited relevance. We develop a typology of the roles based on whether they derive legitimacy from: the public contributors' own knowledge, experience and skills; citizenship; or being an outsider to the organisation. Maximising the value of the opportunity presented by PPI is a significant concern[18, 23, 24] making these findings relevant to organisations, health professionals and public contributors alike.

METHODS

Setting

Established in 2013 as one of 15 regional AHSNs, the WEAHSN operated under an initial five-year licence from the English NHS. The AHSNs had four core objectives focusing on: patient needs and local populations; building a culture of partnership and collaboration; speeding up the adoption of healthcare innovations; and creating wealth[25]. The WEAHSN's membership consisted of 15 NHS and social care providers, seven commissioning bodies, and three universities[26]. The network members collaborated in joint projects in four key work areas: Enterprise and Translation, Patient Safety, Quality Improvement and Informatics. Once the WEAHSN's board had approved a project as fitting with its remit and a priority for members, it was staffed with individuals representing all the interested organisations.

The Managing Director of the WEAHSN's strong personal commitment to public involvement resulted in a specific programme manager to administer PPI, organising recruitment and selection, assigning projects, negotiating attendance, and managing resources. The WEAHSN involved 12 public contributors at any one time, assigning them in pairs to the board and to projects. All the public contributors were expected to undertake a strategic remit in projects, rather than deliver lived experience.

Study design

This study formed part of a wider research programme commissioned by the WEAHSN with case studies focussing on healthcare innovation development, innovation diffusion and PPI. The research programme employed case study as a methodology[27], which allowed the exploration of both context and phenomena. The study viewed PPI as one form of collaboration taking place in a network organisation.

We asked how PPI at the WEAHSN functioned. We hypothesised that the legitimacy of the public contributors was one variable which would influence the effectiveness of the PPI programme. We justified the selection of a longitudinal single case study because of indications that the PPI programme had adopted best practice[28] and was seen as an exemplar[29]. Three projects (embedded subunits) were selected in collaboration with the programme manager to focus on the operational detail of how the PPI worked in practice. We set out to understand the basis for the public contributors' legitimacy through close examination of what happened when they were involved in WEAHSN projects.

Ethics

Ethics approval for this study was obtained from Health and Applied Sciences faculty ethics committee of the University of the West of England on 28th April 2015,

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reference HAS/15/04/145. All the participants provided informed consent after reading written information sheets. The WEAHSN is a small organisation, so to honour our commitment to anonymity participant descriptions are confined to 'professional' or 'public contributor'.

Patient and Public Involvement

A public contributor was involved in this study from its conception, throughout the process, at regular intervals and is a co-author of this paper (NL). The public contributor suggested additional reading; made changes to the participant information and consent forms; provided a sounding board for ideas; challenged logic; shared the experience of being a public contributor, considered the findings in the light of their own experience; and commented on each draft of the research report.

Data collection

JB, who had no prior connection to the WEAHSN, collected data from three sources (non-participant observation, interview, and document review) in order to triangulate. We regarded evidence corroborated by multiple sources to be the strongest available, and as a way to mitigate the limitations of a single case design[27], and to account for reflexivity[27]. However, we also noted dissenting voices in order to capture the richness available.

Non-participant observations were recorded at every project meeting over the 16 months of the study. In total, data were collected in: 18 meetings for project 1 (P1); three for project 2 (P2); and six for project 3 (P3). Additional contemporaneous notes captured non-verbal events such as when meeting chairs made eye contact with public contributors to bring them into discussions. Of the 24 interviews, 23 were face-to-face and one by telephone. All interviews were recorded and transcribed. Five out of the six public contributors agreed to be interviewed. We used purposive maximum variation sampling to select professionals for interview. The 19 professional interviewees had attended the observed project meetings, and came from the widest possible range of job responsibility, hierarchical level, and organisation type[31]. The interviews were guided conversations, to reduce the likelihood of collecting data with a bias towards verification[32]. The documentary data sources included the emails, meeting minutes, and papers plus project management documents and marketing materials aimed at the public.

Analysis

We used the analytic strategy of explanation building, where propositions are explored and refined using the data[27]. Employing NVivo 10 to manage the data, all interview and observation recordings were reviewed, each transcript read and data coded. Where necessary, coding was simultaneous[30]. The code for legitimacy was the single biggest code with over 500 references at initial coding. The majority of references pertained to the roles undertaken by the public contributors. A second coding exercise reviewed only those references coded to legitimacy. The coded data were developed into written findings using assertions or summary statements crafted

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to capture large amounts of data[30]. Assertions were first written and then refined until all the evidence collected under a code had been accounted for.

FINDINGS

The most striking findings related to the valuable roles the public contributors established for themselves, and the way these provided the internal legitimacy left lacking by government and funder mandates. Nine distinct roles were both reported at interview and observed in practice: lived experience, occupational knowledge, occupational skills, patient advocate, keeper of the public purse, intuitive public, fresh-eyed reviewer, critical friend, and boundary spanner. All the public contributors played more than one role during the data collection period (and sometimes more than one role in a single meeting), although none played all nine.

Lived experience

Most professionals and public contributors associated PPI with lived experience. The professionals valued being reminded of what it was like to be a patient. Several professionals assumed that public contributors undertaking this role brought *"other people's views as well as their own"* although only one public contributor reported doing this and another saw it as unnecessary, saying,

> *"Where with the public contributor roles there isn't the necessity to go back to your contacts, your networks if you like, to ask people's opinion."* Public contributor 1, P3

One professional distinguished strategic from lived experience roles in the following way:

> *"…it's quite good to differentiate between people who can participate in an advisory group or a steering group. There's a different type of public contributor that might be more about bringing their lived experience of a condition."* Professional, P1-3

Observational data revealed that four public contributors drew on their lived experience on five separate occasions, despite not working on projects directly relevant to their own health. For example, one public contributor related their own experience as a carer while giving feedback on a community health programme to train healthcare assistants. Three of the five public contributors interviewed suggested that lived experience conferred the most legitimacy. One interviewee said,

> *"…but I think that…really do they not just get in the way, public contributors of…what needs to be done? Apart from…the ones who have had direct experience of the service."* Public Contributor 1, P2

More than one professional noted that the most helpful comments came from public contributors who could generalise their own experience out to other patients, rather than focussing solely on their own situation, which was sometimes seen as having an *"axe to grind"* or an *"agenda"*.

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Occupational knowledge

All the public contributors came to involvement with occupational backgrounds. The professionals acknowledged this, with one saying, *"they might be insurance brokers…or policemen"*. Only two public contributors were observed making direct use of their occupational knowledge. One of these noted the value of their marketing knowledge, despite it being regarded as a *"dirty word"* in the NHS. However not every qualified pubic contributor played this role. One public contributor, with a background relevant to their project reported,

> *"I didn't feel that…my professional side was going to be hugely helpful on this project."* Public Contributor 1, P1

Difficulties in playing this role arose when the lines between public contribution and consultancy blurred. A public contributor noted that the WEAHSN *"get me really cheap"*, a reference to the difference between the hourly rate charged as a consultant and that offered by the WEAHSN to recompense public contributors.

One professional reported that the line between public contribution from an expert in a different field and consultancy had caused *"interesting debates within the project"* and there was some concern to stay within taxation rules distinguishing between public contributors and consultants. Another difficulty arose when the public contributor's occupational background was in health. Some professionals expressed anxiety over whether the voice of the patient was truly reflected.

Occupational Skills

Three public contributors drew on skills acquired through their occupation, rather than direct job-specific knowledge. During one observation, for example, a public contributor introduced themselves as a lawyer, explaining that this gave them an eye for technical detail. This lawyer went on to critique a paper comparing three different training schemes, pointing out that each option had been rated against a different set of criteria. Another public contributor, with a background in marketing, explained that their skills could be used to ensure that the training did not sound *"pompous"* or *"old-fashioned"*. Whilst two public contributors discussed their occupational skills, none of the professionals reported on this role.

Patient Advocate

Ten participants talked about patient advocacy. One public contributor alluded to the role saying,

> *"You don't have to have lived experience to know that patients don't want to wait too long or that they wanted to be…treated as human beings."* Public Contributor 2, P3

One public contributor was observed playing this role on multiple occasions. Rather than anticipating what other patients wanted, the public contributor advocated for patients to be included in decision making so that they could speak for themselves. For example, the public contributor suggested that work including general

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practitioners (GPs) should also include each practice's patient participation group. As another example, the same public contributor asked whether patients played any part in harm prevention training.

Keeper of the public purse

The core of this role was overseeing the way public money was spent, to make best use of it in the face of what one public contributor called *"vested interests"*, explaining,

> *"…you are there to make sure that public money, not just money but… resources in general…are being dealt with appropriately I would say."* Public Contributor 2, P3

Two public contributors were observed playing this role, with one in particular concerned to make sure that the NHS didn't spend money creating materials or programmes that already existed elsewhere. On the other hand, one professional described the public's presence as legitimising the spending.

Intuitive public

In this role, public contributors trialled materials or workshops in advance of a launch to the general public. Three public contributors attended the pilot version of a workshop to give feedback about how it ran. Only one project offered the opportunity to play this role because only one project produced materials aimed at the general public. One professional from the project described the legitimacy of the intuitive public saying, *"so I think it's their…knowledge of if you do it like this it probably might reach more people"*. Another described the legitimacy as flowing from the public to the project,

> *"I think it certainly added a lot of legitimacy to the project because…it would be probably a bit cheeky that the citizen led project without any citizens on."* Professional, P1

However, one professional described this role as *"validation"*, suggesting that the public rubber-stamped what would have happened anyway. Playing this role, one public contributor commented that their involvement had *"tailed off"*. The professionals appeared to see the latter stages of the project as the domain of experts, and could not articulate a prolonged role for the public despite an observed discussion at one point that hinged upon what the public might want.

Fresh-eyed reviewer

A public contributor summarised the legitimacy of this role saying,

> *"It's just that I am another pair of eyes in the room and I don't come from the same background."* Public contributor 1, P2

All the public contributors provided review of materials and ideas put before them. They variously described that they enjoyed a freedom not available to professionals;

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could admit to not knowing something in front of a meeting; or ask seemingly naïve questions. Many professionals valued the views of those unencumbered by NHS organisation structures, language, culture, budgets or timescale. However, if review became the main focus one professional worried that the meeting became a *“showcase”*. One public contributor expressed concern that materials were sometimes sent late in the process, once already finalised, reducing the role to that of merely a *“proof reader”*.

Critical friend

Documentary review showed that the WEAHSN used the term critical friend in the public contributor job description, but did not define or explain it further. On six occasions two public contributors extended the public voice beyond fresh-eyed review of WEAHSN materials and instead proposed new activity or asked new questions. Observed examples included the public contributor asking whether a new approach was a trend or worth investigating and suggesting the next steps for the project. As one participant put it,

> *“You don't have to be an expert at anything to ask the sort of questions that hopefully would make people just sit back and think again.”* Public Contributor 1, P3

The legitimacy of a critical friend is demonstrated by the effective way the public contributors held projects to account by comparing progress to the original aims. One professional described a public contributor as saying,

> *“You said you were gonna do this…and…I haven’t heard anything about that, so what’s happening about it?”* Professional, P3

Boundary spanner

One interviewee talked about this role saying,

> *“[The] NHS never really changes in terms of how things develop in silos and they're…slow to share and push things forward.”* Public Contributor, P3

Two public contributors played this role. One asked a meeting why their area’s GPs were not signed up to a primary care initiative. The other took numerous opportunities to advocate for NHS organisations to work with each other, with local councils, and with community organisations. Three separate observations record the public contributor asking the WEAHSN whether they were sharing with and learning from other AHSNs.

DISCUSSION

This study of a single network organisation found more distinct public contributor roles than previous larger studies across multiple settings[21]. The WEAHSN seems to have provided a particularly benign context for public contributors to undertake nine distinct roles. First, lived experience of a health condition appeared to lack direct

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relevance, with the organisation working directly in neither research nor service delivery. Next, the job description left the nature of the contribution open. Then, like other mandated NAOs, the WEAHSN's government mandate gave it external legitimacy, but not internal legitimacy, compelling the organisation to spend time establishing legitimacy with members by identifying and supporting projects that fitted both its own objectives and its members' interests[19, 6]. Furthermore, the professionals at the WEAHSN played multiple, shifting roles with flexible job content, a common feature of network organisations[33]. In a mandated NAO, the public contributors are just one of many parties who are all attempting to establish legitimacy through finding valuable roles to play. Although the context was especially beneficial to their discovery, nothing about the roles suggests they could not operate in other settings, particularly where lived experience appears to lack relevance.

