Author details:

Dr Emma Craddock, Birmingham City University

Email: Emma.craddock@bcu.ac.uk

Twitter: @emmacraddock89

ORCiD: **0000-0003-1292-8001**

Author Bio:

Dr Emma Craddock is a Senior Lecturer in Health Research at Birmingham City University. Emma's research monograph, based on her PhD research *Living Against Austerity: A Feminist Investigation of Doing Activism and Being Activist* was published in 2020. Her post-doctoral research focuses on a feminist exploration of women's experiences of health and healthcare services, with a focus on community engagement and social justice.

A Qualitative UK Study Exploring Counterpublic Engagement of marginalised women via a Women's Health Network

Keywords: women; public engagement; marginalized populations; community development; United Kingdom; public sphere; PPI

Lay Summary

Public engagement in health is at the forefront of policy and research. The need for engagement with diverse and particularly marginalised groups who face increased health inequalities has been recognised in recent years. Yet, there is a lack of research that focuses on women and particularly marginalised women. This article presents data from semi-structured interviews with members of the Women's Health Network (WHN) in Bradford, one of the most deprived areas of England. WHN is a collective of women who aim to improve the health and wellbeing of women and their families, with a particular focus on seldom heard voices. It explores how engagement of marginalised women and their communities occurs in practice, with this network of public, statutory, voluntary and community services, functioning as a bridge that connects local marginalised women and professional services. It is acknowledged that direct participation of marginalised women is limited but that despite this, WHN's bridging model of public engagement is successful at amplifying lesser heard women's voices by providing a two-way channel of communication between marginalised women and healthcare professionals. The diversity of WHN's membership is central to enabling real representation of marginalised women and their communities.

Abstract

Public engagement is at the forefront of health policy and research. The need for engagement with diverse groups and particularly marginalised groups who face increased health inequalities has been recognised. Yet, there is a lack of research that focuses on marginalised women. This article presents data from semi-structured interviews with members of a Women's Health Network (WHN) in Bradford, one of the most deprived areas of England. WHN is a collective of women who aim to improve women and their families' health, with a particular focus on seldom heard voices. This article critically explores what realistic, representative counterpublic engagement looks like. It reveals the tension between the ideal of public engagement (direct participation) and what happens in practice. Challenges for direct participation of marginalised groups in formal structures require alternative solutions. It is argued that WHN provides an alternative model of counterpublic engagement by bridging the gap between 'seldom heard' women and healthcare providers. WHN creates and sustains a discursive space between subaltern counterpublics and official public spheres, enabling two-way communication. Furthermore, this article problematises the terms 'seldom heard' and 'professionals' for assuming homogeneity and masking diversity. It is argued that WHN's bridging model of subaltern counterpublic engagement is successful at amplifying women's voices and promoting women's health because of the network's diverse membership and reach. This diversity enables authentic representation of varied communities and the discursive movement of issues relating to women's health. WHN thus offers a transferable model of counterpublic engagement in the absence of direct participation.

Introduction

Research in healthcare has historically neglected to take into account women's lived experiences of health and illness. Women have been underrepresented in medical trials. Health conditions that specifically affect women are under-researched and misunderstood (Criado Perez, 2019; Howard et. al., 2017). This has resulted in a lack of sex-disaggregated data and phenomena such as the "Yentl syndrome" (Healy, 1991) where women are misdiagnosed and poorly treated unless their symptoms or diseases mirror those of men. This neglect of women's health is a global issue, reflecting the traditional patriarchal roots of medicine and constitutes an infringement of human rights and equality law. The European Convention on Human Rights, Article 14 sets out the right to not be discriminated against on grounds that include sex. Similarly, the UK's Equality Act 2010, Section 4 lists sex as a protected characteristic. Marmot (2007: 1155) asserts that: "the differential status of men and women in almost every society is perhaps the most pervasive and entrenched inequity. As such, the relation between the sexes represents as pressing a societal issue for health as the social gradient itself." *Health Equity In England: The Marmot Review 10 Years On* (2020) identifies a decrease in women's life expectancy in the most deprived areas of England, evidencing the need to pay attention to women's increasing health inequalities. Women's health promotion is therefore an issue of international significance which affects half of the world's population and is underpinned by a commitment to ensuring women's human rights and equality, challenging patriarchal foundations of healthcare institutions, and gendered health inequalities.

