How can patients, the public and health professionals work better together?

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Debbie is a nurse and used to be a university lecturer at the University of Brighton. She finished her PhD in 2019. She's just embarked on a two-year part-time Economic and Social Research Council funded postdoctoral fellowship under Angie's mentorship Here, Debbie talks about her PhD research and what she hopes it will achieve.

Clinical commissioning for community health and care services

I'll tell you what I found out from my recent research on 'clinical commissioning'; that's the technical term for choosing and buying health and care services. You can't involve service users and the public unless you first engage with them about purpose. Perhaps no great surprises there but you can look more closely at the process or practice of patient and public engagement and involvement (PPEI). There are elements or components that make a difference to how it is done and if it is done well. Things like how people are selected and encouraged to take part, how much paperwork there is to read and check, whether community members have done it before and what it means to take part and be valued. Service users want to be more than '**just generic patient people**.' These elements affect how trust, leadership, learning and partnership are practised. They show where there is scope for improving working together at local community level.

'…we are not sort of just generic patient people…'

Muddled language?

'**How can system partners best work with communities from now on?**' This question from a recent National Voices webinar looked at experiences of community in a time of crisis and grabbed my attention. Is this where my research could add something to the debate? You have no doubt heard it all before; phrases like **people and communities**, **meaningful engagement** and **maintain trust**. I have wrestled with these phrases over the last few years whilst doing my PhD research. I can break out into a cold sweat just thinking about the literature I reviewed!

It is complex trying to grapple with the terminology of patient and public involvement (PPI) or patient and public engagement (PPE) in the English National Health Service (NHS). Of course, this isn't just about semantics. We need to ask what policy is driving the process? Is it about citizens' democratic rights to have a say on how public money is spent fairly? Or about having choice and customer-like feedback to choose and improve services? And more importantly, what does this mean for PPEI for clinical commissioning in the post COVID world? The 'terminological instability' and conceptual muddles described by Forbat, Hubbard and Kearney, amongst others, are well-documented. Ellen Stewart, a social scientist at Edinburgh University interested in 'lay' and 'expert' knowledge for public engagement in health systems has said that it is about the purposes of 'participation'. (For an up to date account of the terminology, see the annotated and critical glossary written by Islam and Small .) After doing my literature review, I decided to use the PPEI acronym because it was about first engaging patients and the public if you were serious about involving them on a peer to peer basis.

Understanding participation and partnership

My research focused on two new **Clinical Commissioning Groups (CCGs)** in England that were formed following the Health and Social Care Act 2012 (HASCA). CCGs are statutory NHS bodies led by General Practitioners (doctors in community or primary care known as GPs), and are legally required to engage and involve service users (patients and carers) and the public. At the time, GPs were fairly new to this type and scale of commissioning. It was a huge change and there were worries about GPs taking charge of such large NHS budgets as clinical leaders. Population sizes could be up to about 860,000 people in a CCG and so we are talking large sums of public money to buy services. (Pages 12 and 13 of this document explain the extensive changes in NHS commissioning that were happening at the time.) Were GPs equipped to lead strategically at such scale despite prior experiences of commissioning and pilot CCG case studies?

I wanted to look at clinical commissioning from a different angle and especially the leadership and trust practices. My background as a lecturer meant I was curious about how the learning was taking place. I had questions about PPEI as a **social practice** rather than focusing on whether participation was ticking the NHS policy box requirements. I looked to the work of several eminent theorists to explore the landscape of commissioning 'communities of practice' (CoPs). I saw these CoPs as the various groups that convene for CCG business such as the Governing Body and the Communications Strategy Group, all of which are required to have service user representatives as well as GP leaders. Tara Fenwick's ideas on professional learning were helpful too for understanding the practices rather than focusing on the 'head' knowledge. You know, when someone has all the facts in their head about how to do something but that doesn't always mean it is done well for the person on the receiving end of the process. Fenwick considers the **material** everyday organic and inorganic stuff such as furniture, forms, passcodes, checklists, minutes and databases that have to be learnt and navigated as well as the **social** entities like the meanings, fears, desires and cultural discourses. We can probably all identify with having to learn new things and new ways of doing something and how that makes us feel. By asking my research question (below), I wanted to explore how GP clinical leaders could learn to engender trust in co-productive working with service user and public 'peers'. In addition, what lessons there could be for health care professional education.