In their search for valuable roles, the public contributors in this study found a surprising number of occasions for drawing on their experiences as patients and carers. In common with the literature, public contributors felt lived experience to be the most legitimate of the roles open to them. Nonetheless, the public contributors also found additional valuable roles on which to establish their legitimacy. The basis of the legitimacy for six of the nine roles can be found in existing literature as lying either in claims to knowledge, experience and skill[14] (lived experience, occupational knowledge, and occupational skill), or in citizenship[14] seen here as attempts to realise a greater public good (patient advocate, and keeper of the public purse). The basis of the legitimacy for the final three roles is based in the public contributor as an outsider[34], able to bring in different perspectives (intuitive public, fresh eyed reviewer, critical friend and boundary spanner). Grouping the roles together, based on the nature of the legitimacy gives the typology in Table 1.

Table 1 Typology of roles

Group 1 roles. Legitimacy based on knowledge, experience and skill	**Group 2 roles. Legitimacy based on citizenship**	**Group 3 roles. Legitimacy based on being an outsider**
Lived experience	Patient advocate	Intuitive public
Occupational knowledge	Keeper of the public purse	Fresh-eyed reviewer
Occupational skills		Critical friend
		Boundary spanner

A previous study of 38 public contributors to health research reported six public contributor roles [21](the expert in lived experience, the creative outsider, the free challenger, the bridger, the motivator, and the passive presence) that can be used to expand the typology in Table 1. Three roles (the expert in lived experience, the creative outsider, and the free challenger) map on to the lived experience, fresh-eyed reviewer and critical friend identified here. The additional three (the bridger, the motivator and the passive presence) can be added to the typology. The motivator increases the enthusiasm and commitment of the professionals. The passive presence reminds the professionals to take the public's perspective into account. Both of these roles base their legitimacy in citizenship through the way each aspires to lead to a public good[35] by changing the behaviour of professionals in positive ways. The bridger aids communication to an outside group, and so legitimacy is based on being

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an outsider to the involving organisation and simultaneously belonging to or having access to that outside group. The motivator, passive presence and bridger roles are shown in their relevant groups in Table 2.

Table 2 Extending the typology with additional roles identified in the literature[21]

Group 1 roles. Legitimacy based on knowledge, experience and skill.	**Group 2 roles. Legitimacy based on citizenship.**	**Group 3 roles. Legitimacy based on being an outsider.**
	Motivator	Bridger
	Passive presence	

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The implications of the typology are wide-ranging. Public contribution is not confined to lived experience. Instead, public contributors draw on a broad set of knowledge, skills and experiences. Public contributors do not need to be representative, either statistically or through being in any sense typical. Knowledge, experience and skills can provide a basis for legitimacy. In addition to drawing on their own background, public contributors can draw on citizenship, without needing to represent others. Broad public good[35], such as achieving the same result with less cost, or operating across organisational boundaries, can be a source of legitimacy in itself. Furthermore, a number of valuable roles can be crafted from being outsiders. The value of the outsider roles does not diminish even if public contributors are experienced to the point of professionalisation: they remain unrestricted by the organisation's boundaries, budgets, and perspectives. The typology goes beyond helping organisations to develop better job descriptions[21], it shows how public contributors can be involved in strategic work, and work unconnected with chronic or even specific conditions. The typology provides the basis for a dialogue to maximise the opportunity presented by PPI.

Whilst the limitation of exploring a single network organisation must be acknowledged, our design approach strengthened our study. The use of maximum variation sampling within the case, multiple sources of triangulating evidence, and the extent to which this study builds on themes already evident in the literature strengthen the credibility of our findings. The WEAHSN is characterised as a mandated NAO which provided a beneficial context for the multiple public contributor roles, although nothing suggests the roles are necessarily unique to the setting.

CONCLUSION

The conflation of PPI with lived experience presented a challenge for public contributors and involving organisations alike. The benign context of the WEAHSN, where the public contributors were just one of the parties trying to establish their legitimacy through finding valuable roles, permitted the discovery of nine distinct roles with three broad bases in legitimacy. As well as suggesting network organisations as a fruitful setting for context-cognisant PPI research, the findings demonstrate the potential value of public involvement in settings where lived experience appears to lack relevance. Furthermore, the lost opportunity represented

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by an exclusive focus on a single role suggests that all involving organisations could benefit from encouraging public contributors to undertake a wide range of roles.

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

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		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3

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Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	4
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Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4-5
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of	5

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		procedures in response to evolving study findings; rationale	
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	5
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	6-9
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	9-11

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Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network.

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ABSTRACT

Objectives: To identify the roles public contributors undertake in the patient and public involvement (PPI) programme at a health network.

Design: A longitudinal case study with three embedded units (projects) involving public contributors. Interviews (n=24), observations (n=27), and documentary data collection occurred over 16 months.

Setting: The West of England Academic Health Science Network (WEAHSN), one of 15 regional AHSNs in England.

Participants: Interviews were conducted with public contributors (n=5) and professionals (n=19) who were staff from the WEAHSN, its member organisations, and its partners.

Findings: Public contributors established their legitimacy by utilising nine distinct roles: 1) lived experience, as a patient or carer; 2) occupational knowledge, offering job-related expertise; 3) occupational skills, offering aptitude developed through employment; 4) patient advocate, promoting the interests of patients; 5) keeper of the public purse, encouraging wise spending; 6) intuitive public, piloting materials suitable for the general public; 7) fresh-eyed reviewer, critiquing materials; 8) critical friend, critiquing progress and proposing new initiatives; and 9) boundary spanner, urging professionals to work across organisations. Individual public contributors occupied many, but not all, of the roles.

Conclusions: Lived experience is only one of nine distinct public contributor roles. The WEAHSN provided a benign context for the study because in a health network public contributors are one of many parties seeking to establish legitimacy through finding valuable roles. The nine roles can be organised into a typology according to whether the basis for legitimacy lies in: the public contributor's knowledge, skills and experience; citizenship through the aspiration to achieve a broad public good; or being an outsider. The typology shows how public contributors can be involved in work where lived experience appears to lack relevance: strategic decision-making; research unconnected to particular conditions; or acute service delivery.

Key words: Patient and public involvement, roles, legitimacy, network organisations.

ARTICLE SUMMARY

Strengths and limitations of this study

- Adopts an embedded case study design enabling the detailed study of how PPI functions
- Adopts maximum variation sampling to gather data from three WEAHSN projects, each using a different approach to PPI
- Extends the previous literature on public contributor roles using corroborating data collected from interviews, observation and documents.
- Emphasises depth of understanding in a single network, which limits generalisability.

INTRODUCTION

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Patient and public involvement (PPI) initiatives in health have been driven by activists [1], are underpinned by government aspiration[2], funder requirements[3], journal reporting[4], and have a growing international presence[5]. While the requirement for PPI from government or funders provides public contributors with external legitimacy[6], they must establish their own internal legitimacy[7]. Internal legitimacy, comprised of authority and credibility within the organisation, is left to be established. The legitimacy conferred through formal selection to the organisation's involvement programme is unlikely to be sufficient [8]. Internal legitimacy hinges on finding a valuable role. Current PPI literature in research and services focuses on public contributors offering their lived experience of health conditions and is associated with changing outcome measures, improving the quality of research and increasing participant enrolment and retention[9-11].

Public contributors can experience challenges to the legitimacy of their lived experience. Some professionals do not believe in the value of experiential knowledge[12], or consider it legitimate only when public contributors are either representative [13] of or connected to their particular patient group[14]. However, there is no guarantee that public contributors will identify with a patient group, nor do groups necessarily share a broad set of interests[15]. PPI places public contributors in a legitimacy double bind where the involvement admits a few individuals whom professionals are able to denigrate as 'unrepresentative' when they speak for a group, and as 'anecdotal' when they offer their own stories[16].

Identifying PPI solely with lived experience presents difficulties. One is the limit placed on the ambition of public contributors[17,18] and the government[2] to see the public involved in decision making at all levels of the English national health service (NHS). To be involved at the higher levels public contributors need to take on more strategic roles in determining health care agendas and directions. In strategic roles, direct lived experience inevitably becomes less and less relevant to the work at hand. There are difficulties for organisations too. PPI based on lived experience tends to work better in areas such as rheumatology where professionals and public contributors can build long-term relationships[19]. Health delivery organisations serving acute rather than chronic conditions, and those working in fields such as implementation[20] and antimicrobial medicines[5] research all report challenges to involving public contributors on the basis of their lived experience.

The nature of the involving organisation is important as PPI is held to be highly context-specific[10, 19]. The WEAHSN worked directly in neither health research nor health services, but was tasked with speeding the adoption and spread of innovation from research organisations and firms to service organisations. Lived experience appeared to lack relevance in many areas of their work. We characterised the WEAHSN not just as a network, but as a mandated network administrative organisation (NAO)[7, 21, 22], created by government to administer a formal, membership-based network of independent organisations. Thinking of the WEAHSN as an NAO allowed us to consider which elements of the context were instrumental to the findings and to generalise beyond the immediate case.

Previous studies reporting on PPI roles beyond lived experience either examined the involving organisation's work[20] and anticipated the public's potential contribution or captured only the public contributors' perceptions about the roles they

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undertook[23]. One study aimed at exploring power relations in PPI discovered a role for the public as challenging outsiders [24]. This paper addresses a gap in the literature by collecting corroborating observation, interview and documentary data concerning public contributor roles. We define involvement as healthcare projects being carried out 'with' or 'by' patients and the public[25]; and we present findings showing the range of roles public contributors undertook when lived experience appeared to be of limited relevance. We develop a typology of the roles based on whether they derive legitimacy from: the public contributors' own knowledge, experience and skills; citizenship; or being an outsider to the organisation. Maximising the value of the opportunity presented by PPI is a significant concern[20, 26, 27] making these findings relevant to organisations, health professionals and public contributors alike.

METHODS

Setting

Established in 2013 as one of 15 regional AHSNs, the WEAHSN operated under an initial five-year licence from the English NHS. The AHSNs had four objectives focusing on: patient needs and local populations; building a culture of partnership and collaboration; speeding up the adoption of healthcare innovations; and creating wealth[28]. The WEAHSN's membership consisted of 15 NHS and social care providers, seven commissioning bodies, and three universities[29]. The network members collaborated in joint projects in four key work areas: Enterprise and Translation, Patient Safety, Quality Improvement and Informatics. Once the WEAHSN's board had approved a project as fitting with its remit and a priority for members, it was staffed with individuals representing all the interested organisations.

The Managing Director of the WEAHSN's strong personal commitment to public involvement resulted in a specific programme manager to administer PPI, organising recruitment and selection, assigning projects, negotiating attendance, and managing resources. The WEAHSN involved 12 public contributors at any one time, assigning them in pairs to the board and to projects. The PPI Manager expected public contributors to take part in strategic projects, rather than deliver lived experience.

Study design

This study formed part of a wider research programme commissioned by the WEAHSN, titled Evidencing the Value of the WEAHSN comprising three case studies focussing on 1) healthcare innovation development, 2) innovation diffusion and 3) PPI. The research programme employed case study as a methodology[30], which allowed the exploration of both context and phenomena. The study viewed PPI as one form of collaboration taking place in a network organisation.

Our research question asked how PPI at the WEAHSN functioned. We hypothesised that the legitimacy of the public contributors was one variable which would influence the effectiveness of the PPI programme. We justified the selection of a longitudinal single case study because of indications that the PPI programme had adopted best practice[31] and was seen as an exemplar[32]. Three projects (embedded subunits) were selected in collaboration with the programme manager to focus on the operational detail of how the PPI worked in practice. We set out to understand the

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basis for the public contributors' legitimacy through close examination of what happened when they were involved in WEAHSN projects.

Ethics

Ethics approval for this study was obtained from Health and Applied Sciences faculty ethics committee of the University of the West of England on 28th April 2015, reference HAS/15/04/145. All the participants provided informed consent after reading written information sheets. The WEAHSN is a small organisation, so to honour our commitment to anonymity participant descriptions are confined to 'professional' or 'public contributor'.

Patient and Public Involvement

A public contributor was involved in this study from its conception, throughout the process, at regular intervals and is a co-author of this paper (NL). The public contributor suggested additional reading; made changes to the participant information and consent forms; provided a sounding board for ideas; challenged logic; shared the experience of being a public contributor, considered the findings in the light of their own experience; and commented on each draft of the research report.

Data collection

JB, who had no prior connection to the WEAHSN, collected data from three sources (non-participant observation, interview, and document review) in order to triangulate. We regarded evidence corroborated by multiple sources to be the strongest available, and as a way to mitigate the limitations of a single case design[30], and to account for reflexivity[30]. However, we also noted dissenting voices in order to capture the richness available.