Patient and Public Involvement (PPI) and Public Engagement in Health

Patient and Public Involvement (PPI) in health has increasingly been recognised on an international level as central to health education, promotion, service design and delivery, and research. The World Health Organization (2016) highlight the value of patient engagement for patient safety, process, systems, and policy improvement. Whilst there are various definitions of patient and public involvement, the underlying themes are "the facilitation and strengthening of the role of those using services as coproducers of health, and health care policy and practice" (WHO, 2016: 6). Thus, patients and the public are recognised as not only knowledge consumers but knowledge producers, who are key stakeholders in healthcare processes and policies, and who possess legitimate knowledge that is a rich source for health education, promotion, and processes.

Although PPI and public engagement are often used interchangeably, there is an important distinction to be made between patients, who are individual service users, and the public, a collective of citizens (Fredriksson and Tritter, 2016: 95). Moreover, the common conceptualisation of the public as an homogenous singular entity masks diversity and has been critiqued by feminist scholars as a myth. Fraser (1992) contends that multiple publics exist, with subaltern counterpublics emerging in response and opposition to official public spheres (the social and political discursive spaces that impact on decision-making). Subaltern counterpublics function as discursive arenas "where members of subordinated social groups invent and circulate counter discourses to formulate oppositional interpretations of their identities, interests, and needs" (Fraser, 1992: 123). This challenges the notion of a singular, united public sphere and draws attention to the exclusions of dominant public spheres. Similarly, Benhabib (1992) critiques the historical distinction drawn between public and private issues as gendered and relegating women's issues to the private sphere. Invoking

Fraser’s (1992) notion of subaltern counterpublics, Behabib (1992) argues for the creation of women’s counterpublics that dissolve the boundaries between traditionally private and public issues and encourage feminist discourse. Following this theoretical framework, in the arena of health, women and marginalised groups of women, can be considered to constitute subaltern counterpublics. ‘Marginalised women’ refers to women who face axes of multiple oppression alongside sex such as ethnicity, socioeconomic class, sexuality, disability, age, migrant status. It is engagement with such subaltern counterpublics that this article focuses on, specifically the discursive movement of topics between subaltern counterpublics of marginalised women and official public spheres comprising healthcare commissioners and providers.

While patient and public engagement is considered important in all countries, “the relative priority placed on this concept and the manner in which it is done still differs widely at present.” (WHO, 2016: 5). There is scope, therefore, for illuminating specific strategies of (counter)public engagement in particular contexts, with the aim of better understanding how such processes operate in different locations, and highlighting any lessons that can be transferred to other contexts. This article’s data and analysis is focused on the geographical context of England, UK. It is intended that providing detailed analysis will provide findings and implications that can be transferred to and compared with other international contexts.

In the UK, recent PPI initiatives have emphasised the need to invest in partnerships that ‘have an ongoing dialogue and avoid tokenism’ to prevent the replication of existing health inequalities and exclusions (National Health Service [NHS], 2017: 7). NHS England’s (2017) statutory guidance for clinical commissioning groups emphasises seeking involvement from those with protected characteristics under the Equality Act 2010. This includes sex alongside age, disability, gender reassignment, marriage and civil partnership, pregnancy and maternity, race, religion or belief, and sexual orientation. Yet, there is a lack of research focusing on women’s and disadvantaged groups’ involvement in PPI initiatives (SERIO, 2018: 34; Stokes et al., 2015). This gap is not specific to the UK context; Kamaraju et al.s’ (2016) study of culturally competent breast health education in community outreach in the USA highlights the need for PPI that engages women facing multiple barriers. Such axes of multiple oppression might include, alongside sex: ethnicity, socioeconomic class, sexuality, disability, age. This article contributes to filling this gap in the literature by providing in-depth description and analysis of a women’s health network in a deprived area of England to consider the extent to which marginalised women are engaged with and represented. It reveals how counterpublic engagement operates on the ground and the challenges of creating and sustaining authentic, direct, participation of marginalised women.

