Public and patient partnerships
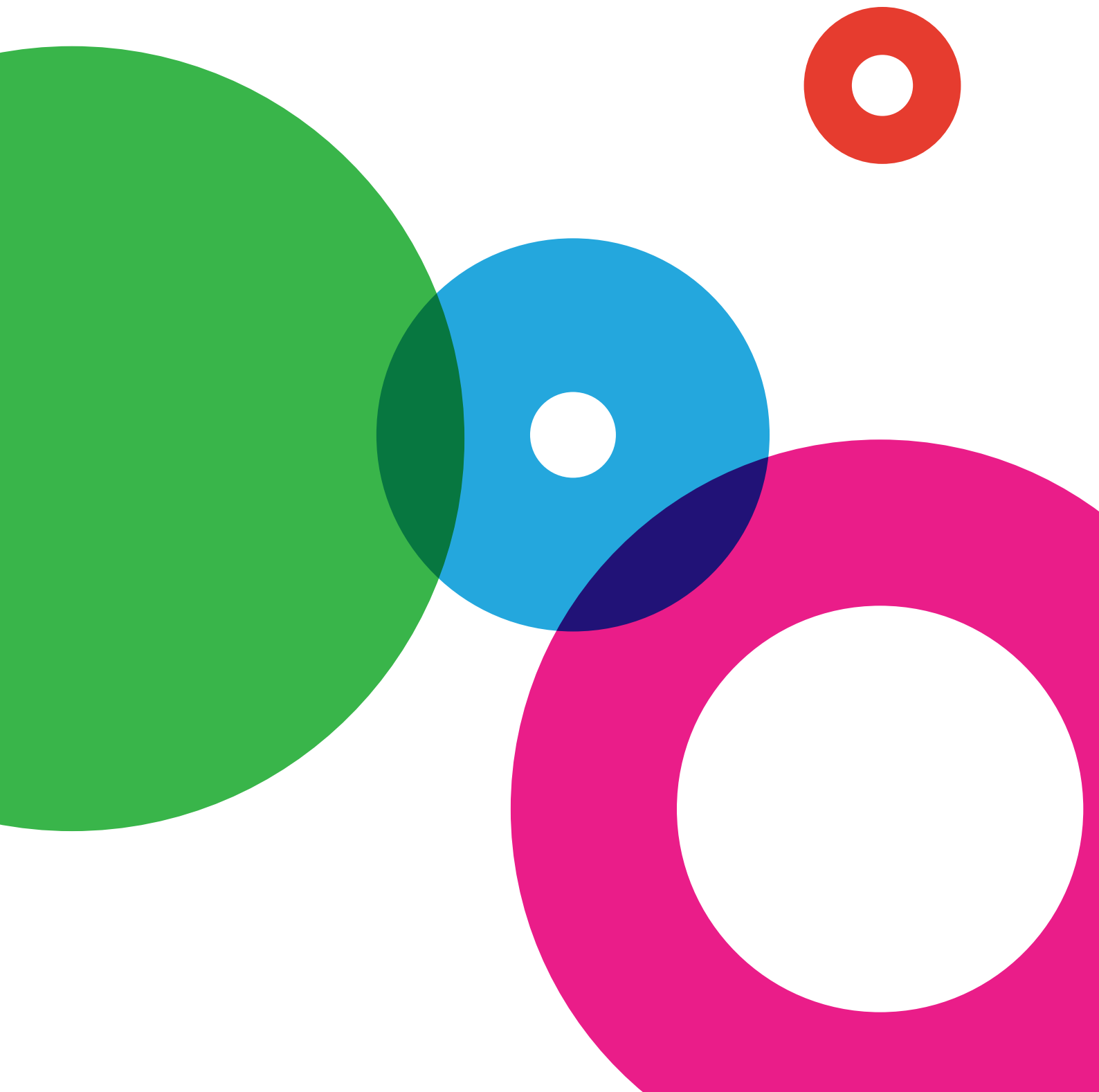How they can address the inequality and finance
gap in health and care

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Background

Both values-based and evidence-based considerations increasingly point to patient and public involvement as being key factors in achieving better patient outcomes.