Non-participant observations were audio-recorded at every project meeting over the 16 months of the study and then transcribed. In total, data were collected in: 18 meetings for project 1 (P1); three for project 2 (P2); and six for project 3 (P3). Additional contemporaneous notes captured non-verbal events such as when meeting chairs made eye contact with public contributors to bring them into discussions. Of the 24 interviews, 23 were face-to-face and one by telephone. The topic guide used at the interviews is included in the supplemental material. All interviews were audio-recorded and transcribed. Five out of the six public contributors involved in the projects that formed our sample agreed to be interviewed. We used purposive maximum variation sampling to select professionals for interview [33]. The 19 professional interviewees had attended the observed project meetings, and came from the widest possible range of job responsibility, hierarchical level, and organisation type[34]. The interviews were guided conversations, to reduce the likelihood of collecting data with a bias towards verification[35]. The documentary data sources included the emails, meeting minutes, and papers plus project management documents and marketing materials aimed at the public.

Analysis

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We used the analytic strategy of explanation building, where propositions created from the research questions are explored and refined using the data[27]. Employing NVivo 10 to manage the data, all interview and observation recordings were reviewed, each transcript read and data coded using deductive codes established from the literature. Where necessary, coding was simultaneous[33]. The code for legitimacy was the single biggest code with over 500 references at initial coding. The majority of references pertained to the roles undertaken by the public contributors. A second coding exercise reviewed only those references coded to legitimacy. The coded data were developed into written findings using assertions or summary statements crafted to capture large amounts of data[33]. Assertions were first written and then refined until all the evidence collected under a code had been accounted for.

FINDINGS

The most striking findings related to the valuable roles the public contributors established for themselves, and the way these provided the internal legitimacy left lacking by government and funder mandates. Nine distinct roles were both reported at interview and observed in practice: lived experience, occupational knowledge, occupational skills, patient advocate, keeper of the public purse, intuitive public, fresh-eyed reviewer, critical friend, and boundary spanner. All the public contributors played more than one role during the data collection period (and sometimes more than one role in a single meeting), although none played all nine.

Lived experience

Most professionals and public contributors associated PPI with lived experience. The professionals valued being reminded of what it was like to be a patient. Several professionals assumed that public contributors undertaking this role brought *"other people's views as well as their own"* although only one public contributor reported doing this and another saw it as unnecessary, saying,

> *"Where with the public contributor roles there isn't the necessity to go back to your contacts, your networks if you like, to ask people's opinion."* Public contributor 1, P3

One professional distinguished strategic from lived experience roles in the following way:

> *"…it's quite good to differentiate between people who can participate in an advisory group or a steering group. There's a different type of public contributor that might be more about bringing their lived experience of a condition."* Professional, P1-3

Observational data revealed that four public contributors drew on their lived experience on five separate occasions, despite not working on projects directly relevant to their own health. For example, one public contributor related their own experience as a carer while giving feedback on a community health programme to train healthcare assistants. Three of the five public contributors interviewed suggested that lived experience conferred the most legitimacy. One interviewee said,

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> *"…but I think that…really do they not just get in the way, public contributors of…what needs to be done? Apart from…the ones who have had direct experience of the service."* Public Contributor 1, P2

More than one professional noted that the most helpful comments came from public contributors who could generalise their own experience out to other patients, rather than focussing solely on their own situation, which was sometimes seen as having an *"axe to grind"* or an *"agenda"*.

Occupational knowledge

All the public contributors came to involvement with occupational backgrounds. The professionals acknowledged this, with one saying, *"they might be insurance brokers…or policemen"*. Only two public contributors were observed making direct use of their occupational knowledge. One of these noted the value of their marketing knowledge, despite it being regarded as a *"dirty word"* in the NHS. However not every qualified pubic contributor played this role. One public contributor, with a background relevant to their project reported,

> *"I didn't feel that…my professional side was going to be hugely helpful on this project."* Public Contributor 1, P1

Difficulties in playing this role arose when the lines between public contribution and consultancy blurred. A public contributor noted that the WEAHSN *"get me really cheap"*, a reference to the difference between the hourly rate charged as a consultant and that offered by the WEAHSN to recompense public contributors.

One professional reported that the line between public contribution from an expert in a different field and consultancy had caused *"interesting debates within the project"*. Another difficulty arose when the public contributor's occupational background was in health. Some professionals expressed anxiety over whether the voice of the patient was truly reflected.

Occupational Skills

Three public contributors drew on skills acquired through their occupation, rather than direct job-specific knowledge. During one observation, for example, a public contributor introduced themselves as a lawyer, explaining that this gave them an eye for technical detail. This lawyer went on to critique a paper comparing three different training schemes, pointing out that each option had been rated against a different set of criteria. Another public contributor, with a background in marketing, explained that their skills could be used to ensure that the training did not sound *"pompous"* or *"old-fashioned"*. Whilst two public contributors discussed their occupational skills, none of the professionals reported on this role.

Patient Advocate

Ten participants talked about patient advocacy. One public contributor alluded to the role saying,

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> *"You don't have to have lived experience to know that patients don't want to wait too long or that they wanted to be…treated as human beings."* Public Contributor 2, P3

One public contributor was observed playing this role on multiple occasions. Rather than anticipating what other patients wanted, the public contributor advocated for patients to be included in decision making so that they could speak for themselves. For example, the public contributor suggested that work including general practitioners (GPs) should also include each practice's patient participation group. As another example, the same public contributor asked whether patients played any part in harm prevention training.

Keeper of the public purse

The core of this role was overseeing the way public money was spent, to make best use of it in the face of what one public contributor called *"vested interests"*, explaining,

> *"…you are there to make sure that public money, not just money but… resources in general…are being dealt with appropriately I would say."* Public Contributor 2, P3

Two public contributors were observed playing this role, with one in particular concerned to make sure that the NHS didn't spend money creating materials or programmes that already existed elsewhere. On the other hand, one professional described the public's presence as legitimising the spending.

Intuitive public

In this role, public contributors trialled materials or workshops in advance of a launch to the general public. Three public contributors attended the pilot version of a workshop to give feedback about how it ran. Only one project offered the opportunity to play this role because only one project produced materials aimed at the general public. One professional from the project described the legitimacy of the intuitive public saying, *"so I think it's their…knowledge of if you do it like this it probably might reach more people"*. Another described the legitimacy as flowing from the public to the project,

> *"I think it certainly added a lot of legitimacy to the project because…it would be probably a bit cheeky that the citizen led project without any citizens on."* Professional, P1

However, one professional described this role as *"validation"*, suggesting that the public rubber-stamped what would have happened anyway. Playing this role, one public contributor commented that their involvement had *"tailed off"*. The professionals appeared to see the latter stages of the project as the domain of experts, and could not articulate a prolonged role for the public despite an observed discussion at one point that hinged upon what the public might want.

Fresh-eyed reviewer

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A public contributor summarised the legitimacy of this role saying,

> *"It's just that I am another pair of eyes in the room and I don't come from the same background."* Public contributor 1, P2

All the public contributors provided review of materials and ideas put before them. They variously described that they enjoyed a freedom not available to professionals; could admit to not knowing something in front of a meeting; or ask seemingly naïve questions. Many professionals valued the views of those unencumbered by NHS organisation structures, language, culture, budgets or timescale. However, if review became the main focus one professional worried that the meeting became a *"showcase"*. One public contributor expressed concern that materials were sometimes sent late in the process, once already finalised, reducing the role to that of merely a *"proof reader"*.

Critical friend

Documentary review showed that the WEAHSN used the term critical friend in the public contributor job description (see supplemental material). On six occasions two public contributors extended the public voice beyond fresh-eyed review of WEAHSN materials and instead proposed new activity or asked new questions. Observed examples included the public contributor asking whether a new approach was a trend or worth investigating and suggesting the next steps for the project. As one participant put it,

> *"You don't have to be an expert at anything to ask the sort of questions that hopefully would make people just sit back and think again."* Public Contributor 1, P3

The legitimacy of a critical friend is demonstrated by the effective way the public contributors held projects to account by comparing progress to the original aims. One professional described a public contributor as saying,

> *"You said you were gonna do this…and…I haven't heard anything about that, so what's happening about it?"* Professional, P3

Boundary spanner

One interviewee talked about this role saying,

> *"[The] NHS never really changes in terms of how things develop in silos and they're…slow to share and push things forward."* Public Contributor, P3

Two public contributors played this role. One asked a meeting why their area's GPs were not signed up to a primary care initiative. The other took numerous opportunities to advocate for NHS organisations to work with each other, with local councils, and with community organisations. Three separate observations record the public contributor asking the WEAHSN whether they were sharing with and learning from other AHSNs.

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DISCUSSION

This study of a single network organisation found more distinct public contributor roles than previous larger studies across multiple settings[23]. The WEAHSN seems to have provided a particularly benign context for public contributors to undertake nine distinct roles. First, lived experience of a health condition appeared to lack direct relevance, with the organisation working directly in neither research nor service delivery. Next, the job description left the nature of the contribution open. Then, like other mandated NAOs, the WEAHSN's government mandate gave it external legitimacy, but not internal legitimacy, compelling the organisation to spend time establishing legitimacy with members by identifying and supporting projects that fitted both its own objectives and its members' interests[21, 7]. Furthermore, the professionals at the WEAHSN played multiple, shifting roles with flexible job content, a common feature of network organisations[36]. In a mandated NAO, the public contributors are just one of many parties who are all attempting to establish legitimacy through finding valuable roles to play. Although the context was especially beneficial to their discovery, nothing about the roles suggests they could not operate in other settings, particularly where lived experience appears to lack relevance.

In their search for valuable roles, the public contributors in this study found a surprising number of occasions for drawing on their experiences as patients and carers. In common with the literature, three out of the five public contributors interviewed felt lived experience to be the most legitimate of the roles open to them. Nonetheless, the public contributors also found additional valuable roles on which to establish their legitimacy. The basis of the legitimacy for six of the nine roles can be found in the literature as lying either in claims to knowledge, experience and skill[16] (lived experience, occupational knowledge, and occupational skill), or in citizenship[16] seen here as attempts to realise a greater public good (patient advocate, and keeper of the public purse). The basis of the legitimacy for the final three roles is based in the public contributor as an outsider[37] and both incorporates and breaks down the idea of a role as a 'challenging outsider [24] , able to bring in different perspectives (intuitive public, fresh eyed reviewer, critical friend and boundary spanner). Grouping the roles together, based on the nature of the legitimacy gives the typology in Table 1.

Table 1 Typology of roles

Group 1 roles. Legitimacy based on knowledge, experience and skill	**Group 2 roles. Legitimacy based on citizenship**	**Group 3 roles. Legitimacy based on being an outsider**
Lived experience	Patient advocate	Intuitive public
Occupational knowledge	Keeper of the public purse	Fresh-eyed reviewer
Occupational skills		Critical friend
		Boundary spanner

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A previous study of 38 public contributors to health research reported six public contributor roles [23](the expert in lived experience, the creative outsider, the free challenger, the bridger, the motivator, and the passive presence) that can be used to expand the typology in Table 1. Three roles (the expert in lived experience, the creative outsider, and the free challenger) map on to the lived experience, fresh-eyed reviewer and critical friend identified here. The additional three (the bridger, the motivator and the passive presence) can be added to the typology. The motivator increases the enthusiasm and commitment of the professionals. The passive presence reminds the professionals to take the public's perspective into account. Both of these roles base their legitimacy in citizenship through the way each aspires to lead to a public good[38] by changing the behaviour of professionals in positive ways. The bridger aids communication to an outside group, and so legitimacy is based on being an outsider to the involving organisation and simultaneously belonging to or having access to that outside group. The motivator, passive presence and bridger roles are shown in their relevant groups in Table 2.

Table 2 Extending the typology with additional roles identified in the literature[23]

Group 1 roles. Legitimacy based on knowledge, experience and skill.	**Group 2 roles. Legitimacy based on citizenship.**	**Group 3 roles. Legitimacy based on being an outsider.**
	Motivator	Bridger
	Passive presence	

The implications of the typology are wide-ranging. Public contribution is not confined to lived experience. Instead, public contributors draw on a broad set of knowledge, skills and experiences. Public contributors do not need to be representative, either statistically or through being in any sense typical. Knowledge, experience and skills can provide a basis for legitimacy. In addition to drawing on their own background, public contributors can draw on citizenship, without needing to represent others. Broad public good[38], such as achieving the same result with less cost, or operating across organisational boundaries, can be a source of legitimacy in itself. Furthermore, a number of valuable roles can be crafted from being outsiders. The value of the outsider roles does not diminish even if public contributors are experienced to the point of professionalisation: they remain unrestricted by the organisation's boundaries, budgets, and perspectives. The typology goes beyond helping organisations to develop better job descriptions[23], it shows how public contributors can be involved in strategic work, and work unconnected with chronic or even specific conditions. The typology provides the basis for a dialogue to maximise the opportunity presented by PPI.