While the majority of studies about community engagement focus on “the community part of the participation rather than professional and organisational part of the mutual collaborations” (Bahraminejad et al., 2014: 964), this article draws on interviews with mostly professional key informants to consider processes of counterpublic engagement from the professional and organisational perspective. Additionally, the sharp distinction that is often drawn between community and professionals is blurred by considering the diversity within professionals and the implications of this.

The Women’s Health Network in Bradford, England

Bradford District is one of the most deprived local authorities in England, ranking 21st out of 317 Local Authority Districts, with vast health inequalities across the region; represented by a difference in life expectancy of 10 years between those in the least and most deprived areas of Bradford District and Craven (NHS Bradford District and Craven CCG, 2021). The Women’s Health Network in Bradford (WHN) is a collective of women living and/or working in Bradford District & Craven who aim to improve the health and wellbeing of women and their families. It was set up in 2016 after 8 months of research and consultation with local and national women and women’s groups, including an assets-mapping exercise (Women’s Health Network Project Team, 2016).

WHN is coordinated by CNet Empowering Communities’ Engaging People Team. CNet Empowering Communities is one of the few remaining community empowerment networks in England, giving a voice to local people and groups within local decision–making boards. The Engaging People Project (EPP) commenced as a new project in 2016 and is funded by the Clinical Commissioning Groups (CCGs) to undertake community engagement. CCGs commission the majority of NHS services in a local area, deciding what services are needed for diverse populations and ensuring these are provided. EPP is a voluntary sector partnership project and is made up of CNet, Hale, Bradford Talking Media, and Healthwatch Bradford and District.

WHN is commissioned by the local CCGS to deliver a minimum of 6 meetings per year and to improve women’s health outcomes. It has two full time members of staff who work with WHN as part of their remit working for EPP. WHN members democratically elect an independent chair every two years. The Chair, alongside CNet, sets the direction of the network in relation to strategic and operational delivery.

WHN's mission is 'to improve the health and wellbeing of women and their families through effective partnership working, with a particular focus on seldom heard voices' (WHN, 2016). The network therefore provides a unique research context to explore effective and meaningful ways of engaging women, particularly marginalised women, in their healthcare, as well as how communication occurs between (marginalised) women and practitioners. This article aims to explore these processes by elucidating the case of the Women's Health Network, drawing on data from semi-structured interviews with key informant women members of the network.

Methods

Methodology

Given the research aim of developing an in-depth understanding of WHN, a qualitative research design was employed. The research was a small-scale study intended to identify what had worked well for WHN as well as areas for improvement, to feedback into the network and share lessons learnt more widely. A particular focus was on the ways in which WHN engaged marginalised women and how communication occurs between local women and practitioners. The research was conducted over a period of 12 months (September 2020- September 2021) by the author of this paper.

Data collection

Having undertaken analysis of WHN's documentation which detailed the network's aims, strategies, and reports of their activities, alongside a scoping literature review to identify key themes, two interview guides were created. One was for professional members and the other was for members of the public, who participate in WHN in a non-professional capacity (referred to as 'individual members' in this article). These interview guides were distributed to the advisory board for comment, ensuring a robust data collection tool.

Given Covid-19 restrictions, semi-structured interviews that lasted approximately 30-60 minutes were conducted over the telephone with 12 members of WHN, including a Clinical Commissioning Groups (CCG) Commissioner, the current Chair of WHN, CNet's Engaging People Project Lead, the previous Chair of WHN, professional and individual members of WHN. As this was a small-scale study without funding for translation, participants were limited to those with sufficient English language ability.

I attended WHN meetings and events from November 2019 until December 2021 to inform the research design and triangulate the interview data with my observations, increasing confirmability of findings.

Sampling strategy

12 participants were recruited purposively via WHN, with help from CNet's Engaging People Project Lead and the current chair of WHN who distributed a call for participants to the network's mailing list. The research was also advertised in WHN meetings by the lead researcher and on Twitter. Members of WHN were familiar with me and my research given my presence in meetings over a 2-year period. The sample was diverse, reflecting different volunteer, charity, community, public and statutory services, of different sizes (for example, one participant worked for the police, another was a volunteer organiser of a small local exercise group for older women), It also reflected diversity of ethnicity, disability and age.