What does it mean to work in partnership as clinicians and service users to commission and lead services?

What did I do? I spent about 12 months at two CCG case study sites in the south of England doing what is called a **focused ethnography**. This allowed me to focus on specific aspects of the PPEI and delve into what was happening in the CoPs. Ethnography always involves observing and I did this as an onlooker rather than as someone participating in the CCG business. Although it is quite a popular way of researching in the NHS, it is time-consuming and so I wanted to share my experience of using this methodology. You can read more about it in a chapter I wrote for a book on conducting critical qualitative health research edited by one of my PhD supervisors, Dr Kay Aranda.

I carried out focus groups which are like small discussion groups around a topic, observed meetings to see what was happening and collected relevant materials such as reports and minutes of meetings. I also conducted face-to-face interviews. All 21 informants from the focus groups and interviews were either service users, lay (public) representatives on CCG Governing Bodies or GP clinical commissioning Leads, living and/or working within the boundaries of the CCG communities. I have written about my research methods in the publication Research Matters which followed after a presentation I gave at a research conference.

Once I had collected all my data, and there was a lot over the 12-month period, coded and sorted into categories, I arranged them into four bundles of what I saw as collective situated learning practices in the CCG CoPs. These were practices around **trust, leadership, learning** and **partnership** and informed the doing or **performance** of PPEI for clinical commissioning. I found it useful to develop a framework constructed from the ideas of the theorists I had studied to interpret PPEI as a social practice. I also drew on the work of Shove, Pantzar and Watson (The Dynamics of Social Practice) who have written about what they call the 'elements' of materials, competences and meanings in social practice. I focused on five elements or components in my conceptual framework (see diagram below) and then applied them to each of my four bundles or sets of practice which generated a number of themes.

Elements (components) of conceptual framework for PPEI
Participation – how involvement is engaged, aligned with policy or imagined
Materiality – concrete or 'reified' requirements, e.g. minutes, checklists, guidelines
Competence – skills, know-how, knowledge
Boundary encounters – past, present and CoP's that affect PPEI for commissioning

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Meanings – the social and symbolic associated with CoPs

This meant I could think about PPEI as a collective ‘thing’ or **entity** and see it more than a tick list of performances to meet material policy requirements. A good analogy, drawing on my nursing background, would be giving injections which is very topical with the Coronavirus vaccines. You can develop a checklist for who, when, where and how (materiality) and ensure the competence (skill and know-how) of the practitioner but that focuses on performance. Considering meanings, past experiences and how people are invited and encouraged to have an injection or vaccine views the practice of giving injections in a more holistic way, as an entity that can inform policy. Think about why people may refuse a vaccine for example, and what implications this would have for immunising populations.

What did I find? My findings on trust practices showed **participation** was about relational ways of engaging and **meanings** about feeling valued. It applied to both service users and clinical leaders as illustrated by one of the GP Leads Lucy, not her real name. She also talked about needing time for PPEI so I included this as a **materiality**. Time is a commodity essential for PPEI if it is to be done well.

Lucy: … well… what I’m going to say is a bit vague, but I really strongly believe in human relationships and relational care and welfare and, you know, that… it really is about meeting people, getting to know them, listening to them, you know, understanding their experience of care, not just collecting bits of data, but it takes time, it takes a lot of time. …we really spent several weeks listening to the patients, finding out how they got into the service, whether they even wanted to be in the service and, you know, what they really wanted, not what we wanted, which was a diagnosis in dementia to put on our register but what they wanted out of it. And you learn so much, but it takes time, it takes lots of time.

