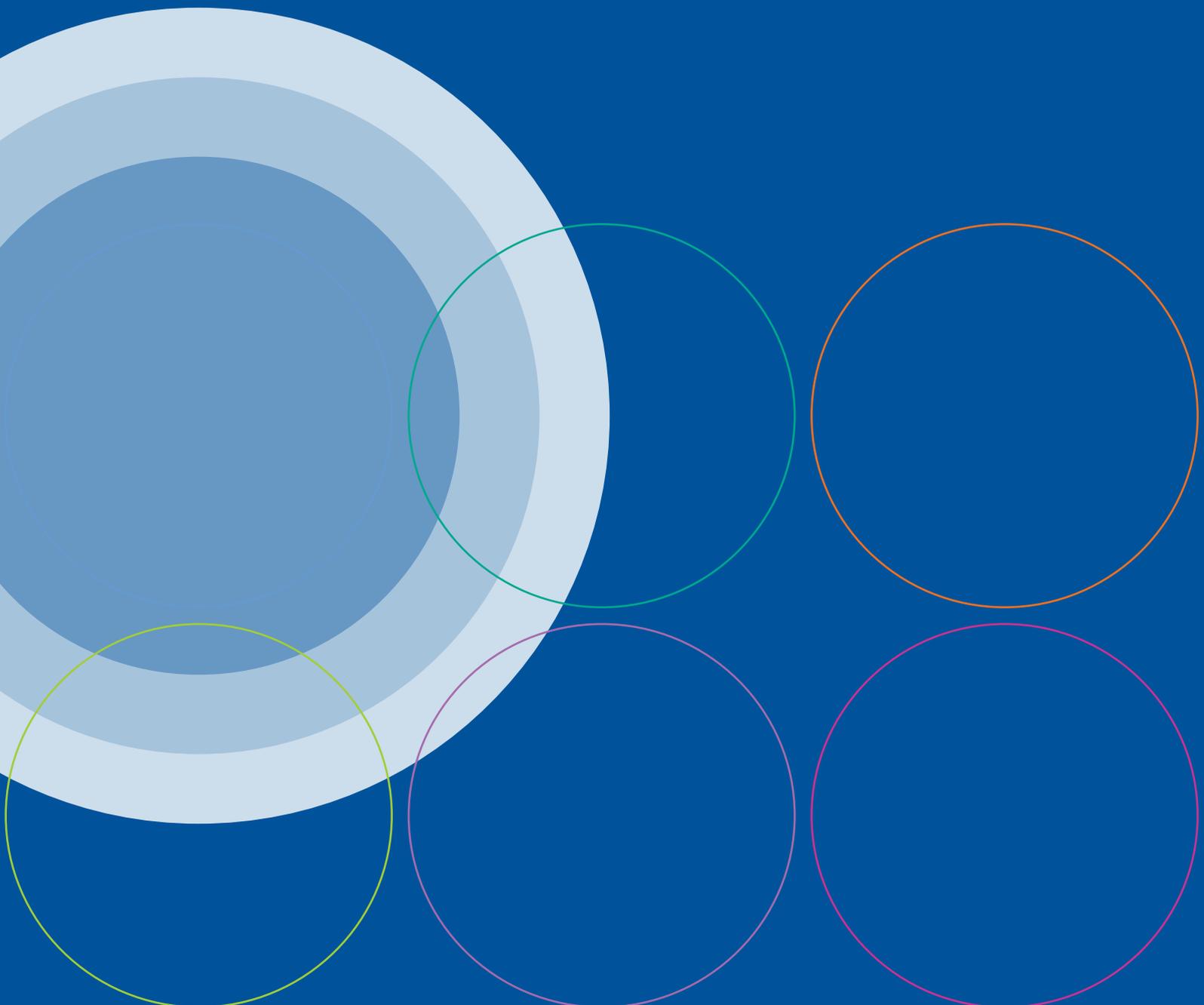


PEOPLE POWERED HEALTH: HEALTH FOR PEOPLE, BY PEOPLE AND WITH PEOPLE

April 2013

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FOREWORD

The NHS has developed incrementally since its inception but the times in which we live require more radical and rapid change. The proximate cause is unprecedented financial pressure on public services which demands innovations on a scale never seen before. The underlying cause is to be found in the ageing population and changing burden of disease which require new and different models of care better suited to the needs of the population today and in the future.

People Powered Health not only makes the case for transformational change but also outlines some of the key features of a system fit for the future. These features include putting people more in control of their health and well being; overcoming fragmentation through the development of integrated care; and giving more attention to resources in the community that can support the transformation that is needed. Critically, the paper also recognises that the main challenge is how to take these ideas from the drawing board into large scale adoption.

In the view of the authors, reforming a whole system calls for action on several fronts: changing how services are commissioned, mobilising and engaging patients, building clinical leadership, making use of financial incentives, changing what gets measured, and shifting investments in technology. As the title of the paper implies, the NHS needs to be open to learning from changes that have already occurred in other sectors where customers have been co-opted into the workforce. Making use of assistive technologies and giving patients access to their medical records are examples of what this might mean.

None of this will happen in the absence of a new type of leadership, described here as system leadership. And here is the rub. The NHS is replete with experienced leaders but most have spent their careers leading organisations and not systems. The challenge is to support these leaders to develop new skills in working across organisations and services particularly at a time when the old hierarchical structures of the NHS are being replaced with more fluid market like arrangements.

To make this point is to highlight the age old tension between planning and markets in bringing about the transformational changes that are needed. Are these changes most likely to result from new entrants to the health care market with service models capable of generating disruptive innovations in care? Or will they be the product of a new generation of system leaders able to break down barriers between existing providers, and with the vision to imagine a quite different future? The answer might be both, if politicians have the courage to permit or even encourage alternative evolutionary paths.

Chris Ham is Chief Executive of The King's Fund

ABOUT THE SERIES

People Powered Health: health for people, by people and with people is intended for leaders, managers and practitioners across the health and social care system. It draws on experience across the NHS over many years, and outlines the changes needed to help the health system make the most of the skills and commitment of employees, patients and communities, in addressing the biggest strategic challenge for health: the rising importance of long-term conditions. As it shows, this challenge requires a new balance between health provision for people, active health management by people, and mutual support with people.

The paper draws on the experience of the six local teams who took part in People Powered Health, which was led by Nesta and the Innovation Unit from summer 2011 to winter 2012. Following this report we will be publishing a series of learning products explaining why the People Powered Health approach works, what it looks like and the key features needed to replicate success elsewhere. The series will include:

- **The Business Case for People Powered Health:** building the business case, foreword by the NHS Confederation.
- **More than Medicine:** new services for People Powered Health, foreword by Macmillan.
- **People Helping People:** peer support that changes lives, foreword by MIND.
- **Redefining Consultations:** changing relationships at the heart of health, foreword by the Royal College of GPs.
- **By us, For us:** the power of co-design and co-delivery, foreword by National Voices.
- **Networks that Work:** partnerships for integrated care services, foreword by ACEVO.
- **People Powered Commissioning:** embedding innovation in practice, foreword by NAPC.

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- Calderdale
- Earl's Court
- Lambeth
- Leeds
- Newcastle
- Stockport

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Finally, we would like to acknowledge all those who have pioneered the thinking and practice of co-production on which People Powered Health is based. There is a growing community of practitioners, leaders and researchers who have developed and applied co-production over many years in public services.^{1,2,3} We want to recognise the important contribution made by the new economics foundation,^{4,5,6} as well as Edgar Cahn, David Boyle, Ben Jupp, Chris Sherwood, Mike Harris and Tom Shirley.^{7,8}

1 EXECUTIVE SUMMARY

This report, and the programme it's part of, make the case for changing the ways in which healthcare is organised. Specifically they show how healthcare can better combine the very best scientific and clinical knowledge with the expertise and commitment of patients themselves, as well as the families, communities and networks that they are part of.

The biggest challenge facing health systems is the rise of long-term conditions. But our existing systems were primarily designed to deliver hospital-based cures. That role remains hugely important. Yet it is becoming less relevant as the day to day management of chronic conditions has to happen in homes and workplaces rather than in medical settings. Just as important, healthcare has to respond to powerful evidence that social factors like isolation and class influence health outcomes.

The implication is that a successful health system needs to be effective in addressing these underlying causes of poor health as well as more familiar medical ones.

Much of this has been recognised for many years. But systems have been remarkably slow to adapt. There are many reasons for this, including the power of vested interests and financial models that do little to incentivise change. Another important factor is that research and development and innovation budgets have tended to prioritise such things as next generation pharmaceuticals, robotics and neurological imaging, rather than new ways of involving patients in their own care, let alone connecting patients to each other to talk or exercise. As a result promising innovations that embody the People Powered Health approach have tended to languish.

Many of these innovations have the potential to deliver substantial savings.

The most robust evidence predicts 7 per cent savings from the People Powered Health approach. These savings come from interventions that reduce expenditure on A&E attendances, planned and unplanned admissions and outpatient admissions.⁹ In national terms, this is equivalent to savings of £4.4bn across England.

A wider range of less robust, but still persuasive, evidence suggests potential savings of 20 per cent.

A major goal of this programme has been to understand how these successful innovations can spread more quickly. That's led us to analyse the barriers and potential enablers, and to address the practical measures that could be implemented relatively quickly, including new approaches to consultations and prescribing, workforce development, collaborative commissioning and a broader range of provision.

The vision

The People Powered Health approach offers a vision for a health service in which:

- The health and social care system mobilises **people** and recognises their assets – personal strengths and abilities as well as family, friends, communities and peer networks that can work alongside healthcare professionals and the community and voluntary sector to support patients to live well with long-term conditions.
- The ability to live well with long-term conditions is **powered** by a redefined relationship, a partnership of equals between people and health care professionals. These

relationships are trusting, purposeful and oriented to the needs of the individual and not the system.

- The **health** and care system organises care around the patient in ways that blur the multiple boundaries within and between health, public health and social care; and with community and voluntary organisations; and the boundaries between formal and informal support.

This vision is grounded in innovations that have emerged in health and social care over the last 20 years. It demands an urgent effort to make those innovations a normal part of our health and care systems. This will require a new balance between health provision for people, active health management by people, and mutual support with people.

What it looks like

This report advocates changing three vital components of the current system:

Changing consultations to create purposeful, structured conversations that combine clinical expertise with patient-driven goals of well-being and which connect to interventions that change behaviour and build networks of support.

- **Consultations** that are flexible, collaborative and have alternative structures, including group consultations, built according to what is most useful to the patient.
- **Self-management** support¹⁰ through care planning¹¹ and shared decision-making.¹²
- **Social prescribing:** a system of collaborative referral and prescription that incorporates social models of support in local communities, such as peer support groups.

Commissioning new services that provide ‘more than medicine’ to complement clinical care by supporting long-term behaviour change, improving well-being and building social networks of support. Services are co-designed to configure and commission services around patients’ needs.

- **Peer support groups** where patients and service users with shared experience or goals come together to offer each other support and advice.¹³
- **Platforms** such as timebanks that facilitate the exchange of time and skills between people.¹⁴
- **Coaching, mentoring and buddying** from professionals or peers offering structured support to help a patient to build knowledge, skills and confidence. This includes health trainers and navigators who guide and support individuals to make healthy lifestyle choices.¹⁵

Co-designing pathways between patients and professionals to focus on long-term outcomes, recovery and prevention. These pathways include services commissioned from a range of providers including the voluntary and community sector.

- **Integrated care**¹⁶ through collaboratives, partnerships and alliances that ensure care is joined-up from the service user’s perspective across health, care and voluntary providers.
- **Self-directed support** and personal health budgets¹⁷ that allows service users to

choose, with support, the solutions they need – increasing choice, control and personalisation.

- **Collaborative commissioning** focused on outcomes, including patient reported outcomes,¹⁸ and involving a wide range of people in commissioning, design and delivery of services.¹⁹

Realising the vision – how to change a whole system

The challenges facing the health and care system mean incremental improvements will be insufficient, instead; the NHS must transform itself through system change. Successful systems change will:

Change the way services are commissioned: to ensure the commissioning process reflects the lived experience of users, leads partnerships and collaborations, and supports market-making.