As Bahraminejad et al. (2014) identify, experiences of professional partners' participation are likely to vary depending on the level of their role within organisations. In order to capture this range, the sample included key informants across the levels of WHN's organisation and membership. Reflecting the make-up of WHN's membership, only three participants attended WHN in an individual, rather than professional, capacity. Sampling saturation occurred alongside data saturation, with recurring themes and narratives being produced in transcripts.

Interviews were recorded and transcribed verbatim by a transcribing company. Participants were given a £20 shopping voucher as a thank you for their time; organisers of WHN chose to donate their voucher to charity, preventing any conflict of interest.

Data analysis

Data analysis was on-going, occurring alongside data collection to inform the direction of the project. This was enabled by transcribing the interviews as soon after recording as possible, making notes during interviews and comparing transcripts and themes by using mind-mapping software.

Thematic analysis, as outlined by Braun and Clarke (2006), was utilised to code the data, create key themes, and group these into wider themes and sub-themes. NVIVO and mind-mapping software were used to support the coding process and the mapping of themes. Despite being the most commonly used form of qualitative data analysis, there are concerns about the credibility of thematic analysis because of its subjective nature. In order to counter such criticisms and to strengthen the quality of the analysis and subsequent findings, the lead researcher consulted with the advisory board to critically explore interpretations. The research findings were disseminated to participants and the wider network at an event in December 2021, receiving overwhelmingly positive feedback in response and participants commending the capturing of the richness of their experiences, thus demonstrating credibility of the findings and analysis.

Quotations from interviews that demonstrate the findings outlined are provided, where relevant and with consent, the participant's role is provided. The majority of quotations are provided without attribution to an individual in order to preserve anonymity and confidentiality.

Advisory Board

The project involved an advisory board comprising 6 individuals (see acknowledgements) including academic experts in community research, women's health, knowledge mobilisation and health evaluation; members of volunteer community organisations and charities, and WHN organisers. The involvement of a diverse, expert advisory board contributed to producing trustworthy and credible research, as well as fostering collaboration, and mentorship.

Ethics

Full ethical approval was granted by Birmingham City University. The research was funded by Birmingham City University. All participants were provided with an information sheet about the research and provided fully informed consent. All data was anonymised and securely stored using encrypted software, ensuring data protection and integrity.

Findings

As outlined in their mission statement and reflected by participants' narratives, a core aim of WHN is engaging "seldom heard" women. This raises two key questions; who are these "seldom heard" women? How are they engaged with (or not)? The following findings section will answer these questions by exploring participants' perspectives of 'seldom heard women', demonstrating the contested nature of the term. This article reveals the paradox of how despite attempts to deconstruct the myth of 'hard-to-reach' groups, in practice, and within the structural constraints of the current context, there are challenges for direct participation of so-called 'hard-to-reach' groups. This raises the question of how we can ensure authentic representation of marginalised groups' perspectives and experiences without forcing participation. It is argued that WHN provides a model of counterpublic engagement by bridging the gap between 'seldom heard' women and healthcare providers. WHN thus creates and sustains a discursive space between subaltern counterpublics and official public spheres, enabling two-way communication.

Who are the ‘seldom heard women’?

Groups commonly identified by participants as ‘seldom heard’ included: South East Asian women; White working-class women; single mothers; Eastern European women; African Caribbean women; older women; LGBT women; Black women; the traveller community. This range reflects the diversity among ‘seldom heard’ women with it being a category that changes over time and across contexts, rather than a fixed or homogenous category.

Indeed, the language of ‘seldom heard’ or ‘hard to reach’ groups was problematised by participants.

> *I mean, I am generally against these kind of labels, where they say, seldom heard, or hard to reach, any of those things. Because I feel as though no one is, but they’re made to be. And there’s things, like we…and I say, we, because I’m obviously, you know, part of my job is reaching out to different communities and people. If I’m looking at myself and looking at the role, I look at seldom heard, easy to ignore, but I’m thinking, I’m not doing something right to be reaching these people, because no one’s hard to reach, no one’s seldom heard. It’s just about how you reach out to them, how you go to them and how you present […]*

This quotation attempts to reverse the power imbalance within terms such as ‘hard-to-reach’ by removing the responsibility, and implied blame, from marginalised groups and placing it on organisations and professionals. This serves to reveal the ways in which structural conditions exclude groups and individuals and situates the problem with these structures, rather than the groups who are excluded (*“they’re made to be”*). The phrase “*easy to ignore*” suggests that individuals are speaking but that they are actively not being listened to, again situating the problem with the organisation or ‘listener’, the one with structural advantages, rather than the disadvantaged individual. At the same time, it is implied that there does need to be a concerted and strategic effort to encourage groups to speak (*“I’m not doing something right to be reaching these people […] it’s about how you reach out to them, how you go to them and how you present*”). Overall, the emphasis is placed on proactively going to communities, rather than passively expecting people to come to organisations.