Whilst the limitation of exploring a single network organisation must be acknowledged, our design approach strengthened our study. The use of maximum variation sampling within the case, multiple sources of triangulating evidence, and the extent to which this study builds on themes already evident in the literature strengthen the credibility of our findings. The WEAHSN is characterised as a mandated NAO which provided a beneficial context for the multiple public contributor roles, although nothing suggests the roles are necessarily unique to the setting.

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CONCLUSION

The conflation of PPI with lived experience presented a challenge for public contributors and involving organisations alike. The benign context of the WEAHSN, where the public contributors were just one of the parties trying to establish their legitimacy through finding valuable roles, permitted the discovery of nine distinct roles with three broad bases in legitimacy. As well as suggesting network organisations as a fruitful setting for context-cognisant PPI research, the findings demonstrate the potential value of public involvement in settings where lived experience appears to lack relevance. Furthermore, the lost opportunity represented by an exclusive focus on a single role suggests that all involving organisations could benefit from encouraging public contributors to undertake a wide range of roles.

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Data statement: The data can be accessed by contacting the corresponding author.

Conflict of interest: None

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Extract from the research protocol

Interview question topic guide

-Questions about involvement in the project: -
How were public contributors recruited to the project?
How were public contributors involved in the project?
How did you understand the role of public contributors?
Did the role of public contributors change over time?
What factors facilitated the involvement of public contributors?
What factors impeded the involvement of public contributors?
Did any project team member take a lead in involvement? What was the nature of that lead?
Is there any evidence of the success indicators for PPI: Did the public contributors meet together? Get offered any training? Did they get paid? Contribute to official information? Co-design the initiative? Did they sit on the governing body?
How were decisions made in the project? What was the role of public contributors? Could public contributors influence decision-making?
Anything the participant would like to say about PPI that has not been covered?

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Academic Health
Science Network

West of England Academic Health Science Network
6th Floor, South Plaza, Marlborough Street
Bristol BS1 3NX

Role Profile

[redacted]

1. Background

The West of England Academic Health Science Network (WEAHSN) is a vibrant and diverse network of partners which includes providers of NHS care working with universities, industry, NHS commissioners and a wide range of other organisations.

People & Health West of England (PHWE) aims to share good practice and resources encouraging the involvement and participation of patients and members of the public. It was set up by the WEAHSN, the Collaboration for Applied Health Research and Care (CLAHRC) West, the Clinical Research Network (CRN) and Bristol Health Partners (BHP). This joint approach is unique. By joining the WEAHSN as a public contributor, you will have the opportunity to take part in PHWE and help shape how we take patient and public involvement forward in the region.

2. Main responsibilities

2.1. To act as a critical friend and offer advice and support to the [redacted]

2.2. To contribute to the planning of 6- 8 workshops.

2.3. To respond and comment on the promotional materials being produced by the design company.

2.4. To prepare for and actively participate in weekly phone meetings. This will include reading meeting papers that may be lengthy and/or complex.

2.5. To undertake activities between meetings as mutually agreed. This may include some or all of the following:

- Membership of a project advisory group.
- Attending events organised by the steering group (for example, a seminar or workshop).
- Giving talks or delivering workshops.
- Involvement in other relevant activities as appropriate.

2.6. To promote the work of the West of England Academic Health Science Network to others.

2.7. When appropriate, provide support to new public members.

3. Commitment

The role is for **[Specify period].**

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Working arrangements will be reviewed after an initial trial period of 3 months thereafter the specific time commitment will be identified mutually agreed.

4. Payment and expenses

Payment for time will be [redacted] per hour, which covers the time spent preparing for meetings such as reading minutes and associated papers. Other out of pocket expenses such as travel [redacted] or carer's allowances will be paid in addition.

5. Induction and support

All new public members will be expected to attend an induction session prior to starting to prepare new members for their role and provide practical information about getting involved (for example, style of meetings, format of papers, how to contribute effectively, expenses and payment).

6. Public contributor role requirements

Skill/Experience	Essential	Desirable
Experience of working with others to address common issues of concern.		
Understanding of quality improvement from a public perspective.		
Knowledge and experience of the NHS, social care and/or public health services as a service user or carer/ family member.		
Proven interpersonal skills and the ability to listen and to express own views about relevant issues in a way that respects the contributions of others and avoids jargon as far as possible.		
Ability to be able to coach and train others, individually or in groups, in the use of techniques that can measure and evaluate improvements.		
Ability to work as part of a group with people from a wide range of different backgrounds.		
Ability to focus on tasks and achieving outcomes.		
Ability to bring relevant knowledge from the perspective of members of the public.		
Ability to draw on personal experiences and work constructively with others towards service improvement.		
A commitment to promoting diversity and equality of opportunity.		
A commitment to prepare fully for meetings.		
Access to the internet and basic IT skills.		
To respect any requests for confidentiality, declare any conflicts of interest if these arise and abide by an agreed code		

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of conduct.		

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3

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Purpose or research question	#4	Purpose of the study and specific objectives or questions	3
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	4
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	5
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4-5
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of	5

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		procedures in response to evolving study findings; rationale	
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	5
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	6-9
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	9-11

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Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network.

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ABSTRACT

Objectives: To identify the roles public contributors undertake to establish their legitimacy in the patient and public involvement (PPI) programme at a health network.

Design: A longitudinal case study with three embedded units (projects) involving public contributors. Interviews (n=24), observations (n=27), and documentary data collection occurred over 16 months.

Setting: The West of England Academic Health Science Network (WEAHSN), one of 15 regional AHSNs in England.

Participants: Interviews were conducted with public contributors (n=5) and professionals (n=19) who were staff from the WEAHSN, its member organisations, and its partners.

Findings: Public contributors established their legitimacy by utilising nine distinct roles: 1) lived experience, as a patient or carer; 2) occupational knowledge, offering job-related expertise; 3) occupational skills, offering aptitude developed through employment; 4) patient advocate, promoting the interests of patients; 5) keeper of the public purse, encouraging wise spending; 6) intuitive public, piloting materials suitable for the general public; 7) fresh-eyed reviewer, critiquing materials; 8) critical friend, critiquing progress and proposing new initiatives; and 9) boundary spanner, urging professionals to work across organisations. Individual public contributors occupied many, but not all, of the roles.

Conclusions: Lived experience is only one of nine distinct public contributor roles. The WEAHSN provided a benign context for the study because in a health network public contributors are one of many parties seeking to establish legitimacy through finding valuable roles. The nine roles can be organised into a typology according to whether the basis for legitimacy lies in: the public contributor's knowledge, skills and experience; citizenship through the aspiration to achieve a broad public good; or being an outsider. The typology shows how public contributors can be involved in work where lived experience appears to lack relevance: strategic decision-making; research unconnected to particular conditions; or acute service delivery.

Key words: Patient and public involvement, roles, legitimacy, network organisations.

ARTICLE SUMMARY

Strengths and limitations of this study

- Adopts an embedded case study design enabling the detailed study of how PPI functions
- Adopts maximum variation sampling to gather data from three WEAHSN projects, each using a different approach to PPI
- Extends the previous literature on public contributor roles using corroborating data collected from interviews, observation and documents.
- Emphasises depth of understanding in a single network, which limits generalisability.

INTRODUCTION

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Patient and public involvement (PPI) initiatives in health have been driven by activists [1], are underpinned by government aspiration[2], funder requirements[3], journal reporting[4], and have a growing international presence[5]. While the requirement for PPI from government or funders provides public contributors with external legitimacy[6], they must establish their own internal legitimacy[7]. Internal legitimacy, comprised of authority and credibility within the organisation, is left to be established. The legitimacy conferred through formal selection to the organisation's involvement programme is unlikely to be sufficient [8]. Internal legitimacy hinges on finding a valuable role. Current PPI literature in research and services focuses on public contributors offering their lived experience of health conditions and is associated with changing outcome measures, improving the quality of research and increasing participant enrolment and retention[9-11].

Public contributors can experience challenges to the legitimacy of their lived experience. Some professionals do not believe in the value of experiential knowledge[12], or consider it legitimate only when public contributors are either representative [13] of or connected to their particular patient group[14]. However, there is no guarantee that public contributors will identify with a patient group, nor do groups necessarily share a broad set of interests[15]. PPI places public contributors in a legitimacy double bind where the involvement admits a few individuals whom professionals are able to denigrate as 'unrepresentative' when they speak for a group, and as 'anecdotal' when they offer their own stories[16].

Identifying PPI solely with lived experience presents difficulties. One is the limit placed on the ambition of public contributors[17,18] and the government[2] to see the public involved in decision making at all levels of the English national health service (NHS). To be involved at the higher levels public contributors need to take on more strategic roles in determining health care agendas and directions. In strategic roles, direct lived experience inevitably becomes less and less relevant to the work at hand. There are difficulties for organisations too. PPI based on lived experience tends to work better in areas such as rheumatology where professionals and public contributors can build long-term relationships[19]. Health delivery organisations serving acute rather than chronic conditions, and those working in fields such as implementation[20] and antimicrobial medicines[5] research all report challenges to involving public contributors on the basis of their lived experience.

The nature of the involving organisation is important as PPI is held to be highly context-specific[10, 19]. The WEAHSN worked directly in neither health research nor health services, but was tasked with speeding the adoption and spread of innovation from research organisations and firms to service organisations. Lived experience appeared to lack relevance in many areas of their work. We characterised the WEAHSN not just as a network, but as a mandated network administrative organisation (NAO)[7, 21, 22], created by government to administer a formal, membership-based network of independent organisations. Thinking of the WEAHSN as an NAO allowed us to consider which elements of the context were instrumental to the findings and to generalise beyond the immediate case.

Previous studies reporting on PPI roles beyond lived experience either examined the involving organisation's work[20] and anticipated the public's potential contribution or captured only the public contributors' perceptions about the roles they

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undertook[23]. One study aimed at exploring power relations in PPI discovered a role for the public as challenging outsiders [24]. This paper addresses a gap in the literature by collecting corroborating observation, interview and documentary data concerning public contributor roles. We define involvement as healthcare projects being carried out ‘with’ or ‘by’ patients and the public[25]; and we present findings showing the range of roles public contributors undertook when lived experience appeared to be of limited relevance. We develop a typology of the roles based on whether they derive legitimacy from: the public contributors’ own knowledge, experience and skills; citizenship; or being an outsider to the organisation. Maximising the value of the opportunity presented by PPI is a significant concern[20, 26, 27] making these findings relevant to organisations, health professionals and public contributors alike.

METHODS

Setting

Established in 2013 as one of 15 regional AHSNs, the WEAHSN operated under an initial five-year licence from the English NHS. The AHSNs had four objectives focusing on: patient needs and local populations; building a culture of partnership and collaboration; speeding up the adoption of healthcare innovations; and creating wealth[28]. The WEAHSN’s membership consisted of 15 NHS and social care providers, seven commissioning bodies, and three universities[29]. The network members collaborated in joint projects in four key work areas: Enterprise and Translation, Patient Safety, Quality Improvement and Informatics. Once the WEAHSN’s board had approved a project as fitting with its remit and a priority for members, it was staffed with individuals representing all the interested organisations.

The Managing Director of the WEAHSN’s strong personal commitment to public involvement resulted in a specific programme manager to administer PPI, organising recruitment and selection, assigning projects, negotiating attendance, and managing resources. The WEAHSN involved 12 public contributors at any one time, assigning them in pairs to the board and to projects. The PPI Manager expected public contributors to take part in strategic projects, rather than deliver lived experience.

Study design

This study formed part of a wider research programme commissioned by the WEAHSN, titled Evidencing the Value of the WEAHSN comprising three case studies focussing on 1) healthcare innovation development, 2) innovation diffusion and 3) PPI. The research programme employed case study as a methodology[30], which allowed the exploration of both context and phenomena. The study viewed PPI as one form of collaboration taking place in a network organisation.

Our research question asked how PPI at the WEAHSN functioned. We hypothesised that the legitimacy of the public contributors was one variable which would influence the effectiveness of the PPI programme. We justified the selection of a longitudinal single case study because of indications that the PPI programme had adopted best practice[31] and was seen as an exemplar[32]. Three projects (embedded subunits) were selected in collaboration with the programme manager to focus on the operational detail of how the PPI worked in practice. We set out to understand the

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basis for the public contributors’ legitimacy through close examination of what happened when they were involved in WEAHSN projects.