[GP Lead interview, 14/06/16]

A surprise finding was the role of the “*awe-inspiring”* commissioning support managers. They have a managerial role and work closely with GP Leads on contracts for buying services which includes engaging and involving service users and the public. Their (**boundary**) **encounters** with past CoPs for primary care commissioning meant they were trusted by all participants. They built on assets relating to PPEI rather than starting afresh with the new NHS structures following the HASCA. Nigel, not his real name, the PPEI Lay representative for one of the CCGs, gave an example:

Nigel: … I think the recruiting here’s been pretty good, I mean XXX [Commissioning Support Manager] a good… an excellent example actually, of how… how… there’s… everybody likes XXX, everybody trusts XXX and she gets things done and she just talks the way you would want somebody to talk and that’s pretty general actually, …

[PPEI Lay representative interview 13, 8/11/16]

For leadership practices, the framework showed the heavy **materiality** or reification where both CCGs relied on process and procedures that were dictated by NHS England. NHS England is the executive public body which oversees commissioning and how CCGs perform. The materiality was a barrier to **participation** at Governing Body meetings just with the sheer volume of data that were only made available to the public one week beforehand. A further finding was the importance of roles to give **meaning** in leadership. For service users, a defined role was important because it had role descriptors and status despite protracted recruitment procedures whereas for the GP there were not the same formal processes. One GP commented that she did not *"stand back quick enough"*, but when it came to the **competence** element, another GP talked about "*no-one wanting to be low in [the] rating"* relative to NHS England CCG requirements.

For learning practices, the **participation** element highlighted "*wearing lots of hats"* to align with CCG requirements and the various CoPs. A lay representative might chair a CoP meeting for example, but also have to attend other CoPs because of his/her governance role. And there were differences in formalised learning processes. One CCG focused on formal education and training for the GP Leads but the service users were learning by doing to demonstrate **competence**. Conversely, the other CCG devoted more time and effort to preparing and supporting the service user representatives in a formalised way with workshops and a conference.

The framework showed unequal relationships for the **participation** element of partnership practices as the quotation below from Hazel (a pseudonym) illustrates. She, and her service user peers, did not want to be "generic patient people." **Meanings** were about seeing you as a person and **competence** demonstrated by a return on your contribution with feedback that PPEI contributions made a difference to commissioning decisions. **Boundary encounters** that furthered partnership practices flagged up belief in the PPEI agenda because CoPs had shown it had worked before.

Hazel: …When they ask us to come along they simply see us as generic patients. Like 'a person in the street' but most of us have skills. We have skills in jobs that we have done and they may be skills that they could very much learn from and would help them. And we want to be true partners and give that kind of skill. They haven't understood that we are not sort of just generic patient people.

[Service users, focus group 3, rural CCG, 27/06/16]

Mapping the findings

I wanted to explore where the five elements intersected to give a better understanding of PPEI in clinical commissioning. Having used my framework to analyse and interpret the component themes for each of the four sets of practices, I converted them into a conceptual map. I did this by combining them and using the most closely aligned verbs. It sounds complicated I know but here is an example. **Materiality** which was evident in all four sets of practices to some extent, had themes around time pressures, reporting processes and physical spaces which became 'time-consuming', 'reporting' and 'resourcing'. The present participles (where the verb ends in ***ing)*** convey activity and performance which I see as 'practising PPEI' but they also construct PPEI as a whole **entity;** the practice of PPEI**.** (Remember my earlier illustration about the practice of 'giving injections' and the doing of as a performance?) The map below shows this more clearly. Some of the activities may be hidden but others are highly visible, similar to an iceberg analogy. Popular science reports that 90% of an iceberg lies hidden below the surface of the water. I used the map to show the PPEI practice for a CoP to reveal what lay beneath the surface. I tried it out with several of the CoPs I observed during the research by shading in the applicable doing words for each element.

Conceptual map for PPEI practices in clinical commissioning

Participation (P)	Materiality (Mat)	Competence (C)	Boundary encounters (BE)	Meanings (M)
Aligning	Time-consuming	Conforming	Inspiring	Valuing
Imagining	Reporting	Performing	Developing	Improving
Persisting	Monitoring	Learning	Remembering	Achieving
Engaging	Processing	Recognising	Enabling	
	Resourcing		Believing	
			Welcoming	

Now what?

My study has some really interesting findings – too many to cover here – so I am excited that the fellowship funded by the Economic and Social Research Council will give me the opportunity to tell more people about the research and explore how it can be used in everyday commissioning contexts. I am also planning to collect new data from clinical commissioning support managers and CCG leads for PPEI as they were not included in the original PhD study. Their perspectives will help enrich the iceberg idea of PPEI and the mapping of the social and material aspects of the practice for learning and evaluation purposes.