Similarly, another participant states:

> *"seldom heard and hard to reach are ones [terms] that really grate on me, because no one is, if we as professionals are willing to come out of our comfort zone and go to them."*

Again, responsibility is placed on the professionals, with the implication that going into communities may be outside of professionals' familiar space and actions. This suggests a disconnect between official public spheres and subaltern counterpublics. It also positions professionals as 'outsiders' to communities. Yet, one of the key strengths of WHN is that the professionals who represent specific groups often live and work in the communities they represent, and have common intersecting axes of oppression, such as ethnicity and sex; reflected by the demographics of the research sample.

Another participant emphasises how terms like 'seldom heard' are labels that are constructed and applied by services to groups, rather than being terms the groups themselves identify with:

> *"It's basically the groups that statutory services are not reaching because they define that term [seldom heard]. Our communities don't go around saying "I'm a seldom heard group" because they're not aware; it's the service response and the service term."*

The reference to "our communities" implies an insider position and a sense of solidarity and belonging, rather than an outsider position. This distinguishes the participant as a professional different to the professional in the previous quotation who would be out of their comfort zone in local communities. WHN thus creates and occupies a unique space of overlap between local marginalised women, and healthcare services commissioners and providers. Furthermore, the boundary between professionals and communities are blurred in the case of WHN, with the heterogeneity of professionals being highlighted.

WHN is sensitive to the need to recognise diversity within 'seldom heard' rather than viewing the group as homogenous.

> *"There's a separate Black health network being set up because Black voices are quite seldom heard when it comes to commissioning. In Bradford, with the equalities work we're doing, I did an engagement piece with a lot of these groups, with the Race Equality Network group, the Black and Minority Ethnic, this were before the national report came out. They very much wanted to be separated from the Asian because they feel that in Bradord, only the Asian voice out of the BAME*

> *that's heard. So we have those links with the other communities and make sure that their voices are heard as well."*

This reflects results from a recent survey conducted by the NHS Race and Health Observator (2021) which found that common terms such as BAME, BME, and ethnic minority were not representative or universally popular. 'Ethnic minority' was the least unpopular term although there were significant differences between ethnic groups with Black and Arab respondents less comfortable with the term. In total, 37.9% were 'happy' with it, 37.9% were 'unhappy'. There was no universally agreed term and the term 'racially minoritised' was less well known. This lack of a consensus reflects the complexities of language-use, with terminology needing to be context-specific and sensitive. It also highlights the challenges present with the need for shorthand terms, evident in this paper. I acknowledge the issues in using 'seldom heard' women and 'marginalised women' but have decided to do so based on the first being the language used by WHN and the second being a commonly recognised term in the literature which reflects the power dynamics of women being marginalised by wider contexts. Such language use will always fall short and risk masking diversity, but it is my hope that by exploring this in more detail, the reader will understand my use of them in a critical way.

Finally, this participant suggests that by creating and sustaining relationships between networks and communities, diverse voices and experiences can be authentically and accurately represented.

Bridging the gap between seldom heard women and professional healthcare providers

Despite the network's aim to include individual members, and particularly 'seldom heard' women, attendees tend to mostly be professional women. This includes a range of community leaders, representatives from local organisations that work with women, healthcare professionals, public services, and voluntary and community sector organisations and charities. Therefore, the network functions as a web that creates opportunities for professionals to share information and to connect, and a source of information which professionals then disseminate to their clients.

The diversity of community workers and groups was cited as a key strength and a potential way of ensuring genuine representation, albeit a step-removed from the original source.

> *And I think the organisations that are attending and that are involved, some of them are really tiny, really small grassroots organisations, and that's fantastic and we,*

> *you know, we absolutely…they are representing and they are connecting to the communities that we want to serve.*

As demonstrated by the above quotation, rather than direct participation of marginalised women, WHN mainly constitutes a forum of diverse representatives who work within communities and have relationships with local marginalised women. In this respect, the network acts as a bridge or conduit between the CCGs, professional services, and local women.