Make the most of new structures: to involve patients in commissioning; develop effective Health and Wellbeing Boards; and foster a diverse range of providers including the voluntary sector.

Encourage patients to take part in People Powered Health: by creating a social movement for change, including leadership from patient organisations to create grassroots demand.

Mobilise clinical leadership: from the Royal Colleges as well as individual clinicians, rewarding People Powered Health clinical behaviours and incorporating principles into professional standards.

Change financial incentives: towards payment for a ‘year of care’, longer term budgeting and a range of integration models that enable value to be shared across primary and secondary care.

Change what gets measured: to encourage recovery over treatment and incentivise demand reduction; and to focus on wellbeing and include patient-set goals.

Shift investment in technology: towards technologies that enable collaboration, self-management and effective communication; and to co-designed technologies developed for, with and by patients.

Transform organisational workforce culture: by making a clear case for change, developing staff motivation, embedding incentives throughout, and making the culture real and normal.

Create a cadre of system leaders: who focus on the overall vision of the system, distribute leadership opportunities and act in the interests of the wider system.

Strengthen the business case: by testing, adapting and iterating People Powered Health approaches, generating evidence that addresses user demand and strengthening networks of evidence makers.

These approaches are not only designed to enable patients to become more confident and better able to manage their conditions. They also aim to address the root causes of health problems, shift long-term behaviours and support social networks that improve health. The prize is the potential to improve health outcomes and reduce costs for the health system.

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	Traditional Health System	People Powered Health
Purpose	Main purpose: to diagnose, treat and cure acute conditions and infectious disease.	Main purpose: to prevent alleviate and manage long term conditions, as well as treating acute conditions swiftly, safely and effectively.
	Medical and physical definition of health dominant.	Social, psychological and medical definition of health.
Place	Health care mainly associated with delivery of services in hospitals and doctors' surgeries.	Health care mainly produced within communities, workplaces and at home, supported by infrastructure of professional services.
	People go to hospital and other formal health settings to be treated.	Accessible and pervasive health care available in community to provide a range of services.
	Health technologies, for testing, diagnosis, treatment mainly in hospitals, used by professionals.	Health technologies increasingly portable, distributed in communities, used by people.
	Innovation is mainly medical and technological.	Innovation is increasingly social and cultural, as well as medical and technological.
People	Health care delivered by doctors, nurses and trained health care professionals.	Health care involves collaboration among teams of people with diverse skills, including clinical and health care professionals but also coaches, trainers, counsellors, community workers and other support roles.
	People are patients in receipt of service.	People are partners in creating their own health.
	Patients are in need and are assumed to lack knowledge and skills.	People are capable of managing their own health issues with the right support.
	Patient motivation and capability secondary.	Motivation and capability of people essential.
	Patients treated individually.	Peer to peer support common.
Process	Orderly diagnosis and treatment by professionals along a defined, institutional care pathway.	Highly collaborative diagnosis and commissioning of solutions, in communities.
	Doctors tell patients what to do after analysing the case.	Doctors and patients agree what to do through conversational consultation.
	Growing clinical specialisation.	Growing cross disciplinary work.
	Health, social care and public health separate.	Health inseparable from social care and public health.
	People expect doctors to prescribe drugs.	Doctors prescribe social solutions as well.
	Health care directed by doctors, patients passive.	Self directed health care increasingly common, patients active.
Product	Medical definition of health: treatments that restore the sick to good health.	Social and medical definition of health: to promote living well, even with long term conditions.
	Public health a marginal, activity added onto medical services.	Medical and social approaches integrated to create new hybrid.
Payment	Services free at point of use.	Services free at point of use.
	Episodic care payments (paying by activity and outputs) reward high throughput.	'Year of care' payments to encourage providers to come together to achieve better outcomes for population.
	Financial systems that account for resources on an annual basis.	Longer-term budgeting that encourages evidence of impact over a longer time span.
	Expenditure supports fragmented care that revolves around institutions and clinical pathways, not patients.	Payments incentivise integration, moving services from acute settings to primary, community and home care.

2 INTRODUCTION

The ambition of People Powered Health is a health and care system powered by the people who work within it and are cared for by it. Health systems need to be powered by scientific and medical knowledge. But they also need to tackle the underlying causes of ill-health. The People Powered Health approach draws on the expertise and commitment of the people it serves, and supports them to change behaviours and create social networks that improve health. That's why we talk about a health system that is run for people, by people and with people.

The biggest challenge facing all health systems is the rise of long-term conditions. Our systems were primarily designed to deliver hospital-based cure, but healthcare is increasingly about managing chronic conditions outside of medical settings. Social factors powerfully influence health in both positive and negative ways – debt and loneliness can cause depression while peer support can help; smoking can cause pulmonary disease while doing exercise can ameliorate it. This means successful strategies to improve health must address the underlying drivers of poor health, not just the symptoms. The People Powered Health approach systematically addresses social drivers in mainstream health, through innovative practice, services and pathways.

The role of the patient in their own care is well recognised in shared decision-making, care planning, supported self-management, peer support and personal health budgets; and these agendas are vital building blocks of the People Powered Health approach. Many staff are working hard to make meaningful change to patient involvement in their own health. However, despite increasing consensus, change still feels patchy, ad hoc and sometimes superficial. For every clinician conducting genuinely collaborative consultations, there are others much earlier in their journey towards collaborative care. Without a clear, ambitious vision well-intentioned practitioners can retreat back to narrow interpretations of health literacy and self-management. People Powered Health sets out a partnership approach to health that tackles the underlying causes of health problems, supports long-term behaviour change and creates social networks that improve health. It does this to improve long-term health outcomes and reduce costs.

The individual elements of the system are already known, the challenge is to effectively spread what works beyond the innovators and early adopters to the mainstream of practice. In a system where innovation has become synonymous with next generation pharmaceuticals, robotics and neurological imaging, ideas like connecting patients to each other to talk or exercise can seem marginal. So perhaps it is not surprising that promising innovations that promote People Powered Health have tended to languish – even when they have the potential to deliver substantial savings.

There has been a failure of similar drives to sufficiently challenge the status quo and this change needs to happen in the midst of financial crisis, structural changes and a rapid increase in people living with long-term conditions, creating the opportunity and the urgency for change. Without this radical change, the health and care system will become rapidly unsustainable; with it, there is the potential to create a system that will sustain and build on the extraordinary achievements of its first 60 years.

3 THE CHALLENGE WE FACE: HEALTH BY PEOPLE AND WITH PEOPLE, NOT JUST FOR PEOPLE

Dorothy²⁰ is 82. She lives alone in the council house in which she brought up her family 50 years ago. As a child she cared for her sick mother and brought up her brothers. She left school at 14 and worked hard in physically demanding, low-paid jobs until they said she had to retire at the age of 60. She now has problems with her joints. The doctors call it poly-myalgia rheumatica. She calls it 'being crippled up'. When the weather is cold and damp (or hot and humid) she can't go out because the muscle pain and stiffness are too much. On top of that, she now gets short of breath, even if she just goes up the garden or to the bus stop. The doctors call it chronic obstructive pulmonary disease. She just says she has a bad chest. She has an oxygen tank at home for when it gets bad and is afraid to leave the house in case she has another attack where she cannot breathe. Last year she ended up in hospital after what the doctors called her 'exacerbation'. She was there for nearly a month.

There are lots of people like Dorothy in the UK. Her story is testament to the great 20th century successes of healthcare that have saved and prolonged lives.²¹ Diseases that were routinely fatal fifty years ago are now being successfully treated, which means many of us are living with conditions that cannot be cured. While sixty years ago, the challenge was to stop Dorothy dying from disease; now the challenge is to support Dorothy to live her life with disease – and for an increasingly long time.²²

The majority of people aged 65 and over live with a long-term condition such as cancer, hypertension, heart disease, diabetes and lung disease, with a quarter, like Dorothy, having two or more conditions.²³ These conditions impact significantly on their wellbeing and the lives of those around them, particularly carers. The consequences of living with disease can be far-reaching: worklessness,²⁴ poor quality of life,²⁵ social isolation and deteriorating mental health.²⁶ So, like many great advances, the effective management of acute and infectious disease has led to unforeseen consequences.

Another consequence is the financial cost of managing long-term conditions. Dorothy's month-long stay in hospital cost about £20,000. She has been taking the same drugs for her rheumatism every day for over twenty years. Overall, half of all GP appointments, two-thirds of all outpatient appointments and seventy per cent of all inpatient bed days are attributed to patients living with long-term conditions.²⁷ This is prohibitively expensive given the expected rise in long-term conditions over the coming years.^{28,29}

And, finally, the progress on infectious disease has left us with not just a clinical challenge, but a social-medical challenge. The diseases causing greatest pressure on our health system today are distinctively different from the 'big killers' of sixty years ago.³⁰ They are socially complex because lifestyles and behaviours are significant risk factors in causing and exacerbating them. These risk factors include smoking, drinking, lack of exercise and inactivity, poor diet and social isolation.³¹ And long-term conditions are at the heart of the health inequalities challenge because they are strongly affected by socio-economic status, education, employment and social exclusion.³²

At the same time, social factors can significantly improve long-term conditions. We know exercise improves blood sugar control for people with type II diabetes;³³ that patients with strong networks of social support are more likely to take their medications;³⁴ and that changing your diet can reduce high blood pressure.³⁵

Lifestyles are influenced by the behaviours of family, friends and neighbours^{36, 37, 38} who provide the real-life social context for diet, exercise, smoking and drinking – and for our capacity and confidence in managing our own care.³⁹ It is hard to change your diet, unless other members of your household change theirs. It is hard to reduce alcohol intake if your social life is centred on the pub. It is easier to quit smoking in a group than on your own.^{40, 41} It also means that a GP telling a patient to lose weight may be insufficient without effective social interventions to support long-term weight loss.

Dorothy is fortunate – she has a strong network of informal care and support from friends, family and neighbours; and looks forward to her weekly ‘knit and knatter’ group. But Dorothy is worried about those friends who don’t have family to help, don’t get out and feel overwhelmed by their ill health. The social fabric of our lives has changed enormously in the last sixty years and health and care systems have not adapted.⁴² It is significant for managing long-term conditions that more people live alone; families and friendships are less likely to be local; and communities have been changed by mobility, migration, and employment.⁴³ Where the supportive social fabric has worn thin, the impact on health outcomes and demand for acute care is clear.⁴⁴

The biggest challenge facing all health systems is the rise of long-term conditions. Health systems were primarily designed to deliver hospital-based cures, but healthcare is increasingly about managing chronic conditions outside of medical settings. Social factors like isolation and class play important roles in influencing health outcomes and successful strategies to improve health need to address these underlying drivers of poor health, not just the symptoms.

The shift to a People Powered Health approach requires everyone – patients, health and care professionals, commissioners and policymakers – to change. This shift will not happen without a compelling vision and practical strategy for whole-system change.

4 PEOPLE POWERED HEALTH: A FUNDAMENTAL SHIFT IN ETHOS AND PRACTICE

The People Powered Health approach offers a vision for a health service in which:

- The health and social care system mobilises **people** and recognises their assets – personal strengths and abilities as well as family, friends, communities and peer networks that can work alongside healthcare professionals and the community and voluntary sector to support patients to live well with long-term conditions.
- The ability to live well with long-term conditions is **powered** by a redefined relationship, a partnership of equals between people and health care professionals. These relationships are trusting, purposeful and oriented to the needs of the individual and not the system.
- The **health** and care system organises care around the patient in ways that blur the multiple boundaries within and between health, public health and social care; with community and voluntary organisations; and the boundaries between formal and informal support.

This vision is grounded in innovations that have emerged in health and social care over the last 20 years. It demands an urgent effort to make those innovations a normal part of our health and care systems. This will require a new balance between health provision for people, active health management by people, and mutual support with people.