I will be inviting feedback on the map so that I can refine how it can be best explained and used to help practice and learning. The mapping can be done by any member of a CoP as a way of evaluating PPEI practice for clinical commissioning. Maybe during and after workstreams within CCGs and for people wanting to learn and understand the practice and performance of PPEI for clinical commissioning. It is for service users and lay representatives in leadership roles as well as GP Leads.

There have been more changes to CCGs since completing my research. Back in 2013 following the HASCA, there were 211 CCGs in England; now that number has almost halved. Some CCGs have merged and NHS commissioning has been scaled up for larger population sizes. There has also been a blurring of divisions between organisations which buy and those that deliver services (purchaser and provider organisations). New partnerships have been formed to integrate health and care systems. Hence, the earlier reference to '**system partners**' but also the concern that patient and public voices are heard and valued in a co-productive manner. In the COVID 19 pandemic, a command and control leadership has prevailed with many asking what has happened to those voices. In reality, it should be nothing about us without us in keeping with the principles advocated by National Voices. I am hoping my research will have broader ramifications if the practice and performance of PPEI for clinical commissioning is to be more clearly understood and embraced for better partnership working.

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The Resilience Revolution Final Research Report 2016-2022

Resilience Revolution's Final Research Report 2016-2022

This report presents the research and evaluation of the Resilience Revolution programme (2016-2022).

The Resilience Revolution is an innovative whole town approach to building resilience, made possible by funding from The National Lottery Fund's HeadStart programme. Funding was available between 2016 and 2022, across 6 areas nationally in the UK with the purpose of testing and learning new ways to support young people's mental health (ages 10-16).

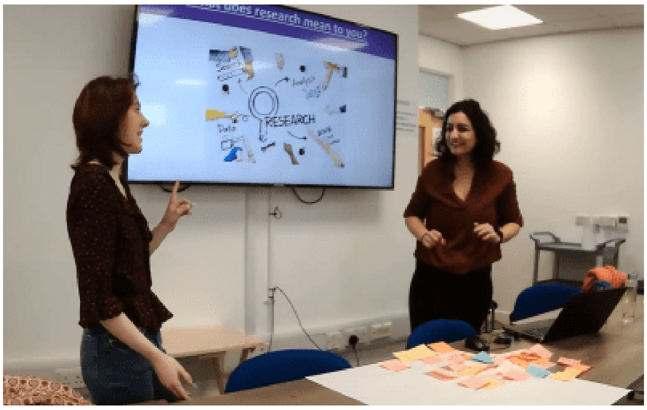
In Blackpool, the programme took the bold step of developing a vision for the whole town; giving everyone who lived, worked or volunteered in the town the opportunity to get involved. The Resilience Revolution embraced co-production as a way to design and test innovative projects. Co production meant a range of people, with different expertise, working together, as equals towards shared goals.

The Research Ready Communities pilot continued

For the past year and a half Boingboing has been working on a Research Ready Communities pilot project in Blackpool alongside the National Institute for Health Research as part of their Under-served Communities programme. Typically, much of the funding for health research in the UK goes to universities in London, Oxford and Cambridge, but health research is needed the most in places like Blackpool, where the harmful impacts of health inequalities are worst felt.

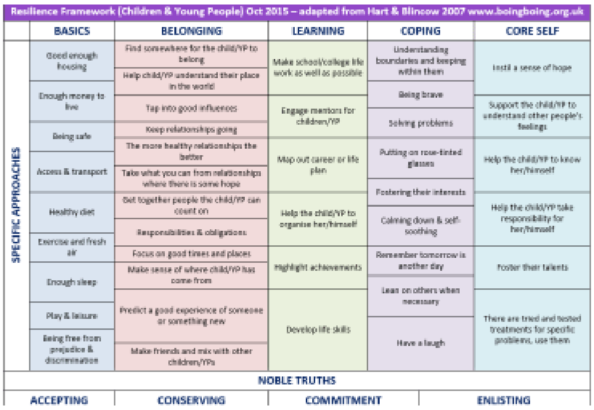
Loops – a review

On 22nd February Grace and Lauren, members of the Activist Alliance, attended the show Loops at the Blackpool Grand Theatre. It was a play made in collaboration with Liverpool Everyman + Playhouse, 20 Stories High theatre company and, "a brilliant group of activists and artists who all shared important stories of what their experiences were, with courage, honesty and jokes”.