> *So, I suppose our role is always piggy in the middle, Emma: we're always connecting the dots between this is what we're hearing at a grass roots level, these are the issues, these are the concerns. And then it's the agendas and the visions on which local people have been consulted. So, we're almost that group, that role in the middle. I suppose Women's Health Network does link to that middle, it's almost a straddling role between the two.*
>
> Engaging People Project Lead.

This straddling role involves being orientated towards both the micro-level of local women and the macro institutional level of the CCGs and service providers. WHN therefore creates and occupies a unique discursive space connecting subaltern counterpublics and official public spheres.

> *So the two strands of the network are the CCGs will pass down specific pieces of research that they need doing, but they will also then listen to the problems that women are telling us.*
>
> Previous Chair of WHN.

WHN translates and disseminates information to local marginalised women and communities:

> *I think it's always been very supportive of each other and each other's works and disseminating the messages, getting information out and trying to reach out to those communities that are isolated or not necessarily, it's that they don't always come forward.*

Again, we see the emphasis placed by participants on going out to communities, rather than expecting them to come to you, and the importance of inter-professional working in order to reach diverse communities.

At the same time, WHN provides a platform to amplify lesser heard women's voices, and to pass messages upwards from local communities, by feeding back information to the CCGs.

> *And it's like the clients that we have that basically wouldn't speak up for – not all of them, but some of them wouldn't speak up for themselves. And we are here to support them by asking the right questions, I think eventually they will be heard.*

This positions professionals in a key role in-between communities and commissioners, with the knowledge, skills, and relationships required to communicate with both. WHN is a key link in the chain of publics which connects two separate spheres and enables this discursive movement in both directions.

Bridging the gap or papering over the cracks? Limitations of the model

As previously discussed, the terms 'hard-to-reach' and 'seldom heard' are challenged by participants. Yet, the fact remains that despite aims for direct participation, marginalised women tend not to directly participate in WHN. WHN instead functions as a bridge between local women and the CCGs and service providers, constituting a network of professionals who act as representatives for local marginalised women. However, this approach has its limitations, as outlined by a CCG commissioner:

> *I think, common with lots of similar kind of networks, sometimes the voices that get heard are the voices of voluntary sector organisations or community groups, rather than always the women that they represent and I think it's important that those groups and organisations are part of the conversation, but that they are bringing the perspective of the communities that they serve and the women that they serve, and not just their own perspectives on an issue. And I think that's something that Women's Health Network are aware of and…but could do better at making sure that when we're capturing conversations, when we're debating a topic in the forum or when we're talking about something, that actually we're able to pull out and distinguish whose voices really are being heard in the room.*

Here, the issue of genuine representation and amplification of marginalised women's voices is raised – how can we ensure that representatives amplify voices from their community rather than relaying their own perspectives? How do we ensure that information is not lost in translation by the addition of a ‘middle (wo)man’? These are key questions around authentic PPI, with the need to balance genuine representation with not placing the burden of responsibility on already disadvantaged women. Furthermore, we must respect the autonomy and desires of women as individuals, which reinforces the need to consider the diversity of ‘seldom heard’ women. Indeed, the assumption is often implicit that individuals will want to participate and this is not always the case.

It seems clear that while current political and healthcare structures ostensibly encourage direct participation of marginalised communities, they are not conducive to such direct participation. Ideally, the solution would be to radically transform such institutions and structures so that their inherent exclusions are removed. However, in practice, there needs to be attempts to move forward within the context that we are faced with and to bridge the gap between the theory of authentic participation (where direct participation is held up as the gold standard) and the reality of what happens in practice. WHN provides a model of counterpublic engagement that helps to bridge the divide between institutions and local communities.