Ethics

Ethics approval for this study was obtained from Health and Applied Sciences faculty ethics committee of the University of the West of England on 28th April 2015, reference HAS/15/04/145. All the participants provided informed consent after reading written information sheets. The WEAHSN is a small organisation, so to honour our commitment to anonymity participant descriptions are confined to ‘professional’ or ‘public contributor’.

Patient and Public Involvement

A public contributor was involved in this study from its conception, throughout the process, at regular intervals and is a co-author of this paper (NL). The public contributor suggested additional reading; made changes to the participant information and consent forms; provided a sounding board for ideas; challenged logic; shared the experience of being a public contributor, considered the findings in the light of their own experience; and commented on each draft of the research report.

Data collection

JB, who had no prior connection to the WEAHSN, collected data from three sources (non-participant observation, interview, and document review) in order to triangulate. We regarded evidence corroborated by multiple sources to be the strongest available, and as a way to mitigate the limitations of a single case design[30], and to account for reflexivity[30]. However, we also noted dissenting voices in order to capture the richness available.

Non-participant observations were audio-recorded at every project meeting over the 16 months of the study and then transcribed. In total, data were collected in: 18 meetings for project 1 (P1); three for project 2 (P2); and six for project 3 (P3). Additional contemporaneous notes captured non-verbal events such as when meeting chairs made eye contact with public contributors to bring them into discussions. Of the 24 interviews, 23 were face-to-face and one by telephone. The topic guide used at the interviews (see the supplemental material) did not ask interviewees about legitimacy directly. Instead, the interview questions probed public contributors’ roles, and what factors facilitated and impeded involvement. All interviews were audio-recorded and transcribed. Five out of the six public contributors involved in the projects that formed our sample agreed to be interviewed. We used purposive maximum variation sampling to select professionals for interview [33]. The 19 professional interviewees had attended the observed project meetings, and came from the widest possible range of job responsibility, hierarchical level, and organisation type[34]. The interviews were guided conversations, to reduce the likelihood of collecting data with a bias towards verification[35]. The documentary data sources included the emails, meeting minutes, and papers plus project management documents and marketing materials aimed at the public.

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Analysis

We used the analytic strategy of explanation building, where hypotheses created from the research questions are explored and refined using the data[27]. Employing NVivo 10 to manage the data, all interview and observation recordings were reviewed, each transcript read and data coded using deductive codes established from the definitions adopted from the literature. To facilitate consistency, the coding definitions were printed out and acted as a point of reference throughout coding[33]. Where necessary, coding was simultaneous[33]. The code for legitimacy was the single biggest code with over 500 references at initial coding. The majority of references pertained to the roles undertaken by the public contributors. A second coding exercise reviewed only those references coded to legitimacy. The coded data were developed into written findings using assertions or summary statements crafted to capture large amounts of data[33]. Assertions were first written and then refined until all the evidence from all the data sources collected under a code had been accounted for. The summary assertions account for differences in views between the public contributors and the professionals where these occurred. As well as the summary assertions, the findings section contains direct quotes only from the interviews, as the observational data from large meetings did not lend itself well to extracting quotations.

FINDINGS

The most striking findings related to the valuable roles the public contributors established for themselves, and the way these provided the internal legitimacy left lacking by government and funder mandates. Nine distinct roles were both reported at interview and observed in practice: lived experience, occupational knowledge, occupational skills, patient advocate, keeper of the public purse, intuitive public, fresh-eyed reviewer, critical friend, and boundary spanner. All the public contributors played more than one role during the data collection period (and sometimes more than one role in a single meeting), although none played all nine.

Lived experience

Most professionals and public contributors associated PPI with lived experience. The professionals valued being reminded of what it was like to be a patient. Several professionals assumed that public contributors undertaking this role brought *"other people's views as well as their own"* although only one public contributor reported doing this and another saw it as unnecessary, saying,

> *"Where with the public contributor roles there isn't the necessity to go back to your contacts, your networks if you like, to ask people's opinion."* Public contributor 1, P3

One professional distinguished strategic from lived experience roles in the following way:

> *"…it's quite good to differentiate between people who can participate in an advisory group or a steering group. There's a different type of public contributor that might be more about bringing their lived experience of a condition."* Professional, P1-3

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Observational data revealed that four public contributors drew on their lived experience on five separate occasions, despite not working on projects directly relevant to their own health. For example, one public contributor related their own experience as a carer while giving feedback on a community health programme to train healthcare assistants. Three of the five public contributors interviewed suggested that lived experience conferred the most legitimacy. One interviewee said,

> *"…but I think that…really do they not just get in the way, public contributors of…what needs to be done? Apart from…the ones who have had direct experience of the service."* Public Contributor 1, P2

More than one professional noted that the most helpful comments came from public contributors who could generalise their own experience out to other patients, rather than focussing solely on their own situation, which was sometimes seen as having an *"axe to grind"* or an *"agenda"*.

Occupational knowledge

All the public contributors came to involvement with occupational backgrounds. The professionals acknowledged this, with one saying, *"they might be insurance brokers…or policemen".* Only two public contributors were observed making direct use of their occupational knowledge. One of these noted the value of their marketing knowledge, despite it being regarded as a *"dirty word"* in the NHS. However not every qualified pubic contributor played this role. One public contributor, with a background relevant to their project reported,

> *"I didn't feel that…my professional side was going to be hugely helpful on this project."* Public Contributor 1, P1

Difficulties in playing this role arose when the lines between public contribution and consultancy blurred. A public contributor noted that the WEAHSN *"get me really cheap"*, a reference to the difference between the hourly rate charged as a consultant and that offered by the WEAHSN to recompense public contributors.

One professional reported that the line between public contribution from an expert in a different field and consultancy had caused *"interesting debates within the project"*. Another difficulty arose when the public contributor's occupational background was in health. Some professionals expressed anxiety over whether the voice of the patient was truly reflected.

Occupational Skills

Three public contributors drew on skills acquired through their occupation, rather than direct job-specific knowledge. During one observation, for example, a public contributor introduced themselves as a lawyer, explaining that this gave them an eye for technical detail. This lawyer went on to critique a paper comparing three different training schemes, pointing out that each option had been rated against a different set of criteria. Another public contributor, with a background in marketing, explained that their skills could be used to ensure that the training did not sound *"pompous"* or *"old-*

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fashioned". Whilst two public contributors discussed their occupational skills, none of the professionals reported on this role.

Patient Advocate

Ten participants talked about patient advocacy. One public contributor alluded to the role saying,

> *"You don't have to have lived experience to know that patients don't want to wait too long or that they wanted to be…treated as human beings."* Public Contributor 2, P3

One public contributor was observed playing this role on multiple occasions. Rather than anticipating what other patients wanted, the public contributor advocated for patients to be included in decision making so that they could speak for themselves. For example, the public contributor suggested that work including general practitioners (GPs) should also include each practice's patient participation group. As another example, the same public contributor asked whether patients played any part in harm prevention training.

Keeper of the public purse

The core of this role was overseeing the way public money was spent, to make best use of it in the face of what one public contributor called *"vested interests"*, explaining,

> *"…you are there to make sure that public money, not just money but… resources in general…are being dealt with appropriately I would say."* Public Contributor 2, P3

Two public contributors were observed playing this role, with one in particular concerned to make sure that the NHS didn't spend money creating materials or programmes that already existed elsewhere. On the other hand, one professional described the public's presence as legitimising the spending.

Intuitive public

In this role, public contributors trialled materials or workshops in advance of a launch to the general public. Three public contributors attended the pilot version of a workshop to give feedback about how it ran. Only one project offered the opportunity to play this role because only one project produced materials aimed at the general public. One professional from the project described the legitimacy of the intuitive public saying, *"so I think it's their…knowledge of if you do it like this it probably might reach more people"*. Another described the legitimacy as flowing from the public to the project,

> *"I think it certainly added a lot of legitimacy to the project because…it would be probably a bit cheeky that the citizen led project without any citizens on."* Professional, P1

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However, one professional described this role as *"validation",* suggesting that the public rubber-stamped what would have happened anyway. Playing this role, one public contributor commented that their involvement had *"tailed off"*. The professionals appeared to see the latter stages of the project as the domain of experts, and could not articulate a prolonged role for the public despite an observed discussion at one point that hinged upon what the public might want.

Fresh-eyed reviewer

A public contributor summarised the legitimacy of this role saying,

> *"It's just that I am another pair of eyes in the room and I don't come from the same background."* Public contributor 1, P2

All the public contributors provided review of materials and ideas put before them. They variously described that they enjoyed a freedom not available to professionals; could admit to not knowing something in front of a meeting; or ask seemingly naïve questions. Many professionals valued the views of those unencumbered by NHS organisation structures, language, culture, budgets or timescale. However, if review became the main focus one professional worried that the meeting became a *"showcase"*. One public contributor expressed concern that materials were sometimes sent late in the process, once already finalised, reducing the role to that of merely a *"proof reader"*.

Critical friend

Documentary review showed that the WEAHSN used the term critical friend in the public contributor job description (see supplemental material). On six occasions two public contributors extended the public voice beyond fresh-eyed review of WEAHSN materials and instead proposed new activity or asked new questions. Observed examples included the public contributor asking whether a new approach was a trend or worth investigating and suggesting the next steps for the project. As one participant put it,

> *"You don't have to be an expert at anything to ask the sort of questions that hopefully would make people just sit back and think again."* Public Contributor 1, P3

The legitimacy of a critical friend is demonstrated by the effective way the public contributors held projects to account by comparing progress to the original aims. One professional described a public contributor as saying,

> *"You said you were gonna do this…and…I haven't heard anything about that, so what's happening about it?"* Professional, P3

Boundary spanner

One interviewee talked about this role saying,

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> *"[The] NHS never really changes in terms of how things develop in silos and they're…slow to share and push things forward."* Public Contributor, P3

Two public contributors played this role. One asked a meeting why their area's GPs were not signed up to a primary care initiative. The other took numerous opportunities to advocate for NHS organisations to work with each other, with local councils, and with community organisations. Three separate observations record the public contributor asking the WEAHSN whether they were sharing with and learning from other AHSNs.

DISCUSSION

This study of a single network organisation found more distinct public contributor roles than previous larger studies across multiple settings[23]. The WEAHSN seems to have provided a particularly benign context for public contributors to undertake nine distinct roles. First, lived experience of a health condition appeared to lack direct relevance, with the organisation working directly in neither research nor service delivery. Next, the job description left the nature of the contribution open. Then, like other mandated NAOs, the WEAHSN's government mandate gave it external legitimacy, but not internal legitimacy, compelling the organisation to spend time establishing legitimacy with members by identifying and supporting projects that fitted both its own objectives and its members' interests[21, 7]. Furthermore, the professionals at the WEAHSN played multiple, shifting roles with flexible job content, a common feature of network organisations[36]. In a mandated NAO, the public contributors are just one of many parties who are all attempting to establish legitimacy through finding valuable roles to play, supporting our hypothesis on the importance of legitimacy. Although the context was especially beneficial to their discovery, nothing about the roles suggests they could not operate in other settings, particularly where lived experience appears to lack relevance.

In their search for valuable roles, the public contributors in this study found a surprising number of occasions for drawing on their experiences as patients and carers. In common with the literature, three out of the five public contributors interviewed felt lived experience to be the most legitimate of the roles open to them. Nonetheless, the public contributors also found additional valuable roles on which to establish their legitimacy. The basis of the legitimacy for six of the nine roles can be found in the literature as lying either in claims to knowledge, experience and skill[16] (lived experience, occupational knowledge, and occupational skill), or in citizenship[16] seen here as attempts to realise a greater public good (patient advocate, and keeper of the public purse). The basis of the legitimacy for the final three roles is based in the public contributor as an outsider[37] and both incorporates and breaks down the idea of a role as a 'challenging outsider [24] , able to bring in different perspectives (intuitive public, fresh eyed reviewer, critical friend and boundary spanner). Grouping the roles together, based on the nature of the legitimacy, gives the typology in Table 1.