CO-PRODUCTION

Co-production is an approach to public services where solutions are designed and delivered with people rather than ‘to’ and ‘for’ them. Co-production sets out an alternative to the dominant model of public services in which professionals design and deliver services for needy users.

Co-production changes the starting question from “*what services do you need?*” to “*how do you want to live your life?*”. The solution often involves professionals enabling people to connect into mainstream life, rather than taxpayer funded services. By doing so it opens up opportunities for long-term recovery, less dependence on formal public services, and more effective ways of combining public resources with the assets of citizens and wider communities.

The underlying principle of co-production is that people’s needs are better met when they are involved in equal and reciprocal relationships with professionals and others, working together to get things done. Nesta and **nef** developed some principles of co-production which included recognising that people have existing capabilities, not just needs; the role of mutuality and reciprocity in public services, including peer support networks; and blurring distinctions between professionals and users so that professionals facilitate rather than deliver.

For more information see [Public Services Inside Out](#)⁴⁵ and the [People Powered Health Co-production Catalogue](#).⁴⁶

PEOPLE POWERED HEALTH: THE PROGRAMME

The vision for a People Powered Health approach has been developed in the context of an 18 month innovation programme on long-term conditions run by Nesta with the Innovation Unit. The People Powered Health programme was launched in England in spring 2011 with a call for ideas for how co-production could be applied at scale to support people to live better lives with long-term conditions. In total 106 teams applied to be part of the programme and after a three-stage selection process, six teams from places across England took part in the programme.

The local teams were each awarded a £100k grant and provided with a range of non-financial support to develop their capacity in fields such as co-production, service design, business case development and commissioning. We established a peer network between the teams to enable them to learn from one another as well as from external experts.

The teams represented different parts of the health system: secondary care and primary care, mental health and cross-condition, individual primary care centre and whole city transformation. We followed their journey in detail, offering support and challenge, and capturing their learning through a series of practical learning products which will be published following this report. Each has been endorsed by an organisation that shares our commitment to the People Powered Health approach, reflecting the wider coalition of support:

- **The Business Case for People Powered Health**, foreword by the NHS Confederation.
- **More than Medicine**: new services for People Powered Health, foreword by Macmillan.
- **People Helping People**: peer support that changes lives, foreword by MIND.
- **Redefining Consultations**: changing relationships at the heart of health, foreword by the Royal College of GPs.
- **By us, For us**: the power of co-design and co-delivery, foreword by National Voices.
- **Networks that Work**: partnerships for integrated care services, foreword by ACEVO.
- **People Powered Commissioning**: embedding innovation in practice, foreword by NAPC.

This report advocates change to three vital components of the current system – consultations, services and pathways – that hold the key to wholesale transformation.

Changing consultations to create purposeful, structured conversations that combine clinical expertise with patient-driven goals of well-being and which connect to interventions that change behaviour and build networks of support.

- **Consultations** that are flexible, collaborative and have alternative structures, including group consultations, built according to what is most useful to the patient.
- **Self-management** support⁴⁷ through care planning⁴⁸ and shared decision-making.⁴⁹

- **Social prescribing:** a system of collaborative referral and prescription that incorporates social models of support in local communities, such as peer support groups.

Commissioning new services that provide ‘more than medicine’ to complement clinical care by supporting long term behaviour change, improving well-being and building social networks of support. Services are co-designed to configure and commission services around patients’ needs.

- **Peer support groups** where patients and service users with shared experience or goals come together to offer each other support and advice.⁵⁰
- **Platforms** such as timebanks that facilitate the exchange of time and skills between people.⁵¹
- **Coaching, mentoring and buddying** from professionals or peers offering structured support to help a patient to build knowledge, skills and confidence. This includes health trainers and navigators who guide and support individuals to make healthy lifestyle choices.⁵²

Co-designing pathways between patients and professionals to focus on long-term outcomes, recovery and prevention. These pathways include services commissioned from a range of providers including the voluntary and community sector.

- **Integrated care**⁵³ through collaboratives, partnerships and alliances that ensure care is joined-up from the service user’s perspective across health, care and voluntary providers.
- **Self-directed support** and personal health budgets⁵⁴ that allows service users to choose, with support, the solutions they need – increasing choice, control and personalisation.
- **Collaborative commissioning** focused on outcomes,⁵⁵ including patient reported outcomes, and involving a wide range of people in commissioning, design and delivery of services.⁵⁶

The People Powered Health approach draws on the work of many people working in health and social care who have pioneered these approaches over many years. They understand the importance of families, communities and peers;⁵⁷ of working in equal partnerships with patients;⁵⁸ of overcoming the boundaries that fragment care;⁵⁹ and the impact of the social determinants of health.⁶⁰ The challenge, therefore, is less one of new ideas and more of large-scale adoption and adaptation of principles and practice.

Systemic innovation is the most ambitious and difficult route to take but it is needed if the People Powered Health approach is to become a reality.

“ [Systemic or transformative innovations] require fundamental changes in organisational, social and cultural arrangements... They entail constructing different relationships between users and services, new institutions and relationships between institutions, new funding regimes, major alterations in governance and accountability, and, not infrequently, a redistribution of rights and responsibilities among the public, managers and professionals.”⁶¹

There are a number of structural barriers that have prevented the People Powered Health approach being adopted at scale. Most notably:

- **What we measure and value.** The current system struggles to measure outcomes, especially outcomes that patients care about it. Instead, its default is to measure activities, inputs and outputs.

- **How we commission and pay for services.** The commissioning and payment of episodic care undermines the development of the People Powered Health approach by disincentivising long-term approaches to integrate care or reduce demand.
- **The dominant culture of the workforce.** NHS workforce culture is strong and, at its best, focuses relentlessly on clinical excellence. However, it has traditionally shown resistance to more equal working relationships between management, clinicians, patients, non-clinical practitioners and communities. It is also dominated by an approach that focuses on individual body parts rather than the wider determinants of health.

Strong leadership is needed to drive the creative re-shaping of the system. The status quo has proven resistant to equivalent challenges and it is difficult to change a system that was built on a different set of assumptions. The changes advocated in this report will transform professional identities and roles, as well as challenge the expectations of patients to be cured by professionals. There will be discomfort on both sides although the shift will, ultimately, be more rewarding for both professionals and patients, and more financially sustainable.

Changes to NHS frameworks, including the NHS England mandate, provide a window of opportunity for radical, systemic innovation. The second half of this paper looks at how the barriers to change can be overcome. First, we look in more detail about what this vision means in practice for three familiar elements of the current system: consultations, services and care pathways.

4.1 PEOPLE POWERED PRACTICE: REDEFINING CONSULTATIONS

“ *The relationship between doctors and patients is at the heart of our health system. If we want a different health system, we need a different type of relationship.*”⁶²

There are over a million consultations held in the NHS every 36 hours – about 300 million every year.⁶³ They happen in GP consulting rooms, in outpatient clinics, at hospital bedsides, at home and on the phone, with countless different health and social care professionals. The vast majority of these interactions follow a set pattern, the rules of engagement, which governs how patients are examined, histories established, symptoms described, test results discussed, progress monitored, treatment options given and decisions made.

This top-down, directive model is both economically unsustainable and inadequate in achieving long-term health outcomes. Face-to-face consultations represent a massive investment in time, buildings, facilities and training; yet they often remain a relatively blunt use of time – underutilising data (e.g. when test results are not fed in beforehand), underutilising the learning moment (e.g. instructing patients in a pressured environment) and underutilising the patient (e.g. reinforcing expectations that the clinician solves the health problem).

The potential for consultations to be a site of innovation is, however, being increasingly recognised. Across the UK services, providers and projects are changing the game, moving towards new models of interactions between patients, service users and the health service that focus on outcomes, not outputs. They are creating purposeful, structured conversations that drive towards patient-driven goals of wellbeing. This new partnership is being demonstrated in settings ranging from acute mental health to musculoskeletal support groups. All rely on a core set of interventions: changing the format of consultations; widening the conversations that take place within them; and rebalancing the relationships of those who take part.

The relationship between patients and healthcare professionals is a key element of the People Powered Health approach; a dynamic built on trust where power, expertise and agency are shared.⁶⁴ Consultations take place in this context of collaboration – a meeting of equal partners with a common purpose. One brings professional expertise, clinical excellence, technical experience, support and navigation. The other brings personalised information on their illness and its effects; knowledge about their lifestyle; their willpower, motivations, goals and aspirations.

The traditional model of consultations reinforces a power imbalance between clinician and patient. It can create paternalistic relationships that reduce patients’ control, risking what the Health Foundation terms the ‘systematic disempowerment’⁶⁵ of patients. There is a widening disconnect between how patients and clinicians view these transactions:

“ *One key issue is that many doctors already feel that they are delivering patient centred care – unfortunately that is not what patients report.*”

Dr Nigel Mathers, Vice Chair, Royal College of General Practice

The nature of the patient–doctor dynamic plays out and is reflected elsewhere – what happens in that enclosed space between clinicians and patients sets the tone for interactions throughout the system. The Health Foundation states that “*not only is the quality of the direct interaction reduced by the current dynamic, but also that the adaptive capacity (ability to innovate) of the NHS is handicapped by the current dynamic (protected doctor and disempowered patient).*”⁶⁶

Changing the format

It is possible to completely transform the dynamic of consultations by altering how they happen. The format of consultations is restricted only by current norms of practice; in reality, they can take a number of different forms. They can be for individuals or groups, delivered in a variety of formats – with more than one patient; with more than one clinician;⁶⁷ over email or Skype;⁶⁸ or with more flexible lengths of appointment according to a patient's needs.

Evidence from Calderdale⁶⁹ and research from the Health Foundation⁷⁰ suggests that one-on-one consultations can be ineffective, with patients failing to take in much of the information that is given to them due to the lack of time for reflection and a pressured environment. In contrast, **group consultations** create a context of open discussion and collaborative problem-solving, facilitated by a practitioner but centred around learning from peers, with space for in-depth discussion about treatment, behaviour, decisions and next steps.⁷¹ Patients build stronger relationships with staff and with other members of the group, creating networks that extend beyond the clinical setting, and progress can be benchmarked against that of others.

While nascent in the UK, group consultations have been trialled in a range of settings in the USA including in maternity⁷² and diabetes care.⁷³ A systematic review of shared appointments for long-term conditions in 2012 showed that group consultations improved intermediate clinical outcomes for type 2 diabetes.⁷⁴ They are also efficient – groups in Calderdale and in the Service User Network (SUN) in Croydon number up to 15 patients at a time and involve one or two clinicians. The SUN programme, which uses group consultations for people with personality disorders, has demonstrated that this model results in people being better able to manage their crises, helping them to avoid harmful situations and reducing admittances to A&E by 30 per cent.⁷⁵

PEOPLE POWERED HEALTH IN CALDERDALE: GROUP CONSULTATIONS IN A PAIN CLINIC

As part of the People Powered Health programme, Calderdale piloted group consultations for patients with musculoskeletal pain. The new model supported patients in self-management, created more equal partnerships between professionals and patients, and ensured that the skills and capabilities of service users played an instrumental role in service improvement and delivery.

Consultations were led by an advanced practitioner and physiotherapist. Instead of a follow-up clinic, patients who have recently had a spinal injection were invited to come to a group consultation for two and half hours. The new model provided a supportive space for patients to motivate one another and rebalanced the consultation dynamic by putting patients in control of the agenda, with the clinician as facilitator.

“ We set an agenda for people to go round the room asking one after another what was the most important thing they could talk about. It happened that by the time they'd got to the end of the group most of the agenda had formed itself... The bond that formed in the group through agenda setting was significant and helpful.”

Dimple Vyas, Consultant Anaesthetist

The focus of the consultations was on the issues patients faced, both collectively and individually, and on setting goals and agendas for future group and individual appointments with clinicians. Follow-up groups happened two weeks after the first session, to give patients time to reflect and progress towards their goals.