The following quotation demonstrates this tension between the idealised aim of direct participation and the practical reality of barriers that prevent such participation:

> *So this is something that we’re looking at actually developing to be fair, so having…instead of being like a conduit in between, seeing if we can have very open, like meet the commissioners type of thing, like a speed dating almost. Where members of the community are invited directly to have that conversation without us being in between. But generally, I suppose what we do is, we take the conversations that we get from services, from our members, and kind of transform that into kind of a set plan, because, sometimes organisations…I wouldn’t say there’s politics or bureaucratics [sic], but there is like a way of communication isn’t there. Right, okay, the conversation that you might have in a community, is very different to how you might have it with a manager, for example. So it’s just sometimes filtering it through a little bit, to make it easier to read.*
>
> Chair of WHN.

At the same time as discussing desires to increase direct participation and remove the conduit function of WHN, the above quotation explains how communication barriers exist within such settings where there is a need to translate conversation into appropriate vernacular according to context. Thus, even if marginalised individuals wanted to and achieved direct participation, they would still face what Fraser (1992) terms ‘informal impediments’, where certain modes of speech, particularly that which is classed, gendered, and racialised, are ignored within the context of official public spheres.

Creating spaces for diverse inter-professional networks: A step towards a solution?

As has been highlighted by participants throughout this paper, one of the key strengths of WHN is the diversity and range of professionals who participate in the network and who represent various community, charity, statutory, and public organisations. This diversity and reach embodies WHN’s focus on ‘effective partnership’ and fulfils the CCG commissioning remit to:

> *bring some different perspectives to health issues that we, as commissioners, are trying to solve, to connect and reach into communities of women and individual women in Bradford district whose voices are generally not heard when it comes to decision making around health. So, they enable us to connect to women that we wouldn’t, otherwise, hear. And to engage those women in thinking about their own…their own choices, their own health and to becoming more active participants in their communities.*

This ‘connecting’ function of WHN is central, as are the emotional and professional connections that are created, maintained, and solidified within WHN and communities. While there is always a risk when direct participation is lacking that diverse voices are not authentically and accurately represented, the diversity of representatives within WHN and the relationships it creates between professionals and services goes some way to mitigating against this risk. Moreover, it is important to remember that professionals are often part of the communities that they live in and work with, rather than disconnected outsiders, and often embody characteristics of the marginalised women they work with and represent at WHN. There is a need therefore to not only deconstruct the myth of homogenous ‘seldom heard’ groups but to also interrogate the assumed homogeneity of ‘professionals’. Doing so reveals the diversity within this group and blurs the boundary often implicitly drawn between professional and communities.

Discussion

There is a need for public engagement in health to be representative, inclusive, and diverse. In particular, attention must be paid to ensuring that marginalised groups are authentically represented and that existing health and social inequalities are not further entrenched by PPI and public engagement strategies. Shimmin et al (2017) highlight the importance of recognising diversity among patients and the public, rather than conceptualising them as an homogenous group which denies the reality of oppression faced by those who are most marginalised. Similarly, it is important to recognise diversity within marginalised groups, as highlighted by participants who problematise the label "seldom heard". As Montesanti et al. (2017: 638) highlight, "marginalization is a multi-layered concept, and individuals can be marginalized at certain stages of the life cycle and for different reasons […] marginalization can also be experienced by those who are born into particular minority groups". De Freitas and Martin (2015: 31) suggest that "both health authorities and civil society organisations have a role in creating 'hybrid' spaces that promote the substantive inclusion of marginalised groups in healthcare decision-making". WHN demonstrates the creation of such a space, enabling discursive movement between subaltern counterpublics and official public spheres. In doing so, WHN not only amplifies lesser-heard women's voices but legitimises them by translating key messages into language that is recognised at the macro level of those who commission health services.

While there is a drive for authentic and meaningful public engagement that is inclusive of marginalised groups and which avoids tokenism, it is also recognised that there are challenges in engaging such groups. As highlighted by participants, individuals do not always have the desire to participate in formal structures of engagement, such as meetings. Abimbola (2019) refers to such assumptions, originally highlighted by Riftkin (2012, 2018) as 'positive *a priori* bias' and attempts to move beyond such assumptions about community engagement. Moreover, health communications often require translating into ordinary speech and tailoring to diverse community's needs, which is a key function of WHN. Indeed, institutions and discourses have implicit rules and codes of behaviour; in order to be heard, one has to comprehend and play by these rules. The professionals that comprise WHN are adept at code-switching, altering their speech to match different sociocultural norms and contexts. Doing so enables them to have an impact on decision-making processes, to communicate openly with marginalised women and to authentically represent their communities.