Sharing decision-making with patients and the wider local community, encouraging 'expert patients', actively seeking and listening to patient experiences and involving patients as co-producers of health services, can lead to improved patient self-management, improved patient safety and more sustainable, person-centred service improvements.

Indeed, the UK would appear to have a very promising foundation for extending and promoting the wider adoption of patient leadership and communities as co-designers of services. The Commonwealth Fund recently cited the UK not only as one of the leading healthcare systems in the world[1], but also as the best system in the world for patient-centred care.

Nevertheless, research by Dr Kath Checkland of the National Primary Care Research Centre suggests that few people really know what effective public or patient involvement means or how to implement it effectively. There are questions around who the public or patients are, and how representative patient representatives actually are. She argues that while it's a positive idea to involve the patient, it is important to be both practical and specific about what this actually means in practice.

"Few people really know what effective public or patient involvement means or how to implement it effectively."

The evidence

Many reports have already highlighted the importance and benefits of self-management, patient safety and patient experience.

- In *Securing our future health* (2002)[2], Wanless argued that improving self-management of conditions would both improve patient outcomes and save resources.

- *Expert patients* (Reform UK, 2015)[3] argues that Wanless' recommendations have yet to be widely implemented, and recommends more flexible approaches to commissioning budgets to achieve the real benefits of effective patient engagement.

- Lord Darzi's *High quality care for all* (2008)[4] defined quality of care as clinically effective, personal and safe. Effectiveness of care included both the clinical procedures and the patient's quality of life after treatment.

- Berwick's report after the Mid-Staffordshire crisis found that the service was failing because it had not been listening to people. The NHS should ensure patients are treated with compassion, dignity and respect in a clean, safe and well-managed environment, and these moral aspirations are at the heart of the values and pledges that underpin the NHS Constitution. In 2012, a NICE quality standard for patient experience was issued, suggesting patient feedback about their experience should be used to improve service quality and listing 14 components of good patient experience.

Berwick's recent comments about improving quality in the NHS (King's Fund 2016) restate that 'listening to patients' is a fundamental NHS system improvement lever.

Co-designers and producers of effective service improvements

Following on from Darzi's report, Britnell (2008) argued that world-class commissioning should begin with 'an absolute and profound assessment of need', which could be 'a local need, based on a GP-practice population, or across a much larger area'.[5] Such needs assessments, which imply at least consultation with actual or potential patients, would inform both service design and accountability. Going further than consultation as a model of patient engagement, Gilbert[6] spoke more recently (2013) about moving towards a model of patient leadership, at the King's Fund conference Patient voice and power in the new NHS.

As The King's Fund noted in 2012: 'Through co-designing with customers, industries and services have sought to better meet the needs of end-users. The principle of co-design is now beginning to be applied to healthcare, with patients working in partnership with professionals to design services and care pathways.'

"Public and patient partnership goes beyond consultation or 'engagement' and embraces both delegation and empowerment."

Theoretical context

The idea of patients as ambassadors or partners draws implicitly on Arnstein's *Ladder of citizen participation* (1969).[7]

A broader understanding and implementation of effective patient engagement and co-production with those using healthcare services can not only improve quality of care and be cost effective, it can also help to engage in an effective and meaningful way with those groups in society that are most vulnerable, such as the homeless, sex workers, refugees and those struggling with addiction. This is illustrated in Newham CCG's work (see page 10).

In order to reap these considerable benefits, public and patient partnership (PPP) working is required. This involves going beyond consultation or 'engagement' and embracing both delegation and empowerment. In practical terms, this means community engagement to establish priorities for action, and community-based commissioning, co-designing and co-producing services that address community-identified priorities.

Working in this way can be understood as synthesising both the medical and social models of health. Doing so implicitly incorporates the insights of both Marmot[8] and others, in addressing both micro-, meso- and macro-level factors that impact on health. This is consistent with literature on community development in non-health areas, such as by Gaventa[9], who recommends 'the framing of a social problem, and a social solution, to arise from within the group, thereby empowering and better enabling the group to take collective action'.

There is robust and well-known evidence about the social determinants of health, including from the British Medical Association[10], among many others. The question has been around how effective community-centred approaches are in tackling these determinants.