Changing the conversation

Consultations as the basic building blocks of interactions between patients and practitioners carry enormous potential as a space in which to jointly assess needs and capabilities; identify health and wellbeing goals; develop and design a plan for treatment; review progress and evaluate success. The role of the professional is to facilitate and advise, not dictate.

“*There's been a cultural and professional change in attitude, mindset and behavior, and I can say that having come originally from a clinical background. Certainly when I did my training as a clinician some years ago, it was very much the professional or the clinician who knew best, knew most – led the conversation. What we're talking about is a change in circumstances where in many cases the person, patient, service user knows best and they lead that relationship and that conversation.*”

Paul Morrin, Director of Integration, Adult Health and Social Care Leeds Community Healthcare Trust

Care planning and **pathway planning** are both structures for managing this process. Both methods aim for the same target – giving patients control over their care, its direction and goals, the knowledge of what to do in moments of crisis, the confidence to take charge of their own health where they are able and a structure of support for when they are not.

Care planning stems from clinical practice and follows a recommended structure, for example that outlined in the NHS Diabetes Year of Care programme. This approach has a built-in aim of supporting patients to better manage their condition through an engaged and informed patient, a healthcare professional committed to partnership working and supported by organisational processes and effective commissioning.⁷⁶

In the People Powered Health approach, care planning is part of wider pathway planning, which encompasses any service that may help with a patient's overall wellbeing. This could range from peer support, to advocacy or assistance with housing, to exercise classes, to volunteering opportunities – with clinical care, self-management and crisis plans included alongside. Those working alongside the patient may be clinicians or different roles, such as peers, health trainers, volunteers or advisors.

PEOPLE POWERED HEALTH IN LEEDS: CARE PLANNING IN PRACTICE

The Leeds Transformation Programme is a city-wide agreement to work towards a new model for health and social care. It has implemented a three-step model of system change for supporting those with long-term conditions: risk stratification; integrated teams; and systematic self-management. A core part of the project is focused on systemising self-management across the city, working jointly with service users, carers, the voluntary sector and local communities to co-design, co-deliver and embed a network of support across health and social care.

The model rests on patients and carers being supported through a care planning process to identify and achieve their own goals, including education programmes in shared working for professionals and patients. The emphasis is on professionals' facilitation and guidance role, helping patients through an evidence-based appraisal of the options available to them.

Care planning is expected to reduce reliance on acute health services, reducing the number of GP visits, length of hospital stays and long-term social care placements, bringing significant financial benefits. It will also improve the health and quality of life of patients by helping them to be more independent, more active in their communities, and expanding their networks of support.

The process can (and often does) result in a written plan (and is better when it does so), but it is the act of collaborative working that is most important, enabling the patient or service user to:

- **Set the agenda of the consultation** around what they would like to achieve. This might be clarity around what their goals are; compiling a list of questions; or constructing a fully formed plan.
- **Set their own goals.** While the medical goal of a hip replacement might be to be able to walk a certain distance unaided, the patient's goals are more likely to include activities such as playing sport, gardening or getting out and about on the bus. The practitioner's role is to assist in choosing achievable goals, and developing a plan to achieve them and identifying potential barriers.
- **Develop a care plan** to map out how these goals will be met, building these into a 'contract of responsibilities', with commitments on action from both sides,⁷⁷ that identifies barriers to progression and builds a package of care that describes where, how often and from whom care and support can be provided.
- **Review progress** according to their own metrics of success. Have any further barriers been identified? Are they ready for the next step? Are these still the right goals?

Changing roles and relationships

Patients' expertise in their own care and condition is becoming more valued by the health service. Just as important is valuing the expertise of non-clinical professionals, volunteers and peers as core, not supplementary, providers of care – and allowing these people to work under the consultations banner. There are a range of possible roles – navigators, health trainers, pathway planners, wellbeing coaches, community matrons and advisors – to offer different viewpoints, contexts and methods of care alongside doctors, nurses and consultants.

The culture change required for collaborative working can be difficult for patients as well as professionals. Both have become accustomed to the current dynamic, even if they are frustrated by it. Successful consultations require engaged, informed patients; practitioners committed to partnership working;⁷⁸ and an atmosphere of trust. Wider culture change is needed, including education and re-training for clinicians; leadership and standards-setting from professional bodies; the fostering of new practices by policymakers and regulators; contexts for new ways of working; and patients and their groups experimenting with how they can best contribute.⁷⁹ In turn, this relies on a referrals system that is robust at both ends: clinicians knowledgeable and willing to refer patients to more than medical provision; and a flexible, agile commissioning process that is responsive to community needs.⁸⁰

4.2 PEOPLE POWERED SERVICES: MORE THAN MEDICINE

“ Medication doesn't help with your relationship concerns; your inability to get a job; not being able to manage on the finances that you've got. Very often these situations can escalate until people get very poorly and aren't able to deal with them on their own... The services here put people back in control, choosing what pace they travel down different pathways. The choice and control are back with the individual, which often means managing without medication. That's very helpful, to have the option of a social solution rather than a medical solution.”

Shirley Dean, Co-Director, All Together Positive, Stockport

In a People Powered Health approach consultations result in social prescribing:⁸¹ referrals, resulting from collaborative consultations, to services that provide more than medicine. That could include prescriptions to non-clinical interventions such as exercise and activity, diet and nutrition, arts-based therapies, peer support, coaching and mentoring, and employment and welfare⁸² support as well as medical interventions.⁸³

Alternative provision is not intended to replace traditional planned medical care, but to complement it by supporting long-term behaviour change, tackling the root causes of health problems, improving confidence and wellbeing, providing social networks of support and reducing demand for unplanned medical care. This means developing an infrastructure to reliably and consistently deliver social models of support to enable people to live healthier lives, to manage their conditions better, and to tackle underlying issues such as debt.

This infrastructure needs to be as reliable and accessible as pharmacies to provide a cost-effective source of long-term behavioural change using both peers and professionals. This alternative provision is significantly less expensive than unplanned and emergency care,⁸⁴ utilising existing but untapped resources in communities, peers, families and patients themselves. It requires:

- **A range of alternative services to which GPs refer, both formal and informal.** Commissioning bodies should be engaging with non-clinical providers, community groups and patient organisations to proactively commission provision that supports patients to build confidence, manage their conditions better, support others and sustain long-term behaviour change.
- **A more collaborative relationship** between commissioners, practitioners, patients, secondary and primary care providers and non-typical provision. Building stronger relationships between all parts of the system results in GPs who are knowledgeable about the alternative provision on offer; consultants being more informed about the patients they are receiving; and the system better able to anticipate need.
- **The ability for patients to self-refer** through more open-access services and better local awareness of available options.
- **Platforms or systems that make the process as straightforward as possible**, including procedures within practices and clinics that systematically prompt referrals to non-medical interventions and alternative provision for patients and carers and service users who meet particular criteria for example based on an analysis of risk factors linked to a demographic profile. This would include referrals to patient and carer organisations, user-led organisations, support groups and other peer networks. Crucially, these systems would not rely on clinicians having a detailed knowledge of all the alternative provision in the local community.

Services that provide more than medicine

Services operating in a People Powered Health approach engage with patients and service users as assets and contributors to care, not just recipients of it. They mobilise communities and networks to support people on their terms – whether it's Bengali men cooking together or a 'knit and knatter' group run by people recovering from mental health problems. These services are co-designed and co-delivered by patients, enabling them to meet not only medical needs but wider social, physical and mental wellbeing goals. They complement medical care in primary and community care settings, and are often built around those services.

Voluntary and community groups

Voluntary and community groups have a vital role to play, providing services that can address the isolation and loneliness associated with long-term conditions as diverse as arthritis, stroke and depression, ranging from healthy eating courses, to art therapy, to yoga and gardening. These opportunities improve health and wellbeing by promoting healthy eating, exercise and activity, as well as providing therapeutic experiences. Crucially, they also provide social relationships – friendships, connections and conversations that are in themselves beneficial to health and wellbeing.⁸⁵

In Tower Hamlets, Bengali men with diabetes can take part in a cooking course organised by Social Action for Health. This course enables men to learn about healthy eating by learning a new skill and creating meals together. Platforms like the Greenwich Healthy Living website⁸⁶ help improve access by collating the services available in an area from a wide variety of providers.

Self-directed support and personal budgets

Personal budgets and self-directed support enable patients and service-users to determine what care and support they need. In Lambeth, mental health service users are taking part in a trial of personal health budgets. Users work with staff to set goals and develop a care plan, and are allocated a personal budget and the decision-making power on how to spend it. They might decide to sort out their accommodation, to pay for a training course to build their confidence and help get back into work, or for respite care twice a year. The budgets help increase service users' choice, flexibility and control over their care.

Peer support groups, peer mentoring and buddying⁸⁷

People who are living with a long-term condition build up a huge amount of expertise in how to navigate the care system and manage their own condition. Peer support groups, peer mentoring and buddying all capitalise on this expertise by linking those with similar conditions so that they can learn from one another and by encouraging patients to build social networks that will support them.

Peer support is not just for patients who are moderately ill. Hospitals have run peer mentoring programmes, or peer support groups with seriously ill patients for many years⁸⁸ to reduce dependency and length of stay and to enable discharge to primary care. Peer support has been shown to reduce the likelihood of psychiatric hospitalisation and demand for other costly services.⁸⁹ Users of peer support in mental health services consistently report high levels of satisfaction and recommend that more opportunities be made available as part of service improvement efforts.⁹⁰

CRAFTY NEEDLES: PEER SUPPORT IN STOCKPORT

Social isolation and loneliness, often linked to old age or a dramatic change in personal circumstances such as bereavement, redundancy or ill health, can be both a cause and a symptom of mental health problems. Crafty Needles, based at the Wellbeing Centre in the heart of Stockport, is just one example of how an activity-focused peer support group can help reconnect people with their community, helping them to get well and stay well.

Essentially a knitting circle for people with mental health issues, Crafty Needles has some important features which help to explain its popularity and success. The group is led by Penny and Cindy, volunteers who are themselves recovering from long-term mental health problems. The group has a purpose: they knit blankets for homeless people and tiny garments for preterm babies in the local neonatal unit. The group is inclusive, helping a range of people – some referred by health professionals, family or friends and some who pop in out of curiosity. This creates such a positive atmosphere that a chess group now meets at the same time to chat too.

Navigators⁹¹

One of the key features of a People Powered Health approach is patient-centred, designed and delivered systems to help people find their way around the health system. These systems could be online guides and directories, or peer or professional navigators whose role it is to guide others.

In social care, navigators often live within the community and work to support local service users to live independently. Local Area Co-ordination⁹² teams support 50–60 families by acting as their first port of call and helping to build informal support networks.

Patient education groups

DESMOND⁹³ (Diabetes Education and Self Management for Ongoing and Newly Diagnosed) is a series of structured group education programmes to help people manage their diabetes. Available to newly diagnosed individuals, teenagers and those with pre-diabetes, the programmes provide learning through story-telling and group discussion rather than traditional didactic health education techniques. The programmes cover medication, healthy eating for diabetes and physical activity.

The Experts Patient Programme is a series of classes for people who have had a long-term condition for over a year. Being taught by expert patients with similar conditions helps members cope with common problems such as depression, exercising and communicating with friends, family and doctors.

Coaches and health trainers

Often, patients need a little help in building their knowledge, skills, motivation or confidence. Coaching can be done by healthcare professionals or other patients and is analogous to the existing role that Health Trainers play in the NHS, enabling patients to help themselves.

In the Earl's Court Health and Wellbeing Centre a nurse has retrained as a wellbeing coach and is supporting patients with long-term conditions and mental health problems. The coach's role is to encourage patients to recognise the changes they want to make and to advise them on how to achieve these changes.

HEALTH TRAINERS IN NEWCASTLE: WORKING TOWARDS INTEGRATION

“ *The role of the health trainers in the centre itself is one of motivation and inspiration. They ask you how you are feeling, how you are moving, how you are doing. I can now walk 100 yards without stopping, it might not sound like much but at one point I couldn't walk one yard without stopping.*”

Albert, patient with COPD from Newcastle

Newcastle has a long history of social prescribing and health trainers are fundamental to the success of their approach. The health trainer programme has specific suitability criteria, with primary criteria that patients are over 50s with a long-term condition, and secondary criteria that they are a smoker, have a BMI over 30 or are from a deprived ward.