By including only those who self-select to participate in formal structures, there is a risk of what Enany et. al. (2013) refer to as “the paradox of user involvement in healthcare service development”. Here, users are stratified into a hierarchy of legitimate lay experts and ‘lay lay’ users, with the former often complicit in this process of stratification which benefits them. The term ‘lay lay’ is intended to reflect this hierarchal relationship between official lay experts and others who are placed below the lay experts. Consequently, users who have impact and are heavily involved as lay experts have prior experience of senior management, are highly educated and articulate, thus preventing inclusion of marginalised and diverse individuals. This hierarchy of user involvement can result in the dismissal of ‘lay lay’ users’ knowledge as being overly subjective, and interpolates such users as lay patients, instead of knowledgeable partners. Similarly, Aveling and Martin (2013: 74) draw attention to the risk that “partnership discourse may be no more than a rhetorical veil, masking the perpetuation of power asymmetries and the exclusion or co-optation of certain stakeholders”. Therefore, it is recommended that rather than focusing on explicit markers of engagement, such as direct participation in formal structures, we recognise subtle indicators of engagement, and the value of alternative models of counterpublic engagement like WHN.

There is a careful balance to be maintained between ensuring representation of marginalised groups, and not placing too heavy a burden of participation upon the shoulders of already disadvantaged individuals. WHN’s function as a bridge between local marginalised women, their communities, and the CCGS is a potential solution to this issue, so long as genuine community representation and relationships occur. Participants’ narratives reinforce the argument that models of community engagement which go to communities are more successful in engaging marginalised groups and improving health outcomes (Bagnall et al. 2015; Cyril et al. 2015; O-Mara Eves et al. 2015). Moreover, WHN highlights the need to consider public engagement and PPI in a more nuanced way that reflects the needs and realities of diverse subaltern counterpublics, and which respects the diversity within marginalised groups, by engaging critically with terms such as “seldom heard”. The diversity of WHN members and their situatedness within local communities is a key condition for authentic and accurate representation in the absence of direction participation.

Study Limitations

The research this article is based on was a small-scale study which entails limitations, namely the transferability of the research findings and the lack of individual women participants in the sample (as a result of changing research plans due to Covid-19 restrictions). Future research should address this limitation by engaging directly with marginalised women through co-production and community engagement research. Additionally, funding for translation services in a larger study would enable a more diverse and inclusive sample.

Nevertheless, the data produced from this research is rich, with a diverse sample that includes key informants, is reflective of WHN's membership, and enables a better understanding of how the network functions in practice. The detailed, contextualised nature of the research and its findings is common to qualitative research; however, it is intended that these findings can be used to compare to other locations and that lessons learnt from this project can be transferred to other settings, taking into account their specific demographics.

Conclusion

Despite the focus on increasing diverse and representative public engagement in healthcare, there has been a lack of research and studies that focus on women and disadvantaged groups (Stokes et al., 2015). Given that women make up half of the population and face specific health inequalities and issues, it is vital that we find ways to include women's voices and experiences in their healthcare provision. Furthermore, it is important to recognise inequalities faced by women who experience additional marginalisation through ethnic minoritisation, socioeconomic class, disability, age, and sexuality. Public engagement initiatives thus need to be flexible, tailored to the communities they work with, and representative of diverse groups of women in order to avoid further entrenching existing inequalities.

This article has revealed the tension between ensuring authentic direct participation of marginalised groups and the practical reality of engaging with these groups and communities. The paradox is that while attempts to deconstruct the myth of 'hard-to-reach' groups are central to WHN, in the context of existing structures, marginalised groups *are* hard to reach. This does not mean we should give up or place the responsibility and blame on the shoulders of such individuals and communities, which is a key risk of language such as 'hard-to-reach'. In the absence of a radical transformation of political and healthcare institutions and structures, this article has argued that WHN provides a model of engaging marginalised women through bridging the gap between communities and healthcare providers. This is achieved through the network's diverse membership and reach which blurs the boundaries between professionals and communities. WHN thus provides a realistic and practical model of subaltern counterpublic engagement and communication between marginalised women and healthcare professionals by creating a unique discursive space that bridges the two.

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Declaration of Interest

The author reports there are no competing interests to declare.

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