Professor Jane South's work[11] cites a recent NIHR-funded systematic review and meta-analysis of the effectiveness of community engagement[12], with 315 studies grouped into three models:

• empowerment

• peer/lay models

• patient/consumer involvement in service development.

The conclusions were:

"Overall, community engagement interventions are effective in improving health behaviours, health consequences, participant self-efficacy and perceived social support for disadvantaged groups. There are some variations in the observed effectiveness, suggesting that community engagement in public health is more likely to require a 'fit-for-purpose' rather than 'one-size-fits-all' approach."

Additionally, as NICE asserts in its introduction to its guidance on community engagement[13], there are a set of evidence-based principles on which to take forward work around community engagement and community development. The review on community engagement by Angela Coulter is another helpful resource[14], as is the paper by Ross Baker [15] and the key resource by Carman[16] (see page 10).

Community-based commissioning
The underpinning idea of holistic models of community-based commissioning is to understand the evidence around the social determinants of health, and recognise that traditional health services cannot comprehensively address the health and social needs of all individuals, especially those from vulnerable groups. Hence, meaningful and sustained community engagement is undertaken to understand community needs and assets. This may be linked to the joint strategic needs assessment. Then, partnership working taps into and mutually develops the knowledge and expertise of the third sector. Non-traditional providers can then deliver both preventive and care services via solution-focused commissioning, adding social value through this community partnership working.

(Professor Jane South, 2011)

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Practical benefits

Widening the concept and practice of patient engagement to include public and patient partnership, which in practice includes community engagement and community-based commissioning, is critical, as it offers an effective means of tackling our greatest health challenge – long-term conditions (LTCs). The costs of LTCs are very high and look set to continue. LTCs are disproportionately prevalent in more economically and socially deprived parts of society. The part that community engagement and public and patient partnership can play in tackling these issues is great and will continue to rise.

The Institute for Healthcare Improvement (IHI) recently noted in its *100 million lives* report[17] that 'better health and healthcare is an intrinsic result of community engagement [and] partnership' – and also noted that socioeconomic factors are critical for public health. While these determinants have been acknowledged, there is still room for growth in understanding how to apply the principles and practice of patient and public partnership to successfully address these issues.

LTCs, including diabetes and obesity, are key national and international health issues. In 2014, there were 15.4 million people living with a long-term condition, and 1.9 million with three or more, which is projected to rise to 2.9 million by 2018.[18] Obesity alone is estimated to cost the NHS £5 billion a year.[19]

It has been clear to both the public and clinicians that individual medical advice concerning type 2 diabetes and obesity is, as Wayne Farrah of Newham CCG explains, 'not working – and it is dispiriting both for both patients and clinicians'. The problem exists because a medical model alone is being used to address a phenomenon with multi-factorial causes, including social and environmental, and this will of course be insufficient as an approach. A ten-minute individual GP consultation is clearly incapable of addressing the wider factors underlying poor health.

In the meantime, it is important to remember that LTCs, in their very nature, form a chronic burden for patients as well as providers. This is why the IHI urges us to 'value the 5,000 hours that a person with an LTC manages their condition at home', and why it is important not to focus solely on short visits to healthcare providers.

Implementing the approach

But what does this all mean at the level of concrete practice and implementation? As we have seen demonstrated in Newham and Sheffield (see page 10), it is important that public and patient partnerships draw on evidence-based principles for community engagement and development. At the same time, it is also critical that PPP is seen as being indispensable for achieving sustainable and effective change, at all stages of the change cycle.

For example, Sheffield system partnerships included patient leaders and it was critical when undertaking groundwork to clarify which question, problem or issue to prioritise. Once the local question in Newham had been collaboratively identified and clarified, further time was given to finding out more about the issue in question, in order to deepen understanding of the factors giving rise to the problem. This gives the critical insights that then underpin and inform the next stage in the change cycle, which involves co-designing and then co-implementing the solution to the problem.

All too often there is pressure for rapid change. This creates stress for staff and patients, and often it is not clear how these changes are going to positively affect or address any specifically identified area for action. These kinds of scenarios explain why it has been estimated that up to 70 per cent of change initiatives fail within the health service.[20] The result is costly, stressful and ultimately unsuccessful innovations that undermine confidence and enthusiasm in future initiatives.