Healthworks, which runs the programme, has 20 paid health trainers who work with clients to develop and work towards achievable goals. This could involve helping them to get started in a local gym, joining them on their weekly shop to choose healthy food or linking them with community-based activities.

Platforms for giving and participating⁹⁴

Timebanking is often used as a platform to enable people to give their time, effort and skills to the community. There is evidence that timebanks can improve health outcomes – an evaluation of the Rushey Green Timebank, based in a primary care centre in South London, found that there was an association between involvement in timebanks and reduced levels of medication and hospitalization.⁹⁵ Research by a health maintenance organisation in Richmond, Virginia (USA) found that involvement in their timebank reduced hospital admissions and visits to casualty and asthma services to the extent that \$217,000 was saved over two years.⁹⁶

Headway East London, which supports people with long-term brain injuries, runs a timebank and other platforms that allow patients, friends, family and carers to contribute their time and skills to the running of the centre. This creates real opportunities for people who find the job market difficult to get into or unsuitable for their condition.

EARL'S COURT HEALTH AND WELLBEING CENTRE: SETTING UP A TIMEBANK

At the Earl's Court Health and Wellbeing Centre, Timebanking UK has set up a timebank alongside the GP practice, dentist and sexual health clinic. The timebank originally focused on health and wellbeing (e.g. physiotherapy, Indian head massage, yoga) but was expanded to acknowledge that many members have skills that are not directly health-related but nonetheless have an impact on wellbeing. Community researchers and navigators offer and promote the timebank to the local community; prospective members are asked to apply formally and their applications are added to a web-based system by navigators, who have an important role matching people who could exchange skills.

Having the timebank embedded in the centre improves access and referrals, with the involvement of everyone who works at the centre in the timebank, including GPs, receptionists and staff, adding credibility and weight.

“ *They can ask anyone in the centre about timebanking – they could be sat in the dentist’s chair and the dentist would be able to tell them about it.*”
Sarah Bird, Timebanking UK

Putting it into practice

The ‘more than medicine’ services described here are not an exhaustive list, and there is no standard model of services that represents a People Powered Health approach – the particular combination of services depends on local circumstances, assets and priorities. A crucial way of ensuring that services really provide what patients need, and in the ways they need it, is for health and care professionals to design services with patients rather than for them. This requires going beyond ‘engagement’, ‘involvement’ and ‘person-centred’ towards real co-design and co-delivery at every level of the health service – design, provision, delivery, commissioning and strategy.

4.3 PEOPLE POWERED PATHWAYS: CO-DESIGNING ROUTES THROUGH CARE

“ For me I just see it as a pathway through woods, a forest, and there are different routes off that path. There’s got to be a starting point on that pathway of where you are and it’s about taking those steps on that pathway. At some points you will walk alone and at other points people will walk along with you. And you set your journey, your stepping stones of how you are going to get through the woods.”

Barry Tildsley, Prevention and Personalisation Coordinator, Stockport

The People Powered Health approach requires more than different consultations and services. It needs to be backed up by a coherent set of systems and structures that join-up care through an unwavering focus on the patient’s perspective – building webs of care, collaboration and communication around patient-centred outcomes and goals.

There is consensus within the NHS that more collaboration around care is needed⁹⁷ and widespread commitment to integrated care. But, from the point of view of patients (and, indeed, many practitioners), standard episodic care creates fragmented and complicated pathways.⁹⁸ Too often, pathways are specific to primary or secondary care, and built around services and institutions – creating discontinuity for patients and ever-shifting system responsibilities. They rarely integrate well with social care or take into account voluntary organisations, informal care networks⁹⁹ or the support services commissioned by local authorities.¹⁰⁰ Pathways are disease-specific, not combining easily for patients with more than one condition, and can result in frustrating services with a risk of patients falling between them.¹⁰¹

What is required is care that is flexible enough to allow real personalisation, including points of entry and exit. This does not necessarily mean a highly complex programme of top-down integration – often it is as much about regular conversations between services and one key point of contact for patients. The route each patient constructs should be determined not by their condition but by their goals, supported by a system that can adapt over time as these progress or change. So, in Lambeth, people with mental health problems can, with support of a Community Options worker, choose between the home treatment team, peer retreat house, crisis house, psychiatrist, peer supporter and therapeutic services. The particular route through these services will differ for individuals depending on the nature and severity of their condition and exacerbations, their wider social support networks and so on. The goal is to enable people to access services that best fit their needs and enable them to recover as effectively as possible to live the life they want.

While standardisation is helpful in achieving some minimum requirements and can create efficiencies, it is not good at exceeding these baselines. Patients living well with long-term conditions should not only be able to understand the pathway they are on but be able to construct it with support from health and care professionals. They should be able to take control of their own journey as a means to taking control of their own health. In a People Powered Health approach pathways:

- Are co-designed by patients, service users, practitioners, carers and peers.
- Focus on long-term outcomes, recovery and prevention according to patients’ own measures of success.
- Cover multiple health conditions by treating each patient as a whole person and tackling barriers to achieving health and wellbeing outcomes rather than (just) symptoms of disease.

- Include treatment, care and support from health, social care and public health.
- Enable collaboration between providers, including voluntary and community organisations and informal care networks.

Systems that support integrated pathways

“A conventional pathway is driven by other people dictating what they think should happen. We want to get away from dictating what services are like and put users in charge of what services could be like. There is a wealth of knowledge and resources within the community of service users and carers. They know what works best for them and their peers.”

Jessica Agudelo, Project Co-Ordinator for Solidarity in a Crisis, Lambeth

At the commissioning level, pathway planning is used to collate individuals' needs to better plan community services. Consistent, collaborative and clear pathways help place these discrete interactions in the context of a wider conversation between the patient and the health service. This requires changes at the system level, to transform the way services are funded, measured, commissioned and work together.

Integrated care,¹⁰² collaboratives and alliances. Care which is joined-up and consistent from the service user or patient's perspective – this often involves different NHS, social care and voluntary sector providers working together in a collaborative or alliance.

Self-directed support and personal health budgets.¹⁰³ A sum of money from health or social care providers given to people with health and/or social care needs that allows them to purchase directly the services or care that they feel they need. The aim is to increase service users' choice, flexibility and control and move away from a top-down, directive approach to healthcare.

Patient reported outcomes and experience measures.¹⁰⁴ Measures of the quality of care that go beyond traditional clinical measures and take into account the patient's appraisal of quality; these include patient reported outcomes measures (PROMs) and experience measures.

Co-produced commissioning and outcomes-based commissioning.¹⁰⁵ New approaches to commissioning include: co-produced commissioning, where a diverse range of people including patients, service-users and carers are involved in the commissioning process; and outcomes-based commissioning, where providers have the flexibility to use innovative processes and service models as long as the outcomes are achieved.

REDESIGNED MENTAL HEALTH PATHWAYS IN STOCKPORT

“We talk about people's hope and dreams and then give them the means to get there.”

Nick Dixon, Joint Commissioning Manager (Mental Health), Stockport Council

A collaborative approach to commissioning and a strong consortium of providers underpin the new Prevention and Personalisation Service run by Stockport Mind and All Together Positive, a user-led social enterprise. The service supports users of mental health services to co-create care pathways, guided by a Wellbeing Pathway Planner and supported by access to a wide range of services from networked

providers including peer groups, debt and housing advice and clinical support. The three steps of the pathway planning process take place over a timeframe that works best for each individual:

- **Initial emotional support**, talking through why the service user is there and how they feel about themselves and their life in general, including but beyond their mental health.
- **Identifying aspirations** – what they would like their lives to look in a week, month or year's time which is the basis for the outcomes to achieve.
- **Identifying barriers** preventing them from moving forward or that are keeping them in secondary care (from medication to social isolation), and putting together a plan to remove or overcome these.

Webs of care

For patients with multiple long-term conditions, multiple pathways will be integrated to create a connected, collaborative web of care. This goes beyond integrating primary and secondary care, to connect and co-ordinate all services and people that patients have a relationship with – community, primary, secondary and tertiary care; health and social care; the NHS and voluntary sector; informal care from the community, friends, family and neighbours; and, where appropriate, other public services such as employment, housing and education. For those with multiple long-term conditions, this means unified rather than disease-specific pathways.

There is no right or wrong way to create these integrated webs of care and they do not always require formal service integration, but rather effective connections and alignments. They will need to be supported by funding (such as pooled budgets, personal budgets, sharing value across the supply chain); new approaches to commissioning (co-produced commissioning, joint commissioning); digital technology (patient-held medical records); and outcomes measures that look at a patients' whole journey rather than fragmented point-in-time interactions.

5 REALISING THE VISION - HOW TO CHANGE A WHOLE SYSTEM

After a period of structural reform and successive improvement, productivity and efficiency drives, there is an understandable sense that the NHS is weary of change. Managers and clinicians yearn for a period of stability. However, the challenges facing the system mean that this is not possible – incremental improvements will be insufficient. To fend off the pressures of economics and demographics, the NHS must transform itself by adapting and scaling the building blocks that combine to shift the whole system.

Over the last 15 years, the NHS has done more of everything – more procedures, new procedures, and at times and in places more convenient to the patient. The system does not need more pressure, but it does need to rethink not just the solutions the NHS provides but the problems it is seeking to tackle. The People Powered Health approach seeks to recognise the biggest challenge facing clinicians and managers – that they cannot keep us healthy on their own and provide a way through the bind of ‘more for less’ by helping patients to do more for themselves and each other.

The evidence shows that service providers best respond to disruptive innovations when they engage with their customers to help create them and build new business models around them. To grasp the potential of the People Powered Health approach, the NHS needs to engage with patients and citizens, clinicians and managers from across the system. It also needs to build new business models – new ways of producing value – that focus less exclusively on the contributions of clinicians.

This will not be easy. The NHS cannot innovate without working collaboratively with patients, and it cannot work with patients without significant innovation. It will require investment in changing the culture as well as new practices and technologies. The latter is relatively easy: as described in previous chapters, there is an abundance of innovative and well endorsed practice that can be brought into the mainstream. Embedding the underlying principles into NHS culture will be harder.

Concerted work is needed to change the social norms, workforce culture, business models and institutional architecture that surround the NHS to realise the full value of these new practices and technologies.

We need to shift the incentives, measures and choices facing patients and other stakeholders within and beyond the NHS. Below we describe ten important ways in which local system leaders can build a People Powered Health system. These have been drawn from the experiences of the teams that took part in the People Powered Health programme, the contributions and insights from a wide range of experts that participated in the programme and our wider work to understand how systemic innovation takes place.

5.1 CHANGE THE WAY SERVICES ARE COMMISSIONED

“Commissioning is about enabling an effective dynamic with communities and individuals to understand their needs, their assets and their aspirations in order to fund and guarantee effective, meaningful and efficient support.”

Lambeth Living Well Collaborative

Commissioners are rising to the challenge of structural reform and budget cuts by working ever harder and deploying tried and tested procurement approaches to reduce costs. But the broader challenges facing the NHS require radically new models. Conventional approaches to achieving efficiencies through better procurement will not be sufficient to meet the needs, obstacles and opportunities ahead. The traditional structures of the NHS have produced systemic biases towards cost-effective procurement rather than the types of smart, agile commissioning for long-term outcomes that commissioners themselves have been pushing for.

Changes to NHS frameworks, including the Commissioning Board mandate, provide a window of opportunity. There is renewed support for commissioners to take radical steps towards not just the commissioning of new kinds of services but entirely new models of commissioning that:

- Ensure the commissioning process **reflects the lived experience of users**.
- Re-frame the commissioner as the **leader of partnerships and collaboratives**.
- Move away from commissioning as procurement to **commissioning as market-making**.