Table 1 Typology of roles

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Group 1 roles. Legitimacy based on knowledge, experience and skill	**Group 2 roles. Legitimacy based on citizenship**	**Group 3 roles. Legitimacy based on being an outsider**
Lived experience	Patient advocate	Intuitive public
Occupational knowledge	Keeper of the public purse	Fresh-eyed reviewer
Occupational skills		Critical friend
		Boundary spanner

A previous study of 38 public contributors to health research reported six public contributor roles[23] (the expert in lived experience, the creative outsider, the free challenger, the bridger, the motivator, and the passive presence) that can be used to expand the typology in Table 1. Three roles (the expert in lived experience, the creative outsider, and the free challenger) map on to the lived experience, fresh-eyed reviewer and critical friend identified here. The additional three (the bridger, the motivator and the passive presence) can be added to the typology. The motivator increases the enthusiasm and commitment of the professionals. The passive presence reminds the professionals to take the public's perspective into account. Both of these roles base their legitimacy in citizenship through the way each aspires to lead to a public good[38] by changing the behaviour of professionals in positive ways. The bridger aids communication to an outside group, and so legitimacy is based on being an outsider to the involving organisation and simultaneously belonging to or having access to that outside group. The motivator, passive presence and bridger roles are shown in their relevant groups in Table 2.

Table 2 Extending the typology with additional roles identified in the literature[23]

Group 1 roles. Legitimacy based on knowledge, experience and skill.	**Group 2 roles. Legitimacy based on citizenship.**	**Group 3 roles. Legitimacy based on being an outsider.**
	Motivator	Bridger
	Passive presence	

The implications of the typology are wide-ranging. Public contribution is not confined to lived experience. Instead, public contributors draw on a broad set of knowledge, skills and experiences. Public contributors do not need to be representative, either statistically or through being in any sense typical. Knowledge, experience and skills can provide a basis for legitimacy. In addition to drawing on their own background, public contributors can draw on citizenship, without needing to represent others. Broad public good[38], such as achieving the same result with less cost, or operating across organisational boundaries, can be a source of legitimacy in itself. Furthermore, a number of valuable roles can be crafted from being outsiders. The value of the outsider roles does not diminish even if public contributors are experienced to the point of professionalisation: they remain unrestricted by the organisation's boundaries, budgets, and perspectives. The typology goes beyond helping organisations to develop better job descriptions[23], it shows how public contributors can be involved in strategic work, and work unconnected with chronic or even

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specific conditions. The typology provides the basis for a dialogue to maximise the opportunity presented by PPI.

Whilst the limitation of exploring a single network organisation must be acknowledged, our design approach strengthened our study. The use of maximum variation sampling within the case, multiple sources of triangulating evidence, and the extent to which this study builds on themes already evident in the literature strengthen the credibility of our findings. The WEAHSN is characterised as a mandated NAO which provided a beneficial context for the multiple public contributor roles, although nothing suggests the roles are necessarily unique to the setting.

CONCLUSION

The conflation of PPI with lived experience presented a challenge for public contributors and involving organisations alike. The benign context of the WEAHSN, where the public contributors were just one of the parties trying to establish their legitimacy through finding valuable roles, permitted the discovery of nine distinct roles with three broad bases in legitimacy. As well as suggesting network organisations as a fruitful setting for context-cognisant PPI research, the findings demonstrate the potential value of public involvement in settings where lived experience appears to lack relevance. Furthermore, the lost opportunity represented by an exclusive focus on a single role suggests that all involving organisations could benefit from encouraging public contributors to undertake a wide range of roles.

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Extract from the research protocol

Interview question topic guide

-Questions about involvement in the project: -
How were public contributors recruited to the project?
How were public contributors involved in the project?
How did you understand the role of public contributors?
Did the role of public contributors change over time?
What factors facilitated the involvement of public contributors?
What factors impeded the involvement of public contributors?
Did any project team member take a lead in involvement? What was the nature of that lead?
Is there any evidence of the success indicators for PPI: Did the public contributors meet together? Get offered any training? Did they get paid? Contribute to official information? Co-design the initiative? Did they sit on the governing body?
How were decisions made in the project? What was the role of public contributors? Could public contributors influence decision-making?
Anything the participant would like to say about PPI that has not been covered?

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People in Health
West of England
Better involvement · Better research · Better health

West of England
Academic Health
Science Network

West of England Academic Health Science Network
6th Floor, South Plaza, Marlborough Street
Bristol BS1 3NX

Role Profile

[redacted]

1. Background

The West of England Academic Health Science Network (WEAHSN) is a vibrant and diverse network of partners which includes providers of NHS care working with universities, industry, NHS commissioners and a wide range of other organisations.

People & Health West of England (PHWE) aims to share good practice and resources encouraging the involvement and participation of patients and members of the public. It was set up by the WEAHSN, the Collaboration for Applied Health Research and Care (CLAHRC) West, the Clinical Research Network (CRN) and Bristol Health Partners (BHP). This joint approach is unique. By joining the WEAHSN as a public contributor, you will have the opportunity to take part in PHWE and help shape how we take patient and public involvement forward in the region.

2. Main responsibilities

2.1. To act as a critical friend and offer advice and support to the [redacted]

2.2. To contribute to the planning of 6- 8 workshops.

2.3. To respond and comment on the promotional materials being produced by the design company.

2.4. To prepare for and actively participate in weekly phone meetings. This will include reading meeting papers that may be lengthy and/or complex.

2.5. To undertake activities between meetings as mutually agreed. This may include some or all of the following:

- Membership of a project advisory group.
- Attending events organised by the steering group (for example, a seminar or workshop).
- Giving talks or delivering workshops.
- Involvement in other relevant activities as appropriate.

2.6. To promote the work of the West of England Academic Health Science Network to others.

2.7. When appropriate, provide support to new public members.

3. Commitment

The role is for **[Specify period].**

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Working arrangements will be reviewed after an initial trial period of 3 months thereafter the specific time commitment will be identified mutually agreed.

4. Payment and expenses

Payment for time will be [redacted] per hour, which covers the time spent preparing for meetings such as reading minutes and associated papers. Other out of pocket expenses such as travel [redacted] or carer's allowances will be paid in addition.

5. Induction and support

All new public members will be expected to attend an induction session prior to starting to prepare new members for their role and provide practical information about getting involved (for example, style of meetings, format of papers, how to contribute effectively, expenses and payment).

6. Public contributor role requirements

Skill/Experience	Essential	Desirable
Experience of working with others to address common issues of concern.		
Understanding of quality improvement from a public perspective.		
Knowledge and experience of the NHS, social care and/or public health services as a service user or carer/ family member.		
Proven interpersonal skills and the ability to listen and to express own views about relevant issues in a way that respects the contributions of others and avoids jargon as far as possible.		
Ability to be able to coach and train others, individually or in groups, in the use of techniques that can measure and evaluate improvements.		
Ability to work as part of a group with people from a wide range of different backgrounds.		
Ability to focus on tasks and achieving outcomes.		
Ability to bring relevant knowledge from the perspective of members of the public.		
Ability to draw on personal experiences and work constructively with others towards service improvement.		
A commitment to promoting diversity and equality of opportunity.		
A commitment to prepare fully for meetings.		
Access to the internet and basic IT skills.		
To respect any requests for confidentiality, declare any conflicts of interest if these arise and abide by an agreed code		

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of conduct.		

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3

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Purpose or research question	#4	Purpose of the study and specific objectives or questions	3
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	4
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	5
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4-5
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of	5

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		procedures in response to evolving study findings; rationale	
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	5
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	6-9
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	9-11

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Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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BMJ Open

Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network.

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Developing a typology of the roles public contributors undertake to establish legitimacy: a longitudinal case study of patient and public involvement in a health network.

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ABSTRACT

Objective: To identify how public contributors established their legitimacy in the functioning of a Patient and Public Involvement programme at a health network

Design: A longitudinal case study with three embedded units (projects) involving public contributors. Interviews (n=24), observations (n=27), and documentary data collection occurred over 16 months.

Setting: The West of England Academic Health Science Network (WEAHSN), one of 15 regional AHSNs in England.

Participants: Interviews were conducted with public contributors (n=5) and professionals (n=19) who were staff from the WEAHSN, its member organisations, and its partners.

Results: Public contributors established their legitimacy by utilising nine distinct roles: 1) lived experience, as a patient or carer; 2) occupational knowledge, offering job-related expertise; 3) occupational skills, offering aptitude developed through employment; 4) patient advocate, promoting the interests of patients; 5) keeper of the public purse, encouraging wise spending; 6) intuitive public, piloting materials suitable for the general public; 7) fresh-eyed reviewer, critiquing materials; 8) critical friend, critiquing progress and proposing new initiatives; and 9) boundary spanner, urging professionals to work across organisations. Individual public contributors occupied many, but not all, of the roles.

Conclusions: Lived experience is only one of nine distinct public contributor roles. The WEAHSN provided a benign context for the study because in a health network public contributors are one of many parties seeking to establish legitimacy through finding valuable roles. The nine roles can be organised into a typology according to whether the basis for legitimacy lies in: the public contributor's knowledge, skills and experience; citizenship through the aspiration to achieve a broad public good; or being an outsider. The typology shows how public contributors can be involved in work where lived experience appears to lack relevance: strategic decision-making; research unconnected to particular conditions; or acute service delivery.

Key words: Patient and public involvement, roles, legitimacy, network organisations.

ARTICLE SUMMARY

Strengths and limitations of this study

- Adopts an embedded case study design enabling the detailed study of how PPI functions.
- Adopts maximum variation sampling to gather data from three WEAHSN projects, each using a different approach to PPI.
- Extends the previous literature on public contributor roles using corroborating data collected from interviews, observation and documents.
- Emphasises depth of understanding in a single network, which limits generalisability.

INTRODUCTION

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Patient and public involvement (PPI) initiatives in health have been driven by activists [1], are underpinned by government aspiration[2], funder requirements[3], journal reporting[4], and have a growing international presence[5]. While the requirement for PPI from government or funders provides public contributors with external legitimacy[6], they must establish their own internal legitimacy[7]. Internal legitimacy, comprised of authority and credibility within the organisation, is left to be established. The legitimacy conferred through formal selection to the organisation's involvement programme is unlikely to be sufficient [8]. Internal legitimacy hinges on finding a valuable role. Current PPI literature in research and services focuses on public contributors offering their lived experience of health conditions and is associated with changing outcome measures, improving the quality of research and increasing participant enrolment and retention[9-11].

Public contributors can experience challenges to the legitimacy of their lived experience. Some professionals do not believe in the value of experiential knowledge[12], or consider it legitimate only when public contributors are either representative [13] of or connected to their particular patient group[14]. However, there is no guarantee that public contributors will identify with a patient group, nor do groups necessarily share a broad set of interests[15]. PPI places public contributors in a legitimacy double bind where the involvement admits a few individuals whom professionals are able to denigrate as 'unrepresentative' when they speak for a group, and as 'anecdotal' when they offer their own stories[16].

Identifying PPI solely with lived experience presents difficulties. One is the limit placed on the ambition of public contributors[17,18] and the government[2] to see the public involved in decision making at all levels of the English national health service (NHS). To be involved at the higher levels public contributors need to take on more strategic roles in determining health care agendas and directions. In strategic roles, direct lived experience inevitably becomes less and less relevant to the work at hand. There are difficulties for organisations too. PPI based on lived experience tends to work better in areas such as rheumatology where professionals and public contributors can build long-term relationships[19]. Health delivery organisations serving acute rather than chronic conditions, and those working in fields such as implementation[20] and antimicrobial medicines[5] research all report challenges to involving public contributors on the basis of their lived experience.

The nature of the involving organisation is important as PPI is held to be highly context-specific[10, 19]. The WEAHSN worked directly in neither health research nor health services, but was tasked with speeding the adoption and spread of innovation from research organisations and firms to service organisations. Lived experience appeared to lack relevance in many areas of their work. We characterised the WEAHSN not just as a network, but as a mandated network administrative organisation (NAO)[7, 21, 22], created by government to administer a formal, membership-based network of independent organisations. Thinking of the WEAHSN as an NAO allowed us to consider which elements of the context were instrumental to the results and to generalise beyond the immediate case.

Our study's objective was to identify how public contributors establish their legitimacy in the functioning of the WEAHSN's PPI programme. Previous studies reporting on valuable PPI roles beyond lived experience either examined the

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involving organisation's work[20] and anticipated the public's potential contribution or captured only the public contributors' perceptions about the roles they undertook[23]. One study aimed at exploring power relations in PPI discovered a role for the public as challenging outsiders [24]. This paper addresses a gap in the literature by collecting corroborating observation, interview and documentary data concerning public contributor roles. We define involvement as healthcare projects being carried out 'with' or 'by' patients and the public[25]; and we present results showing the range of roles public contributors undertook when lived experience appeared to be of limited relevance. We develop a typology of the roles based on whether they derive legitimacy from: the public contributors' own knowledge, experience and skills; citizenship; or being an outsider to the organisation. Maximising the value of the opportunity presented by PPI is a significant concern[20, 26, 27] making these results relevant to organisations, health professionals and public contributors alike.