At both Sheffield and Newham, PPP shifted to being seen as essential to the design and implementation of sustainable and meaningful change rather than an unaffordable luxury. Understanding this means that the time cycle of improvement initiatives will also change. Although more time is taken initially to identify, understand and co-design a solution to the problem, the implementation phase then takes place more rapidly, is sustained and sustainable.

What does good public and patient partnership look like and how can it be carried out?

Having secured a commitment to PPP, it is also essential to appreciate three further key elements or aspects that enable it to be incorporated successfully. Although understanding that PPP is 'the right thing to do', it is not enough on its own to be able to implement changes that will deliver concrete and radical health improvements.

The first of the three key elements needed is the role of the 'translator', which draws on the work of Newham CCG, profiled at the NHS Confederation's first patient partnership event. This is a role that enables collaboration at each level of the change cycle, from groundwork to design and then implementation. The translator is someone who is both deeply rooted and respected in the community, and also has good relationships with clinicians and managers. In other words, they have credibility with clinicians and the community and will not be perceived as the 'expert from the CCG' or the board of management. However, they will also have the support of very senior managers within the health organisation, who perceive their work as essential.

A second element is budgetary and financial flexibility to allow the collaboratively designed solution to be commissioned and implemented. At the very least, it is important to consider how funding mechanisms can help or hinder, and what can be commissioned to supply what is needed to address the problem. For example, if community factors are behind the prevalence of LTCs, then it is likely that community organisations should be commissioned to provide services that will address the issue.

Factors ensuring/embedding successful change initiatives:

- patient partnership
- courageous leadership
- inclusion
- addressing power and culture
- utilising a strengths/assets-based approach.

(Roz Davies, Recovery Enterprises, Sheffield)

This kind of approach is known already as integrated commissioning. Collaborate/The New Local Government Network also refer to this as place-based or outcomes-focused commissioning. This is where the value becomes apparent having focused clearly on specifying the desired aim/s of the change process.[21] (For example, a focus on tackling diabetes, *then* working out what to do in collaboration with the community from specifying programme aims all the way to agreeing evaluation methods.)

"It is important to consider how funding mechanisms can help or hinder, and what can be commissioned to supply what is needed to address the problem."

The third element is that evaluation and outcome measures for improvement are built in. That is, ensuring there is something in place to assess whether the aim has been achieved. This goes beyond engaging in PPP just because it is 'the right thing to do', it is important to be both concrete and specific. A further issue to take into account, as Berwick has recently iterated (see IHI report), is that evaluation is about assessing the achievement of the desired improvements, and is not about accountability, primarily. Punitive measures can lead to misreporting, while gathering information that allows a genuine assessment of desired achievements increases motivation, while success can be demonstrated and celebrated.

"A further issue to take into account, as Berwick has recently iterated, is that evaluation is about assessing the achievement of the desired improvements, and is not about accountability, primarily."

Key factors for good public and patient partnership for effective change:

- Coherent theoretical model of health to underpin work

- Understand basic principles and evidence around effective change management, especially asset-based approaches such as appreciative inquiry

- Understand that effective sustainable change requires time to:

  - develop and establish relationships between community and clinicians/managers

  - co-develop a clear and specific vision

  - co-produce an implementation strategy

  - resource/enable community to implement the strategy

- Evaluation – use specific aims from the vision to develop informative measures that are meaningful to patients, clinicians and managers.

Conclusion

Good practice in patient engagement has traditionally aimed to improve patient safety, improve patient self-management, and gain feedback for service monitoring and improvements. However, as important and useful as these are, excellent practice involves extending the model of engagement to include genuine and meaningful public and patient partnership. This is an indispensable key that can facilitate effective and concrete gains even in apparently intractable LTCs, or other health problems with multi-factorial causes.

The effective practice of this work will entail effective patient engagement and community development as intrinsic activities. It will be essential to partner with individuals that have community credibility, as well as with clinicians and managers. Such individuals must also have influence and impact at a senior level, and will demonstrate equal respect for community organisations, while also helping all parties through managing expectations.

Enabling innovative and tailored local solutions to collaboratively identified problems, benefits from appropriate flexible financial systems and may involve integrated budgets across the health and local authority sectors.