The role of commissioners

People Powered Health reframes the role of the commissioner as one of **leadership of partnerships and collaboratives** – working with those from every part of health and social care, including patients, practitioners and providers. Commissioning shouldn't be a top-down process, but a dynamic one that understands the needs and aspirations of its population and wraps services and support around individuals. In Lambeth and Stockport, commissioners have forged collaborative commissioning vehicles – alliances of providers and communities of people working together to assess local need and assets, co-design the services required, produce tenders and, in some cases, co-deliver services. These approaches require transparency about budgets and close working with the health, mental health and social care sectors, primary and secondary care, the voluntary sector and local authorities.

Market-making is a core commissioning task. For those seeking to drive a People Powered Health approach service design, maintaining dialogue, and nurturing and developing current and potential providers, are key. It requires a preventative infrastructure of community-based provision to complement clinical input – a range of services as reliable as a pharmacy is at dispensing drugs through which people can access interventions and services to improve their health. Commissioners and system leaders do not design services directly, instead they create and safeguard the conditions in which they can be designed by those who know what's needed.

There are a range of methods and ways of working that can ensure that the commissioning process **reflects the lived experience of users**. These processes include co-designing services and systems with users, both in commissioning specific services and fostering

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communities to decide which services they would like provided; and using community researchers as a link between commissioners, patients and the wider community by researching local need, identifying gaps in provision, gathering feedback and disseminating information.

Using the commissioning process to **support and engage citizens and communities** unlocks resources and strengthens local resilience. Communities must be viewed not just as end users of services but as partners in deciding what these should look like and what should be commissioned.

This is an emerging vision of commissioning that could transform the health service. New processes and services are being tested in sites around the country, with the evidence base growing and becoming more detailed by the day. Some of the examples from the People Powered Health programme have been straightforward to implement; many have taken time, energy and significant culture change. All have been driven or supported by strong commissioning leadership.

“ I think it's really important the clinical commissioners are bold and brave and broader in their thinking about commissioning services that integrate health, social care, co-production and social values. That is not difficult; in fact, it's much more simple than you think.”

Frankie Lynch, Chief Operating Office, North West London commissioning support unit

5.2 MAKE THE MOST OF NEW STRUCTURES

NHS reforms in England have created a new landscape of structures and systems with new institutions and organisations whose roles and functions are still being defined. This presents an opportunity to embed the principles of a People Powered Health approach in the new structures.

- Clinically led commissioning will put commissioning decisions into the hands of clinicians who can engage with their local population. Newly created clinical commissioning groups are now commissioning community, mental health and acute care. NHS England has authorised these clinical commissioning groups, is producing guidance, allocating resources and commissioning primary and specialist care.
- Health and Wellbeing Boards will include representatives from health and social care and elected public representatives to improve local provision and ensure integrated care. The National Institute for Clinical Excellence will cover social care, ensuring more holistic guidance. The disparate elements of public health are being brought together to form Public Health England, with the bulk of responsibility shifting to local authorities.
- There is a more explicit emphasis on the importance of the patient voice and involvement. The Care Quality Commission's HealthWatch will be responsible for championing patient views and reporting to the Secretary of State, NHS England, Monitor and local authorities. Local subsidiaries of HealthWatch will work with clinical commissioning groups and Health and Wellbeing Boards.
- The NHS provider market is opening up to support plurality and patient choice. Charity and independent providers that match the NHS on price will be able to provide services if licensed by Monitor, whose role it is to promote efficiency and ensure competition.

In principle, these changes are part of a longer-term movement towards a more decentralised, flexible, outcome-focused and patient-centred health and social care system. Its rapid implementation creates both challenges and opportunities.

The opportunities for embedding the People Powered Health approach

Clinical commissioners and NHS England support changes to the way services are commissioned locally. They systematically involve patients and communities in the whole commissioning process, resulting in new types of services being commissioned across primary and secondary care. Services are commissioned based on outcomes, with long-term payment models for providers. For clinical commissioners this could involve directly commissioning more non-clinical services that have in the past been maintained by grants to third sector organisations.

NHS England ensures it involves patients and carers at every level, including designing, commissioning, delivering and evaluating services. Listening to patients – through real-time patient feedback and the friend and family test – is important, but patient and public involvement should aim not just to collect and analyse feedback but to actively involve service-users in design and decision-making processes. At the macro level this means grounding NHS England's decision-making in patient perspectives. This goes beyond representation of small numbers of 'users' and includes systematic harnessing of user perspectives as an integral part of how priorities and decisions are made. On a micro level this should include progress on the shared decision-making programme.¹⁰⁶

In some ways that encouragement is already coming from system leaders. In November 2012 the Secretary of State for Health published a Mandate which defined a set of outcomes that NHS England needs to work towards. One of the 19 objectives in that Mandate concerns the increased empowerment of patients:

From the Mandate between the Secretary of State and the NCB published on Nov 13 2012

- 2.1** We want to empower and support the increasing number of people living with long-term conditions. One in three people are living with at least one chronic disease. By 2018 nearly 3 million people, mainly older people, will have three or more conditions all at once.

- 2.5** The NHS Commissioning Board's **objective** is to ensure the NHS becomes dramatically better at involving patients and their carers and empowering them to manage and make decisions about their own healthcare and treatment. For all the hours that most people spend with a doctor or nurse, they spend thousands more looking after themselves or a loved one.

This Mandate ensures that the organisation responsible for nearly all of the commissioning in the country is mandated to become “*dramatically better at involving patients and the carers*”. The whole architecture of commissioning is brand new and we do not know how the Mandate will impact upon the work of local clinical commissioning groups. However the importance given to increased empowerment is an important signal about the Government’s ambition to see a People Powered Health approach implemented.

Health and Wellbeing Boards push the integration agenda beyond health and social care.

These boards have the potential to be a driver of integration. At their best they will align public health and other local authority responsibilities including social care and housing, and the different parts of the NHS, and look across and beyond these sectors to improve local health and wellbeing and put the People Powered Health approach into practice.

A diverse range of providers is fostered and maintained. The voluntary and community sector has a unique and long history of advocating for People Powered Health approaches. However, it often lacks the risk capital or business development skills to put together large bids to provide services, making it difficult for these providers to compete with NHS or private sector providers. Voluntary sector providers need to be supported to enter and compete in this new diversified market. One way of achieving this is by encouraging provider consortia.

5.3 ENCOURAGE PATIENTS TO TAKE PART IN PEOPLE POWERED HEALTH

The People Powered Health approach requires a change in culture for patients as much as for professionals. This includes a change in their expectations of where ‘health’ is created and by whom. It means a shift away from being a patient ‘consuming’ services and being ‘cured’ by professionals. It can involve a managed discharge process from hospital-based care and into community-based care which can generate fear and uncertainty. Understandably, patient attachment to conventional models of care and current services can be strong. We have built up expectations over 60 years of what a good health service should look like and what constitutes good care. Letting go of these attachments can be difficult and unsettling and requires faith that the system will respond appropriately if acute needs arise.

The role of patient organisations

The trend in healthcare over the last 20 years has been towards a more devolved and decentralised system. But to generate change at scale, demand is required from the grassroots – the patients, service-users and carers – to pull innovation through the system. In this decentralised system, a social movement approach becomes a more powerful way of effecting change at scale. Local patients demanding change is becoming as important as convincing the Secretary of State. National regulators, agencies and NHS England will follow.

The major patient organisations already argue that patients need to be equal partners in their care. The Richmond Group’s report on patient-centred care¹⁰⁷ demonstrates a consensus for people powered approaches to care.

Patient organisations now need to mobilise local networks of patients and carers to actively build a social movement in support of a People Powered Health approach. These groups put patients first and foremost, and they are trusted. They can explain to patients why change is necessary and how a more equal and collaborative partnership with staff and a stronger focus on patients’ own contributions will benefit them. Without this, there is a danger that the People Powered Health approach and its emphasis on self-management support, different types of provision, reduced dependency on unplanned and emergency care and peer support are seen as only a route to save money rather than improving patient outcomes.

Patient organisations also need to continue to actively engage commissioners. They should lobby to ensure that commissioners involve patients and the community much more fully in the commissioning process. They are also a route by which commissioners can identify patients and service users to involve in the commissioning process.

5.4 BUILD CLINICAL LEADERSHIP

In the People Powered Health programme patients and clinicians have shown that working together makes both sides more powerful. In the process, clinicians have had to re-interpret their role as facilitators of better health, not just curers of disease. There are already many clinicians who are pioneering People Powered Health approaches at the margins, but new ways of encouraging, rewarding and embedding this new kind of professionalism are needed. It needs the active support and engagement of professional organisations, the Royal Colleges in particular.

The Royal Colleges have a core commonality: their Royal Charters put the interests of patients first. This is a strong platform from which to advocate for the People Powered Health approach, and it unites these diverse organisations behind a common cause.

It also provides a basis for a shared agenda between the professions and Government: the long-term economic challenges facing health, tackling the rise of long-term conditions, improving quality and reducing demand for emergency and unplanned care.

The role of the Royal Colleges

Royal Colleges should **encourage their members to engage and tackle the long-term economic issues of the NHS**. Some clinicians still assume current efficiency savings are a short-term matter. However, it is already becoming apparent that the current Quality, Innovation, Productivity and Prevention programme and other attempts to reduce costs are here for the long term.¹⁰⁸

The Colleges also need to **build a case for patient value**. The default position for some clinicians remains that patients with long-term conditions are recipients of care, who need more clinical time, equipment or drugs. Royal Colleges need to demonstrate to their members that treating patients as equal partners and supporting them to manage their own care with confidence and control will lead to better health outcomes and reduce demand for acute medical resources.

Once the case for patient value has been made and accepted, the **principles of the People Powered Health approach need to be incorporated into existing professional standards**. Ideally, standards would be rewritten to incorporate the shift in role of both patients and clinicians. These standards define what best practice is and what constitutes good care; it is essential, therefore, that they reflect the shift towards more equal and collaborative partnerships between clinicians and patients.

Even with professional standards that reflect the vision of People Powered Health, front-line clinicians will find it challenging to change their practice and the way in which care is organised. The Royal Colleges should help them to do this – whether by providing additional professional development and training or making the case to change the way services are commissioned. The Royal College of GPs is leading the way through its take-up of care planning.

5.5 CHANGE FINANCIAL INCENTIVES

The current system of financial incentives in the NHS represents significant barriers to the implementation of the People Powered Health approach. Annual budgeting, the dominance of payments for episodic care and the current patterns of expenditure across primary and secondary care support fragmented care that revolves around institutions and clinical pathways, not patients.

How health and social care invests the funding it receives

Resources are currently accounted for on an annual basis, which makes it difficult to invest in an activity that takes more than a year to show a financial benefit. The economics of the health system are largely measured over the short term, while the changing nature of long-term illness demands investment that is measured over the long term.

The way in which providers are paid¹⁰⁹

Providers are paid for episodes of care which encourages the fragmentation of care rather than prevention and recovery. Episodic care payments (paying for each treatment, intervention or stay in hospital separately) do not incentivise a more long-term approach that integrates different types of care. They do not incentivise pursuit of long-term outcomes and are a disincentive to reducing demand.

For patients with long-term conditions, payment methods should be developed for a 'year of care' that better reflect the long-term relationships between patients and the system that are at the heart of the People Powered Health approach. As the costs of unplanned and emergency acute care would be taken from the 'year of care' fee, it would be possible to develop incentives to encourage providers to improve longer-term patient outcomes.

Patterns of expenditure across different types of care

This approach to financial incentives and investment needs to result in more coherent expenditure across sectors. Ultimately, the goal must be a drop in expenditure on acute hospital and residential care and an increase in expenditure on primary, community and home care.

Unless reduction in demand for hospital care can realise real cash savings (pounds sterling not spent), the idea of investment and return on that investment across different parts of the NHS cannot become real. There have been a large number of schemes within the NHS that have promised savings to hospitals from investment elsewhere, but these have not materialised.¹¹⁰ Vertical integration of services and integration of primary and secondary care can help realise these savings.