[Watch our workshops: how to do community co-research on health equity]

Created as part of the ongoing Community Solutions for Health Equity project that Boingboing Foundation are proudly part of, we are pleased to share recordings of a series of workshops held recently in Blackpool. These workshops are free resources to be taken advantage of by any community members or organisations looking for a beginner’s guide to developing the research skills and knowledge needed to explore health inequalities in coastal areas.



Resilience Framework (Children & Young People) Oct 2015 – adapted from Hart & Blincow 2007 www.boingboing.org.uk

	BASICS	BELONGING	LEARNING	COPING	CORE SELF
SPECIFIC APPROACHES	Good enough housing	Find somewhere for the child/YP to belong Help child/YP understand their place in the world	Make school/college life work as well as possible	Understanding boundaries and keeping within them Being brave	Instil a sense of hope
	Enough money to live Being safe	Tap into good influences Keep relationships going	Engage mentors for children/YP	Solving problems	Support the child/YP to understand other people's feelings
	Access & transport	The more healthy relationships the better Take what you can from relationships where there is some hope	Map out career or life plan	Putting on rose-tinted glasses Fostering their interests	Help the child/YP to know her/himself
	Healthy diet	Get together people the child/YP can count on Responsibilities & obligations	Help the child/YP to organise her/himself	Calming down & self-soothing	Help the child/YP take responsibility for her/himself
	Exercise and fresh air Enough sleep	Focus on good times and places Make sense of where child/YP has come from	Highlight achievements	Remember tomorrow is another day	Foster their talents
	Play & leisure Being free from prejudice & discrimination	Predict a good experience of someone or something new Make friends and mix with other children/YPs	Develop life skills	Lean on others when necessary Have a laugh	There are tried and tested treatments for specific problems, use them
			NOBLE TRUTHS		
ACCEPTING		CONSERVING	COMMITMENT		ENLISTING

[The Boingboing Resilience Framework]

The Resilience Framework is a handy table that summarises ‘what works’ when supporting children and young people’s resilience according to the Resilience Research base. The Resilience Framework forms a cornerstone of our research and practice. On this page we have pulled together lots of useful links so you can find out all about the Resilience Framework.

Prevention in Health and Social Care Inquiry Submissions

Co-leaders of the Resilience Revolution made not one, but two submissions to the UK Parliament ‘Prevention in Health and Social Care’ inquiry last month. The inquiry is about preventing ill health, now and in the future.

A guide to becoming more eco-friendly in Blackpool and the Fylde Coast

Hi, I’m Maya, and I wanted to say a big thank you to you for reading. These guides were created to help people in Blackpool and the Fylde Coast become more environmentally friendly, without feeling too overwhelmed by climate issues. They were produced as part of the Boingboing Activist in Residence project, which gave me the opportunity to work as an Eco-activist in Residence at Blackpool Victoria Hospital. I decided that I wanted to use this role to make two guides: one for local residents, and another for Blackpool Teaching Hospitals’ Green Champions.

NIHR | National Institute for Health and Care Research

An introduction to the Research Ready Communities pilot

For the past year and a half Boingboing has been working on a Research Ready Communities pilot project in Blackpool alongside the National Institute for Health Research as part of their Under-served Communities programme. Typically, much of the funding for health research in the UK goes to universities in London, Oxford and Cambridge, but health research is needed the most in places like Blackpool, where the harmful impacts of health inequalities are worst felt.

Online Resilience Forum – 3rd April 2023 – Psychological distress and resilience among a population affected by conflict

This Online Resilience Forum from CRSJ and Boingboing is for anyone interested in resilience research. This month's forum is on 'psychological distress and resilience among a population affected by conflict' presented by University of Brighton PhD student Omar S Rasheed.

Older Entries