METHODS

Setting

Established in 2013 as one of 15 regional AHSNs, the WEAHSN operated under an initial five-year licence from the English NHS. The AHSNs had four objectives focusing on: patient needs and local populations; building a culture of partnership and collaboration; speeding up the adoption of healthcare innovations; and creating wealth[28]. The WEAHSN's membership consisted of 15 NHS and social care providers, seven commissioning bodies, and three universities[29]. The network members collaborated in joint projects in four key work areas: Enterprise and Translation, Patient Safety, Quality Improvement and Informatics. Once the WEAHSN's board had approved a project as fitting with its remit and a priority for members, it was staffed with individuals representing all the interested organisations.

The Managing Director of the WEAHSN's strong personal commitment to public involvement resulted in a specific programme manager to administer PPI, organising recruitment and selection, assigning projects, negotiating attendance, and managing resources. The WEAHSN involved 12 public contributors at any one time, assigning them in pairs to the board and to projects. The PPI Manager expected public contributors to take part in strategic projects, rather than deliver lived experience.

Study design

This study formed part of a wider research programme commissioned by the WEAHSN, titled Evidencing the Value of the WEAHSN comprising three case studies focussing on 1) healthcare innovation development, 2) innovation diffusion and 3) PPI. The research programme employed case study as a methodology[30], which allowed the exploration of both context and phenomena. The study viewed PPI as one form of collaboration taking place in a network organisation.

We justified the selection of a longitudinal single case study because of indications that the PPI programme had adopted best practice[31] and was seen as an exemplar[32]. Three projects (embedded subunits) were selected in collaboration with the programme manager to focus on the operational detail of how the PPI worked in practice. We set out to understand the basis for the public contributors' legitimacy

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through close examination of what happened when they were involved in WEAHSN projects.

Ethics

Ethics approval for this study was obtained from Health and Applied Sciences faculty ethics committee of the University of the West of England on 28th April 2015, reference HAS/15/04/145. All the participants provided informed consent after reading written information sheets. The WEAHSN is a small organisation, so to honour our commitment to anonymity participant descriptions are confined to 'professional' or 'public contributor'.

Patient and Public Involvement

A public contributor was involved in this study from its conception, throughout the process, at regular intervals and is a co-author of this paper (NL). The public contributor suggested additional reading; made changes to the participant information and consent forms; provided a sounding board for ideas; challenged logic; shared the experience of being a public contributor, considered the results in the light of their own experience; and commented on each draft of the research report.

Data collection

JB, who had no prior connection to the WEAHSN, collected data from three sources (non-participant observation, interview, and document review) in order to triangulate. We regarded evidence corroborated by multiple sources to be the strongest available, and as a way to mitigate the limitations of a single case design[30], and to account for reflexivity[30]. However, we also noted dissenting voices in order to capture the richness available.

Non-participant observations were audio-recorded at every project meeting over the 16 months of the study and then transcribed. In total, data were collected in: 18 meetings for project 1 (P1); three for project 2 (P2); and six for project 3 (P3). Additional contemporaneous notes captured non-verbal events such as when meeting chairs made eye contact with public contributors to bring them into discussions. Of the 24 interviews, 23 were face-to-face and one by telephone. The topic guide used at the interviews (see the supplemental material) did not ask interviewees about legitimacy directly. Instead, the interview questions probed public contributors' roles, and what factors facilitated and impeded involvement. All interviews were audio-recorded and transcribed. Five out of the six public contributors involved in the projects that formed our sample agreed to be interviewed. We used purposive maximum variation sampling to select professionals for interview [33]. The 19 professional interviewees had attended the observed project meetings, and came from the widest possible range of job responsibility, hierarchical level, and organisation type[34]. The interviews were guided conversations, to reduce the likelihood of collecting data with a bias towards verification[35]. The documentary data sources included the emails, meeting minutes, and papers plus project management documents and marketing materials aimed at the public.

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Analysis

We used the analytic strategy of explanation building, where the research objective is explored and refined using the data[27]. Employing NVivo 10 to manage the data, all interview and observation recordings were reviewed, each transcript read and data coded using deductive codes established from the definitions adopted from the literature. To facilitate consistency, the coding definitions were printed out and acted as a point of reference throughout coding[33]. Where necessary, coding was simultaneous[33]. The code for legitimacy was the single biggest code with over 500 references at initial coding. The majority of references pertained to the roles undertaken by the public contributors. A second coding exercise reviewed only those references coded to legitimacy. The coded data were developed into written results using summary statements crafted to capture the large amounts of data related to roles[33]. Summary statements relating to the nine roles were first written and then refined until all the evidence from all the data sources collected under a code had been accounted for. The summary statements accounted for differences in views between the public contributors and the professionals where these occurred. As well as the summary statements, the results section contains direct quotes only from the interviews, as the observational data from large meetings did not lend itself well to extracting quotations.

RESULTS

The most striking results related to the number of valuable roles the public contributors established for themselves, and the way these provided the internal legitimacy left lacking by government and funder mandates. Nine distinct roles were both reported at interview and observed in practice: lived experience, occupational knowledge, occupational skills, patient advocate, keeper of the public purse, intuitive public, fresh-eyed reviewer, critical friend, and boundary spanner. All the public contributors played more than one role during the data collection period (and sometimes more than one role in a single meeting), although none played all nine.

Lived experience

Most professionals and public contributors associated PPI with lived experience. The professionals valued being reminded of what it was like to be a patient. Several professionals assumed that public contributors undertaking this role brought *"other people's views as well as their own"* although only one public contributor reported doing this and another saw it as unnecessary, saying,

> *"Where with the public contributor roles there isn't the necessity to go back to your contacts, your networks if you like, to ask people's opinion."* Public contributor 1, P3

One professional distinguished strategic from lived experience roles in the following way:

> *"…it's quite good to differentiate between people who can participate in an advisory group or a steering group. There's a different type of public*

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> *contributor that might be more about bringing their lived experience of a condition."* Professional, P1-3

Observational data revealed that four public contributors drew on their lived experience on five separate occasions, despite not working on projects directly relevant to their own health. For example, one public contributor related their own experience as a carer while giving feedback on a community health programme to train healthcare assistants. Three of the five public contributors interviewed suggested that lived experience conferred the most legitimacy. One interviewee said,

> *"…but I think that…really do they not just get in the way, public contributors of…what needs to be done? Apart from…the ones who have had direct experience of the service."* Public Contributor 1, P2

More than one professional noted that the most helpful comments came from public contributors who could generalise their own experience out to other patients, rather than focussing solely on their own situation, which was sometimes seen as having an *"axe to grind"* or an *"agenda"*.

Occupational knowledge

All the public contributors came to involvement with occupational backgrounds. The professionals acknowledged this, with one saying, *"they might be insurance brokers…or policemen".* Only two public contributors were observed making direct use of their occupational knowledge. One of these noted the value of their marketing knowledge, despite it being regarded as a *"dirty word"* in the NHS. However not every qualified pubic contributor played this role. One public contributor, with a background relevant to their project reported,

> *"I didn't feel that…my professional side was going to be hugely helpful on this project."* Public Contributor 1, P1

Difficulties in playing this role arose when the lines between public contribution and consultancy blurred. A public contributor noted that the WEAHSN *"get me really cheap"*, a reference to the difference between the hourly rate charged as a consultant and that offered by the WEAHSN to recompense public contributors.

One professional reported that the line between public contribution from an expert in a different field and consultancy had caused *"interesting debates within the project"*. Another difficulty arose when the public contributor's occupational background was in health. Some professionals expressed anxiety over whether the voice of the patient was truly reflected.

Occupational Skills

Three public contributors drew on skills acquired through their occupation, rather than direct job-specific knowledge. During one observation, for example, a public contributor introduced themselves as a lawyer, explaining that this gave them an eye for technical detail. This lawyer went on to critique a paper comparing three different training schemes, pointing out that each option had been rated against a different set

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of criteria. Another public contributor, with a background in marketing, explained that their skills could be used to ensure that the training did not sound *"pompous"* or *"old-fashioned"*. Whilst two public contributors discussed their occupational skills, none of the professionals reported on this role.

Patient Advocate

Ten participants talked about patient advocacy. One public contributor alluded to the role saying,

> *"You don't have to have lived experience to know that patients don't want to wait too long or that they wanted to be…treated as human beings."* Public Contributor 2, P3

One public contributor was observed playing this role on multiple occasions. Rather than anticipating what other patients wanted, the public contributor advocated for patients to be included in decision making so that they could speak for themselves. For example, the public contributor suggested that work including general practitioners (GPs) should also include each practice's patient participation group. As another example, the same public contributor asked whether patients played any part in harm prevention training.

Keeper of the public purse

The core of this role was overseeing the way public money was spent, to make best use of it in the face of what one public contributor called *"vested interests"*, explaining,

> *"…you are there to make sure that public money, not just money but… resources in general…are being dealt with appropriately I would say."* Public Contributor 2, P3

Two public contributors were observed playing this role, with one in particular concerned to make sure that the NHS didn't spend money creating materials or programmes that already existed elsewhere. On the other hand, one professional described the public's presence as legitimising the spending.

Intuitive public

In this role, public contributors trialled materials or workshops in advance of a launch to the general public. Three public contributors attended the pilot version of a workshop to give feedback about how it ran. Only one project offered the opportunity to play this role because only one project produced materials aimed at the general public. One professional from the project described the legitimacy of the intuitive public saying, *"so I think it's their…knowledge of if you do it like this it probably might reach more people"*. Another described the legitimacy as flowing from the public to the project,

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> *"I think it certainly added a lot of legitimacy to the project because…it would be probably a bit cheeky that the citizen led project without any citizens on."* Professional, P1

However, one professional described this role as *"validation",* suggesting that the public rubber-stamped what would have happened anyway. Playing this role, one public contributor commented that their involvement had *"tailed off"*. The professionals appeared to see the latter stages of the project as the domain of experts, and could not articulate a prolonged role for the public despite an observed discussion at one point that hinged upon what the public might want.

Fresh-eyed reviewer

A public contributor summarised the legitimacy of this role saying,

> *"It's just that I am another pair of eyes in the room and I don't come from the same background."* Public contributor 1, P2

All the public contributors provided review of materials and ideas put before them. They variously described that they enjoyed a freedom not available to professionals; could admit to not knowing something in front of a meeting; or ask seemingly naïve questions. Many professionals valued the views of those unencumbered by NHS organisation structures, language, culture, budgets or timescale. However, if review became the main focus one professional worried that the meeting became a *"showcase"*. One public contributor expressed concern that materials were sometimes sent late in the process, once already finalised, reducing the role to that of merely a *"proof reader"*.

Critical friend

Documentary review showed that the WEAHSN used the term critical friend in the public contributor job description (see supplemental material). On six occasions two public contributors extended the public voice beyond fresh-eyed review of WEAHSN materials and instead proposed new activity or asked new questions. Observed examples included the public contributor asking whether a new approach was a trend or worth investigating and suggesting the next steps for the project. As one participant put it,

> *"You don't have to be an expert at anything to ask the sort of questions that hopefully would make people just sit back and think again."* Public Contributor 1, P3

The legitimacy of a critical friend is demonstrated by the effective way the public contributors held projects to account by comparing progress to the original aims. One professional described a public contributor as saying,

> *"You said you were gonna do this…and…I haven't heard anything about that, so what's happening about it?"* Professional, P3

Boundary spanner

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One interviewee talked about this role saying,

> *"[The] NHS never really changes in terms of how things develop in silos and they're…slow to share and push things forward."* Public Contributor, P3

Two public contributors played this role. One asked a meeting why their area's GPs were not signed up to a primary care initiative. The other took numerous opportunities to advocate for NHS organisations to work with each other, with local councils, and with community organisations. Three separate observations record the public contributor asking the WEAHSN whether they were sharing with and learning from other AHSNs.

DISCUSSION

This study of a single network organisation found more distinct public contributor roles than previous larger studies across multiple settings[23]. The WEAHSN seems to have provided a particularly benign context for public contributors to undertake nine distinct roles. First, lived experience of a health condition appeared to lack direct relevance, with the organisation working directly in neither research nor service delivery. Next, the job description left the nature of the contribution open. Then, like other mandated NAOs, the WEAHSN's government mandate gave it external legitimacy, but not internal legitimacy, compelling the organisation to spend time establishing legitimacy with members by identifying and supporting projects that fitted both its own objectives and its members' interests[21, 7]. Furthermore, the professionals at the WEAHSN played multiple, shifting roles with flexible job content, a common feature of network organisations[36]. In a mandated NAO, the public contributors are just one of many parties who are all attempting to establish legitimacy through finding valuable roles to play, supporting our hypothesis on the importance of legitimacy. Although the context was especially beneficial to their discovery, nothing about the roles suggests they could not operate in other settings, particularly where lived experience appears to lack relevance.