The pressure on finances is already intense and likely to increase in the next few years. The most common reaction is incremental, staying within the existing paradigm while finding small reductions from every cost area, every year. However, there is an emerging movement away from short-term financial incentives to longer-term models, as seen in the use of social impact bonds,¹¹¹ the work of QIPP to move away from annualised budgeting¹¹² and the 'year of care' model.¹¹³

5.6 CHANGE WHAT GETS MEASURED

“*Seeing services as a delivery mechanism rather than a transformative experience has led to a particular form of information gathering and system measurement. Existing targets have tended to focus energy on underperformance in operational efficiency, at the expense of underperformance in the transformation of people's lives.*”¹¹⁴

The People Powered Health approach focuses on patient-centred and designed outcomes, measured against the progress and goals that patients define. In contrast, the prevailing system focuses on disease rather than people, encouraging specialisation rather than caring for the whole person – leading to separation rather than integration of services. It encourages treatment over recovery, and recovery from disease over wellbeing. It incentivises more, not less, activity by providers, disincentivising demand reduction. And it privileges professional- over patient-set goals.

In December 2011 the Department of Health published the NHS Outcomes Framework,¹¹⁵ marking a move towards prioritising population outcomes over clinical activity.¹¹⁶ Local commissioning groups and providers will have increasing power to measure what matters in their communities. The Framework sets out five key outcome areas:

1. Preventing people from dying prematurely.
2. Treating and caring for people in a safe environment and protecting them from harm.
3. Enhancing quality of life for people with long-term conditions.
4. Helping people recover.
5. Ensuring that people have a positive experience of care.

Alongside the Framework, there is renewed interest in payment by results. A large amount of what currently falls into this category is actually payment for activity, but this is changing. The proportion of the NHS budget linked to improved outcomes will rise, and the proportion linked to inputs and activity will fall, over the next five to ten years.

Patients are increasingly involved in measuring outcomes, both in terms of their health and their experience of care. Patient reported outcome and experience measures (PROMs and PREMs) are established in many areas and are moving away from surface patient satisfaction to more meaningful measures of patient confidence, control and activation.

In the short and long term, steps must be made towards a system of measurement that supports commissioners, practitioners and patients to assess progress and evaluate need. The priorities from the perspective of the People Powered Health approaches are:

Measure health outcomes that matter to patients

Too many of the measures that drive accountability are designed by professionals for professionals. Measuring just some of the outcomes that patients care about would result in changes to both provision and bio-medical indicators. In terms of the Outcomes Framework, these measures include.

Enhancing quality of life of patients living with long-term conditions:

- Patient wellbeing, confidence and control over their own health.
- Behaviour change, improvements in lifestyle and motivation to improve health.

- Healthy social networks of support and care, reducing social isolation.
- Patient perception of progress made towards wellbeing goals.

Helping people recover:

- Reduced demand for unplanned or emergency care and reduced reliance on medication.
- Recovery from mental health problems and addictions.

Having a positive experience of care:

- More equal and effective relationships between patients and staff.
- More activated patients engaged in their own care with increased participation in services, including volunteering, peer support and service co-design and delivery.

STOCKPORT'S PREVENTION AND PERSONALISATION SERVICE: MEASURING WHAT MATTERS

Stockport's Prevention and Personalisation service for people with mental health issues measures progress against an individual's desired outcomes, supported by frameworks that look at headway made in categories such as volunteering, employment, finances and wellbeing. Individuals' mental and emotional health are measured through WEMWBS, the Warwick-Edinburgh Mental Well-Being Scale. Service users are asked to complete this as early as possible in the process to have an accurate baseline and again around three months later. The tool includes questions such as 'how often do you feel loved?', and talking these through can be a valuable emotional process in itself.

Involve patient and carers in measurement

Patient measurement needs to go further and deeper than PROMs and PREMs. Patients should be involved in measuring the distance they have personally travelled as part of an ongoing approach to reviewing their progress and care. These measurements should be relevant and valuable to patients and carers, not just to practitioners and institutions. And they should enable clinicians to see the consequences (intended and unintended) of their actions on patients' behaviour, understanding and outcomes.

5.7 SHIFT INVESTMENT IN TECHNOLOGY

Despite the huge investment in the past decade, the use of technology in the NHS does not enable a People Powered Health approach. Technology is developed in a centralised way, it is purchased by disease- or provider-specific silos, and it is rarely co-designed with patients. Three types of technology underpin the People Powered Health approach.

Communication technologies provide alternative ways for patients to communicate with health and care professionals and to communicate with each other in patient networks. At Newham University Hospital diabetes clinic follow-up appointments take place over Skype.¹¹⁷ Sites like PatientsLikeMe and Patients Know Best have become a powerful way for patients with similar conditions to support one another.¹¹⁸

Assistive medical technologies allow individuals to monitor and manage their health at home by tracking patterns and monitoring deteriorations in their vital statistics. This self-management support enables patients to care for themselves and avoids unnecessary admissions. The 3millionlives project aims to roll out such tools to 3 million people who are frail or have a long-term condition.¹¹⁹

Connecting **data and information systems** is crucial for integrating care and empowering patients – connecting not only different providers to each other but allowing patients to access and control their own health records and information. Technological improvements also mean we can analyse bigger datasets, pooling data from across institutions and from different sources, including patients themselves, and using it in intelligent ways, but this needs to be accompanied by a culture shift towards collaboration and transparency.¹²⁰

Some of these issues have been recognised by the Department of Health's recent information strategy,¹²¹ but there is much further to go to fully realise the power of data and information to inform health decision-making by both clinicians and patients.

Shifting from centralised to distributed solutions

Commissioners and providers have the flexibility to buy and develop systems that are appropriate for local circumstances. These local systems should meet common standards so they can connect with one another. However, this decentralised approach is not a fully distributed approach.

Patients Know Best¹²² is an example of a distributed model. The patient holds their own health information and they invite professionals to join their trusted circle and add information to their health record. Systems such as this are powerful as they invert the traditional information asymmetry in health and social care. They are a simple way of allowing the patient to share their record with medical professionals, social care professionals and their informal support network. The potential of cloud-based services such as Cloud4Health,¹²³ which allows different providers to share information and interact with patients, should also be developed.

Shifting to collaborative technologies

Technologies have the potential to change the relationship between patients and professionals by enabling them to work together more effectively. The Government has pledged that all patients will have access to their GP records by 2015, but access to static information is not enough – patients should be able to share their record with whomever they want, add up-to-date information that is relevant, post queries, make suggestions and use the record as a platform to plan their future care. Innovations like Tyze, which enable people to engage their family and community networks alongside professionals to support their care, will become increasingly important.

Co-designing technologies for co-production

Technologies for co-production need to be co-designed with patients and practitioners to ensure that they meet their needs. This is challenging, but many of the failures of technologies so far have been due to a lack of involvement from the people who will actually be using them at every stage in the journey.

5.8 TRANSFORM ORGANISATIONAL WORKFORCE CULTURE

“When system components such as sharing test results with people before the care planning¹²⁴ consultation were introduced without addressing the fundamental philosophy of the programme and the mind-set of staff, this proved ineffective in engaging, empowering or activating staff.”

Sue Roberts, Chair, Year of Care Partnerships

The experience of the People Powered Health programme has shown that culture change and workforce development are pivotal. Getting these right can make the rest of the process fast, productive and successful; getting them wrong can create entrenched barriers to change.

Make a clear and compelling case for change. Staff need to know why change is necessary both for the organisation and for improving the lives of patients, service users and carers. The People Powered Health approach goes to the core of changing the way in which medical staff interact with patients; staff need to understand its significance and support the change. They need to be engaged in thinking about what this means for their day-to-day work.

Embed interventions and incentives throughout the organisation to ensure it becomes committed as a whole to new ways of working. Change has to happen on an organisational level. This means leveraging every asset available to get the process moving.

Make the culture real (and normal) as an everyday part of the organisation. Embedding culture is difficult – there’s a point at which you have to stop referring to the ‘new’ culture, so that it can just become ‘how we do things around here’ and part of normal life.

THE LAMBETH LIVING WELL COLLABORATIVE: CHANGING ORGANISATIONAL CULTURE AT BREAKFAST

“You can develop as many whizzy new services or amend services that exist, but until you address how people work together you are never going to address the service change you want.”

Denis O’Rourke, Assistant Director, Integrated Commissioning in Mental Health for NHS Lambeth

A strength of the Lambeth Living Well Collaborative is its focus on the need for culture change. In order to create a collaborative of people from different organisations, it has been essential also to create a shared set of values and a shared vision. A key element of success is its fortnightly breakfasts, where the Collaborative come together and problem-solve as a group. The group meets on Thursday mornings in a café run by one of the member organisations – a charity that works with former and current service users and trains them in hospitality and cookery. Over breakfast and a cup of tea they have the opportunity to address the problems that are facing the sectors represented and make concrete plans of action.

5.9 CREATE A CADRE OF SYSTEM LEADERS

The People Powered Health approach relies on partnerships of equals, with every individual bringing assets, experience, skills and capabilities. But that does not mean there is no room for strong system leadership. The changes needed cannot – and should not – be viewed as the responsibility of patients and their families alone. Strong leadership is needed to drive the shaping of the system by teams of patients, clinicians, families and communities, with structural support from national and local representative bodies and local authorities.

System leadership sees, and acts on, the system as a whole. It recognises the interdependence between providers, commissioners, and communities. It recognises, too, that the relationships between these organisations can have profound effects on outcomes. This clearly requires a different set of skills and behaviours to those of running a single organisation. There is no blueprint, but research and practice suggest some common elements.

Vision and purpose. Effective leadership requires the generation of collective vision and shared purpose. Across localities, system leaders have the challenge of making this vision both broadly based and more compelling – capable of engaging diverse groups. Radical change across different organisations has to engage diverse groups and interests and to do so without the authority of positional or hierarchical power.

Leadership capacity-building. System leadership is both an individual and a collective role. It expands its scope and influence through the collective. System leaders create opportunities for joint work and analysis of past practices – activities that can liberate creative energies by challenging historical assumptions. In so doing they also distribute leadership opportunities, creating space for new leaders to grow.

Professional generosity and exchange. System leaders open up professional practices to external scrutiny and for wider adoption. They make professional learning public and shared (as has long been the case in law and medicine). A system will only thrive through the collective and cumulative contributions of multiple participants and stakeholders.

Crucially, the People Powered Health approach requires a focus on leadership rather than individual leaders. No single person will possess all the necessary qualities to effect such a wholesale change; nor should one person hold all the responsibility for doing so. Making the changes will require a host of alliances, collaboratives and partnerships – teams of people that collectively have the ‘leadership skills’ needed.

Recognising the importance of these interconnections, system leaders seek not only to do different things but also to do things differently in the interest of the wider system, including:

Recognise that in systems made up of people there will be multiple perspectives on a problem or situation. This means that change is most likely to be achieved through drawing on those diverse perspectives.

Build the autonomy of those in the system by setting a few simple rules, but maintaining high minimum standards. To marry flexibility with quality assurance, this needs to be done within a clear overall framework.

Support autonomy by connecting individuals to one another. Allowing people autonomy within systems does not mean leaving them in isolation – systems can help them to solve

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problems together and to share learning.

Support learning and continuous improvement by creating feedback loops. This means giving people access to information that can help them understand the factors affecting the performance of the system.

Maintain an open and vibrant learning culture. Learning cultures need leaders to recognise and model the importance of learning.

5.10 STRENGTHEN THE BUSINESS CASE FOR PEOPLE POWERED HEALTH

“We know that the evidence for some medicines is good, but that evidence has been generated as the result of millions and millions of pounds of investment by the drug companies. Unfortunately there is nobody who is investing in generating the evidence for our model in the same way. We do know that there is emerging evidence from good practice around the country but it's not a level playing field.”
Guy Pilkington, Chair of Newcastle West Clinical Commissioning Group

The business case for People Powered Health predicts savings of 7 per cent to a local health economy,¹²⁵ based on NHS Level A standards of evidence, which means randomised control trials (RCTs) and meta-analyses of RCTs. These savings are from reducing expenditure on A&E attendances, planned and unplanned admissions and outpatient admissions. In national terms, this is equivalent to savings of £4.4 billion across England.