As with other change initiatives, key to success is clarity of purpose and vision, then collaboratively working out the details of how this would be delivered and identifying who might best be to deliver the service(s) required.

The understanding has to be that engagement, or public and patient partnership working, is non-negotiable in terms of getting things done. However, it is also important to recognise that time is needed for this way of working. A key message from those on the front line of innovative change is 'don't expect too much too quickly'. (Newham's work took place over three years.) However, it is clear from the evidence where such work has been undertaken effectively, that the rewards in terms of concrete improvements in population health, in otherwise intractable health challenges, are more than worth the investment, both in terms of cost and in population health gain. Public and patient partnership cannot be overlooked if we are to have any significant impact on the major health challenges both now and in the future.

> "My role is to understand what the clinicians are saying and translate that for the community, and also understand what the community is saying and translate that for the clinicians. Partnership working also means we don't expect everyone in the community to come to the CCG at our convenience, but we will go to them."

Wayne Farrah, Vice Chair, Newham CCG.

Getting started – the Carman framework

In beginning a programme of improvement, many health organisations have found the Carman framework a helpful starting point. It enables organisations to map where they are, and where they might be intending to go.

Carman proposed three levels of patient engagement, across the three main areas in healthcare: direct care (the focus of Darzi); organisational design and governance; and, ultimately, policymaking. The three levels of engagement possible within each of these three areas are consultation; involvement; and partnership and shared leadership. Factors affecting effective patient engagement are patients themselves (particularly negative experiences of the patient role, health literacy); healthcare organisations' policies, practice and culture; and social norms, regulation and the broader policy environment.

Case studies
Newham CCG – reducing type 2 diabetes through public and patient partnership
Type 2 diabetes was identified collaboratively by Newham CCG and the community as a key health issue that needed to be addressed urgently. It was clear that individual advice was not working.

Designing effective interventions required recognising that people do not exist in isolation. Harnessing community knowledge, expertise and organisations was going to be necessary if the social determinants of chronic complex LTCs were going to be addressed.

The collaborative solution was the Newham Community Prescription (NCP) project. This involved a lead provider, a hub and spoke model where 50 per cent activity was delivered by commissioning local community partners to provide exercise and other social and community services to people identified by GPs as being at risk of type 2 diabetes. The GP would then refer them into the scheme, having discussed with patients their preferences and interests.

The scheme was evaluated throughout by Intelligent Health, which found that of the 1,079 patients who attended the NCP, 224 would have developed diabetes within two years. The uptake in physical activity, with its reduction of risk of developing type 2 diabetes, meant that 129 patients would not now develop diabetes. Given the cost per person with type 2 diabetes is £517 in treatment and £777 in complications, this creates a total saving of £333,594 each year, compared with a cost of the programme of £247,862 over two years.

Sheffield: Recovery Enterprises
Recovery Enterprises was established in 2012 by a group of people who live with mental health conditions. They wanted to work with an organisation who would specialise in helping them to fulfil their ambitions. Recovery Enterprises now supports the development of enterprising ideas, enabling them to flourish into businesses that benefit wellbeing. They do this by running a central hub that provides support to groups who are looking to develop their ideas. The hub offers a range of skills, resources and advice through its networks and team, all keen to help grow great ideas and confidence in abilities.

In April 2016 Recovery Enterprises, in collaboration with the NHS Confederation and other Sheffield healthcare organisations, held a leadership event to share learning on how to work in partnership with patients to co-produce innovation and positive change in healthcare.

Among other speakers at the event, TedX speaker and author Kate Allatt shared her inspiring story of recovery from locked-in syndrome. She focused on integrating peer support for healthcare right from diagnosis through to recovery and ongoing self-management. Kidney transplant patient and management expert, David Coyle, has worked in partnership with Devices for Dignity (part of Sheffield Teaching Hospitals NHSFT) driving forward patient-led technology design and development. He stressed that NHS organisations need to design and implement appropriate remuneration models for patient partners.

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NHS CONFEDERATION

NHS Confederation
50 Broadway London SW1H 0DB
Tel 020 7799 6666
Email enquiries@nhsconfed.org
www.nhsconfed.org

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