In their search for valuable roles, the public contributors in this study found a surprising number of occasions for drawing on their experiences as patients and carers. In common with the literature, three out of the five public contributors interviewed felt lived experience to be the most legitimate of the roles open to them. Nonetheless, the public contributors also found additional valuable roles on which to establish their legitimacy. The basis of the legitimacy for six of the nine roles can be found in the literature as lying either in claims to knowledge, experience and skill[16] (lived experience, occupational knowledge, and occupational skill), or in citizenship[16] seen here as attempts to realise a greater public good (patient advocate, and keeper of the public purse). The basis of the legitimacy for the final three roles is based in the public contributor as an outsider[37] and both incorporates and breaks down the idea of a role as a 'challenging outsider' [24] , able to bring in different perspectives (intuitive public, fresh eyed reviewer, critical friend and boundary spanner). Grouping the roles together, based on the nature of the legitimacy, gives the typology in Table 1.

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Table 1 Typology of roles

Group 1 roles. Legitimacy based on knowledge, experience and skill	Group 2 roles. Legitimacy based on citizenship	Group 3 roles. Legitimacy based on being an outsider
Lived experience	Patient advocate	Intuitive public
Occupational knowledge	Keeper of the public purse	Fresh-eyed reviewer
Occupational skills		Critical friend
		Boundary spanner

A previous study of 38 public contributors to health research reported six public contributor roles[23] (the expert in lived experience, the creative outsider, the free challenger, the bridger, the motivator, and the passive presence) that can be used to expand the typology in Table 1. Three roles (the expert in lived experience, the creative outsider, and the free challenger) map on to the lived experience, fresh-eyed reviewer and critical friend identified here. The additional three (the bridger, the motivator and the passive presence) can be added to the typology. The motivator increases the enthusiasm and commitment of the professionals. The passive presence reminds the professionals to take the public's perspective into account. Both of these roles base their legitimacy in citizenship through the way each aspires to lead to a public good[38] by changing the behaviour of professionals in positive ways. The bridger aids communication to an outside group, and so legitimacy is based on being an outsider to the involving organisation and simultaneously belonging to or having access to that outside group. The motivator, passive presence and bridger roles are shown in their relevant groups in Table 2.

Table 2 Extending the typology with additional roles identified in the literature[23]

Group 1 roles. Legitimacy based on knowledge, experience and skill.	Group 2 roles. Legitimacy based on citizenship.	Group 3 roles. Legitimacy based on being an outsider.
	Motivator	Bridger
	Passive presence	

The implications of the typology are wide-ranging. Public contribution is not confined to lived experience. Instead, public contributors draw on a broad set of knowledge, skills and experiences. Public contributors do not need to be representative, either statistically or through being in any sense typical. Knowledge, experience and skills can provide a basis for legitimacy. In addition to drawing on their own background, public contributors can draw on citizenship, without needing to represent others. Broad public good[38], such as achieving the same result with less cost, or operating across organisational boundaries, can be a source of legitimacy in itself. Furthermore, a number of valuable roles can be crafted from being outsiders. The value of the outsider roles does not diminish even if public contributors are experienced to the point of professionalisation: they remain unrestricted by the organisation's boundaries, budgets, and perspectives. The typology goes beyond helping

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organisations to develop better job descriptions[23], it shows how public contributors can be involved in strategic work, and work unconnected with chronic or even specific conditions. The typology provides the basis for a dialogue to maximise the opportunity presented by PPI.

Whilst the limitation of exploring a single network organisation must be acknowledged, our design approach strengthened our study. The use of maximum variation sampling within the case, multiple sources of triangulating evidence, and the extent to which this study builds on themes already evident in the literature strengthen the credibility of our results. The WEAHSN is characterised as a mandated NAO which provided a beneficial context for the multiple public contributor roles, although nothing suggests the roles are necessarily unique to the setting.

CONCLUSION

The conflation of PPI with lived experience presented a challenge for public contributors and involving organisations alike. The benign context of the WEAHSN, where the public contributors were just one of the parties trying to establish their legitimacy through finding valuable roles, permitted the discovery of nine distinct roles with three broad bases in legitimacy. As well as suggesting network organisations as a fruitful setting for context-cognisant PPI research, the results demonstrate the potential value of public involvement in settings where lived experience appears to lack relevance. Furthermore, the lost opportunity represented by an exclusive focus on a single role suggests that all involving organisations could benefit from encouraging public contributors to undertake a wide range of roles.

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Conflict of interest: None

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Extract from the research protocol

Interview question topic guide

-Questions about involvement in the project: -
How were public contributors recruited to the project?
How were public contributors involved in the project?
How did you understand the role of public contributors?
Did the role of public contributors change over time?
What factors facilitated the involvement of public contributors?
What factors impeded the involvement of public contributors?
Did any project team member take a lead in involvement? What was the nature of that lead?
Is there any evidence of the success indicators for PPI: Did the public contributors meet together? Get offered any training? Did they get paid? Contribute to official information? Co-design the initiative? Did they sit on the governing body?
How were decisions made in the project? What was the role of public contributors? Could public contributors influence decision-making?
Anything the participant would like to say about PPI that has not been covered?

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Academic Health
Science Network

West of England Academic Health Science Network
6th Floor, South Plaza, Marlborough Street
Bristol BS1 3NX

Role Profile

[redacted]

1. Background

The West of England Academic Health Science Network (WEAHSN) is a vibrant and diverse network of partners which includes providers of NHS care working with universities, industry, NHS commissioners and a wide range of other organisations.

People & Health West of England (PHWE) aims to share good practice and resources encouraging the involvement and participation of patients and members of the public. It was set up by the WEAHSN, the Collaboration for Applied Health Research and Care (CLAHRC) West, the Clinical Research Network (CRN) and Bristol Health Partners (BHP). This joint approach is unique. By joining the WEAHSN as a public contributor, you will have the opportunity to take part in PHWE and help shape how we take patient and public involvement forward in the region.

2. Main responsibilities

2.1. To act as a critical friend and offer advice and support to the [redacted]

2.2. To contribute to the planning of 6- 8 workshops.

2.3. To respond and comment on the promotional materials being produced by the design company.

2.4. To prepare for and actively participate in weekly phone meetings. This will include reading meeting papers that may be lengthy and/or complex.

2.5. To undertake activities between meetings as mutually agreed. This may include some or all of the following:

- Membership of a project advisory group.
- Attending events organised by the steering group (for example, a seminar or workshop).
- Giving talks or delivering workshops.
- Involvement in other relevant activities as appropriate.

2.6. To promote the work of the West of England Academic Health Science Network to others.

2.7. When appropriate, provide support to new public members.

3. Commitment

The role is for **[Specify period].**

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Working arrangements will be reviewed after an initial trial period of 3 months thereafter the specific time commitment will be identified mutually agreed.

4. Payment and expenses

Payment for time will be [redacted] per hour, which covers the time spent preparing for meetings such as reading minutes and associated papers. Other out of pocket expenses such as travel [redacted] or carer's allowances will be paid in addition.

5. Induction and support

All new public members will be expected to attend an induction session prior to starting to prepare new members for their role and provide practical information about getting involved (for example, style of meetings, format of papers, how to contribute effectively, expenses and payment).

6. Public contributor role requirements

Skill/Experience	Essential	Desirable
Experience of working with others to address common issues of concern.		
Understanding of quality improvement from a public perspective.		
Knowledge and experience of the NHS, social care and/or public health services as a service user or carer/ family member.		
Proven interpersonal skills and the ability to listen and to express own views about relevant issues in a way that respects the contributions of others and avoids jargon as far as possible.		
Ability to be able to coach and train others, individually or in groups, in the use of techniques that can measure and evaluate improvements.		
Ability to work as part of a group with people from a wide range of different backgrounds.		
Ability to focus on tasks and achieving outcomes.		
Ability to bring relevant knowledge from the perspective of members of the public.		
Ability to draw on personal experiences and work constructively with others towards service improvement.		
A commitment to promoting diversity and equality of opportunity.		
A commitment to prepare fully for meetings.		
Access to the internet and basic IT skills.		
To respect any requests for confidentiality, declare any conflicts of interest if these arise and abide by an agreed code		

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of conduct.		

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Reporting checklist for qualitative study.

Based on the SRQR guidelines.

Instructions to authors

Complete this checklist by entering the page numbers from your manuscript where readers will find each of the items listed below.

Your article may not currently address all the items on the checklist. Please modify your text to include the missing information. If you are certain that an item does not apply, please write "n/a" and provide a short explanation.

Upload your completed checklist as an extra file when you submit to a journal.

In your methods section, say that you used the SRQRreporting guidelines, and cite them as:

O'Brien BC, Harris IB, Beckman TJ, Reed DA, Cook DA. Standards for reporting qualitative research: a synthesis of recommendations. Acad Med. 2014;89(9):1245-1251.

		Reporting Item	Page Number
Title			
	#1	Concise description of the nature and topic of the study identifying the study as qualitative or indicating the approach (e.g. ethnography, grounded theory) or data collection methods (e.g. interview, focus group) is recommended	1
Abstract			
	#2	Summary of the key elements of the study using the abstract format of the intended publication; typically includes background, purpose, methods, results and conclusions	2
Introduction			
Problem formulation	#3	Description and signifcance of the problem / phenomenon studied: review of relevant theory and empirical work; problem statement	3

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Purpose or research question	#4	Purpose of the study and specific objectives or questions	3
Methods			
Qualitative approach and research paradigm	#5	Qualitative approach (e.g. ethnography, grounded theory, case study, phenomenolgy, narrative research) and guiding theory if appropriate; identifying the research paradigm (e.g. postpositivist, constructivist / interpretivist) is also recommended; rationale. The rationale should briefly discuss the justification for choosing that theory, approach, method or technique rather than other options available; the assumptions and limitations implicit in those choices and how those choices influence study conclusions and transferability. As appropriate the rationale for several items might be discussed together.	4
Researcher characteristics and reflexivity	#6	Researchers' characteristics that may influence the research, including personal attributes, qualifications / experience, relationship with participants, assumptions and / or presuppositions; potential or actual interaction between researchers' characteristics and the research questions, approach, methods, results and / or transferability	5
Context	#7	Setting / site and salient contextual factors; rationale	4
Sampling strategy	#8	How and why research participants, documents, or events were selected; criteria for deciding when no further sampling was necessary (e.g. sampling saturation); rationale	4
Ethical issues pertaining to human subjects	#9	Documentation of approval by an appropriate ethics review board and participant consent, or explanation for lack thereof; other confidentiality and data security issues	4-5
Data collection methods	#10	Types of data collected; details of data collection procedures including (as appropriate) start and stop dates of data collection and analysis, iterative process, triangulation of sources / methods, and modification of	5

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		procedures in response to evolving study findings; rationale	
Data collection instruments and technologies	#11	Description of instruments (e.g. interview guides, questionnaires) and devices (e.g. audio recorders) used for data collection; if / how the instruments(s) changed over the course of the study	5
Units of study	#12	Number and relevant characteristics of participants, documents, or events included in the study; level of participation (could be reported in results)	4
Data processing	#13	Methods for processing data prior to and during analysis, including transcription, data entry, data management and security, verification of data integrity, data coding, and anonymisation / deidentification of excerpts	5
Data analysis	#14	Process by which inferences, themes, etc. were identified and developed, including the researchers involved in data analysis; usually references a specific paradigm or approach; rationale	5
Techniques to enhance trustworthiness	#15	Techniques to enhance trustworthiness and credibility of data analysis (e.g. member checking, audit trail, triangulation); rationale	5
Results/findings			
Syntheses and interpretation	#16	Main findings (e.g. interpretations, inferences, and themes); might include development of a theory or model, or integration with prior research or theory	6-9
Links to empirical data	#17	Evidence (e.g. quotes, field notes, text excerpts, photographs) to substantiate analytic findings	6-9
Discussion			
Intergration with prior work, implications, transferability and contribution(s) to the field	#18	Short summary of main findings; explanation of how findings and conclusions connect to, support, elaborate on, or challenge conclusions of earlier scholarship; discussion of scope of application / generalizability; identification of unique contributions(s) to scholarship in a discipline or field	9-11

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Limitations	#19	Trustworthiness and limitations of findings	11
Other			
Conflicts of interest	#20	Potential sources of influence of perceived influence on study conduct and conclusions; how these were managed	12
Funding	#21	Sources of funding and other support; role of funders in data collection, interpretation and reporting	12

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