If anything, this 7 per cent prediction is conservative. While the evidence base is emerging and growing rather than comprehensive, the median of all evidence considered suggests potential savings of 20 per cent.

In an environment of limited and competing resources, securing the investment to do something different is difficult. Findings to-date suggest that typical interventions associated with the People Powered Health approach can be delivered for an annual cost of between £100 – £450 per patient. Costs can be reduced through service design and effective use of clinical, volunteer and patient time. The key is to have a robust business case, a management tool for evaluating the likely costs, benefits, opportunities and risks of different options, including – crucially – maintaining the status quo.

Growing the business case

Test, adapt, iterate. The first step in building an evidence base and a business case needs to be increasing the number of places systematically implementing these types of interventions. This means providers and commissioners experimenting to test new ideas and generating robust evidence of impact in real time, including through the use of control groups or randomisation. Experimental methods, including prototyping, also enable problems to be fixed quickly and with minimal impact, enabling models to be developed quickly and tailored to local circumstances.

Collect and synthesise different types of evidence. Evidence is needed about standard clinical outcomes – bed days saved, re-admission rates, test results – but also outcomes that are important to patients.¹²⁶ We know social isolation is linked to poorer health outcomes but very few NHS organisations measure the impact of their services on people's social capital. Randomised controlled trials are increasingly used to measure the impact of social policy, but need to be supplemented by other forms of evidence. Synthesising a mix of quantitative, qualitative, ethnography, case-control and cohort studies is the key to building a strong business case overall. Nesta has developed a set of Standards of Evidence¹²⁷ to guide evidence of impact for social outcomes and the Alliance for Useful Evidence promotes debate about evidence and practice.

Build networks of evidence makers across the NHS and social care. The efforts of individual localities are unlikely to be enough to generate the level of evidence needed by clinicians and commissioners. Small projects will have small samples sizes that will not have the power to definitively prove impact and it is vital that larger scale trials and studies take place. Different parts of the health and social care sectors are likely to have very different business cases, benefits and risks. There is an important role for the Academic Health Science Networks and What Works centres to orchestrate knowledge and build the evidence base for these approaches.

Enable information-sharing between organisations. The costs and benefits of the People Powered Health approach transcend traditional organisational boundaries including those around primary, acute, community, public health and social care. For example, Earl's Court Health and Wellbeing Centre may be a primary care clinic, but its social value services (timebank, wellbeing coach, peer mentors) impact on sectors outside primary care. To properly take into account the impact of these programmes, evidence must be collected from across the health, public health and social care sectors.

To radically transform the health and care system, we need to improve the whole system – not just shift costs from one area to another. Proving the effectiveness of these programmes, and ensuring that the system as a whole becomes more efficient, requires information to be shared. Information sharing and information governance is complex, but it is not impossible: Torbay Care Trust and Torbay Council have been sharing information on service users with the individuals' consent for the last eight years.¹²⁸ Clear and coherent guidance is needed on how to share information and how we can track people in between services – and that, in turn, relies on trying out a variety of methods.

“*At first, the idea of quantifying what is in effect a cultural shift seemed problematic. Would it shift the focus onto numerical outputs rather than conditions needed for co-production? We felt such conditions had to be defined and established to truly allow us to scale up the project. What we found was that the business case became a critical driver for change. It drew together new data in new ways and it created discourse between people who've never even met. In short, it was key to creating the very conditions we were so concerned it would disrupt.*”

Nick Dixon, Joint Commissioning Manager, Stockport Council

6 CONCLUSION

This report has set out an ambitious vision for a health and care system that combines the very best scientific and clinical knowledge with the expertise and commitment of patients themselves and the resources and capabilities of their families, networks and communities, to meet the challenge of long-term health conditions.

What we have called People Powered Health is grounded in the practical innovations that have emerged over 20 years and a deep understanding of the changes that need to happen in different parts of the system to make those innovations a more normal part of life.

We have tried to identify practical measures that could be implemented quickly by practitioners that want to be part of this change, including new approaches to consultations and prescribing, workforce development, collaborative commissioning and a broader range of provision.

But to realise the potential also requires a fundamental shift in the way that we all think about health and care systems, including:

- Relationships between staff and patients and their carers that are characterised by **mutuality and reciprocity** – recognising the **assets and strengths that all patients and carers bring**, irrespective of how sick they are or how great their need.
- **Patients treated as equal partners** who are expected, and supported, to collaborate and participate fully to achieve better health. Patients not treated as passive recipients of care but as active, valuable agents working to improve health.
- The NHS and social care **supporting and nurturing caring relationships** and networks of support provided by peers, families, communities, professionals and volunteers.
- The NHS and social care actively avoiding the risk of dependency on services by **enabling individuals, families and communities to do more for themselves**, with professionals acting as much facilitators and catalysts of change as providers of services.
- The boundaries between who is providing healthcare and who is receiving healthcare becoming blurred. Patients are not just consumers of services but **producers of better health** and providers of care for themselves and others.

Clinicians dealing with long-term conditions need to change consultations in both hospital and community settings, creating purposeful, structured, collaborative conversations that combine clinical expertise with patient-driven goals of well-being and which connect to interventions that change behaviour and build networks of support.

More than ever, GPs are the brokers of care in the NHS and are in a pivotal position. If the People Powered Health approach is to thrive, the quality of support, coaching and service brokerage that GPs provide to their patients is more important than ever. They need to be incentivised to provide excellent support for patients to care for themselves and their peers.

We also need **new services**, that provide ‘more than medicine’ to complement clinical care by supporting long term behaviour change, improving well-being and building social networks of support. Services should be co-designed around patients’ needs

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and accountable for achieving outcomes defined by patients. Care plans, co-designed pathways and patient reported outcome measures will remain marginal to the current system unless they become part of what we ask clinicians and services to achieve, and how providers are remunerated for their services.

Lastly, we need **Pathways** that are designed between patients and professionals to focus on long-term outcomes, recovery and prevention. These pathways should include services commissioned from a range of providers including the voluntary and community sector. These 'webs of care' should support people with long-term conditions to help themselves and one another to stay well; and they should be evaluated and remunerated according to the success with which they help people to rehabilitate and recover, stay well and lead as fulfilling lives as possible.

Patients, patients groups, clinicians, managers and policymakers are already coming together to affirm the potential of the People Powered Health approach, to demand change and to build new models of care together. The success of this coalition rests on clear evidence that it can deliver better outcomes for patients, at the same time as saving significant amounts of money for the NHS.

If we can achieve this, we have the chance to both improve the health of people with long-term conditions and to improve the health of the NHS.

APPENDIX: THE WORK OF PEOPLE POWERED HEALTH PROGRAMME TEAMS

CALDERDALE & HUDDERSFIELD

Ambition: Systematic buddy support and group consultations across COPD and Pain pathways

Calderdale and Huddersfield Foundation Trust's vision was to turn into an integrated care organisation and shift service provision for people with long-term conditions away from the acute setting and into the community.

Building on the work of the Co-creating Health programme, they aimed to mainstream coproduction by: rolling out Self-Management Support patient groups; creating a formal buddy system to provide ongoing support in the community to people living with long-term conditions; introducing group consultations and system navigators; and redesigning services for pain management with service professionals, patients and carers.

The trust already had trained up service users to be tutors in their self-management course and was committed to using these routes to enable service users to become more employable in services and beyond. Feedback on group consultations suggests this has resulted in people understanding their condition more fully, alongside their peers, and using lower dosages of medicine.

LAMBETH

Ambition: Borough wide mental health services on a co-production basis

The Lambeth Living Well Collaborative is working to enable people with severe mental illness and complex life problems to recover and stay well, and to participate fully and on an equal footing in family, community life and in the wider society.

They are delivering this vision by collaboratively redesigning mental health pathways in Lambeth based on an "easy in easy out" principle which works towards prompt discharge from secondary care combined with an easy route back in to see a consultant if a person's condition deteriorates. They have worked to produce a greater supply of low and medium level services in the community, for example an information and referral "navigator" service for people who are experiencing mental health issues, a choice of services like talking therapies, peer support groups, exercise groups, health and wellbeing activities and a network of mutual support provided through timebanks.

This has been part of creating a preventative infrastructure that frees up capacity for secondary services to see the people they need to see right at the time when they need to be seen. Recent developments include the launch of the Community Options Team which is working with 70 residents, and the Primary Care Community Mental Health Service which increases the capacity of primary care to support individuals through a multi-disciplinary team including a GP with special interest in mental health.

LEEDS

Ambition: Co-production, Risk Stratification, and integrated Health and Social Care Teams across multiple long term conditions

Two key innovations had already been introduced in health and social care services in Leeds: the use of risk stratification and the integration of health and social care teams. These have enabled the proactive and systematic management of people identified as being at risk of needing health and social care. The partnership in Leeds built on this work to bring a strong emphasis on personalised care and co-production, establishing a third innovation – a systematic approach to self-management at a neighbourhood level.

The partnership – composed of the senior executives and frontline staff from Leeds Community Healthcare, the three clinical commissioning groups, NHS Leeds, Leeds Partnership Foundation Trust, LINK representatives, public health and adult social care commissioners – aimed to deliver better outcomes for those most at risk.

It has tested integrated teams delivering person centred assessment and care in three neighbourhoods and worked on rolling out this approach across the whole Leeds area. Groups were set up in each of the three neighbourhoods to develop ideas around specific co-production strategies for each locality.

NEWCASTLE

Ambition: City-wide Social Prescribing

The project was led by the Newcastle West Clinical Commissioning Group and aimed to develop a single approach to social prescribing in primary care for the city of Newcastle to improve the quality of life for vulnerable adults with the full range of long-term conditions and mental health issues.

Social prescribing supports GPs to refer and encourage people to take up activities instead of, or alongside, their medical prescription. This could include going to the gym, joining a reading group, or taking up a hobby. By developing a model to meet the range of needs of patients with long-term conditions the project has tried to move away from a disease specific view of long-term conditions.

The partnership's approach was underpinned by the recognition of the importance of non-traditional service provision as complementary to traditionally commissioned services. The ambition has been for the social prescribing system to be embedded in all long-term condition pathways used across Newcastle, enabling better responses to co-morbidity. The Newcastle team also created a visual map of existing primary care services and is continuing to work with health care professionals and service users to scale up social prescribing.

EARL'S COURT

Ambition: Hardwiring co-production into a primary care setting

A partnership between Turning Point, Greenbrook (a GP-led primary care provider), Terrence Higgins Trust & NHS Dentists is hardwiring co-production into the running of a brand new Health and Wellbeing Centre which includes a GP led health centre, community sexual health services and NHS dentistry.

This innovative new Centre opened in December 2011 and includes an extended community offering with: a team of wellbeing navigators working on reception providing signposting, employment and healthy lifestyles support, community space, community researchers, a wellbeing motivational coaching service for patients with long-term conditions and a peer support programme run through a timebank.

They have also worked on the design of referral and after care protocols to support health professionals to work with patients on managing their long term conditions.

STOCKPORT

Ambition: Access and Discharge routes into co-produced mental health services

Stockport Council with Pennine Care NHS Trust have been working to redesign mental health services to discharge people from specialist services through to supportive and welcoming community alternatives.

Through the development of local wellbeing centres, by enlisting the support of volunteers and peer support groups, and by giving people the use of personal budgets to direct their own recovery, many people have gone on to find support in non-clinical services after discharge.

These same opportunities, including a voluntary sector co-produced crisis service, has extended options for GP referral providing an alternative to the Mental Health Trust for people experiencing mental distress and for people wishing to manage their difficulties and build resilience in a community setting.

By bringing staff from the Trust and local user led organisations to work together in a team, the principles of co-production has inspired this project to transform people's lives.

Recent developments include the launch of All Together Positive, a user led organisation and a peer support service to ensure that there are opportunities for people who are accessing or being discharged from mental health services to make use of co-produced services.

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