Nesta...

Innovation Unit

WORKING TOWARDS PEOPLE POWERED HEALTH

INSIGHTS FROM PRACTITIONERS

Working towards People Powered Health is one of a series of products from the People Powered Health programme alongside other practical tools and methods for practitioners and policymakers.

Introduction

We are living longer and many of our health outcomes are improving but we also face challenges from the increasing demand for health and social care services from an ageing population, many of whom have one or more long–term conditions. We know that the NHS spends 70 per cent of its budget on people with long–term conditions, and this figure is set to rise sharply in the coming decades. At the same time, the economic downturn and tighter spending constraints are putting immense pressure on the health system to find more efficient and cost effective methods of delivery, without compromising on quality.

In the second half of the 20th century innovations in pharmaceuticals, medical instruments and clinical procedures have delivered increases in life expectancy and improved healthcare. Yet, these innovations are no longer delivering the type of productivity gains that they once did. We therefore need to look elsewhere to find the types of radical solutions that will enable people to live well with their long–term conditions. For instance, can we re-imagine and reshape how clinicians and patients work together? How can we tap into the assets, skills, expertise and knowledge of both clinicians and patients, in order to create better health outcomes?

People Powered Health is about creating a healthcare system in which clinicians and patients collaborate to enable people to live better with their conditions. We know that 'co-production' is challenging for both professionals and for patients.[1] This resource focuses on the challenges for professionals and, in particular, how workforce culture needs to change to enable co-production to move from the margins to the mainstream.

We asked a range of experts – clinical, academic, policy as well as commissioners and service providers – to write down their ideas about the relationship between co-production and workforce culture. We were interested in the extent to which they thought culture is a barrier and what can be done about it. The responses are an interesting snapshot of the perspectives of experienced professionals working in and around co-production and health. Some focus on incentive structures, such as recruitment, training and appraisal systems, while others focus on less tangible changes to professional practice, culture and behaviour.

Across the varied contributions, three key themes have emerged. Firstly, many of the contributors focused on changing relationships. They argued that whilst transactional interactions were appropriate in some contexts, there would need to be a shift to more relational forms of care, in order to create more opportunities for patients and clinicians to collaborate and in order to help people find better ways of managing their long-term conditions. Secondly, it was clear that this would mean changing practice. This requires engaging with both how clinicians and patients think and feel about what healthcare should be, and a number of contributors suggest tools, methods and opportunities to make this possible. Thirdly, a number of experts focused on changing organisations. This involves working both within and across organisations and professional boundaries.

We hope you enjoy reading the different perspectives of this diverse group of professionals, all reflecting on how healthcare is practiced and what could be done differently to support more collaborative approaches to health.

Halima Khan
Director, Public Services Lab, Nesta

For more information about People Powered Health, co-production in health and this paper, please visit: **http://www.nesta.org.uk/areas_of_work/public_services_lab/people_powered_health**
Contact us at **pph@nesta.org.uk**, and contribute to the debate at #PPHealth

Summary

Changing relationships...

As you might expect, all our contributors agree that we need to **move beyond the dominant medical model in the NHS**. What is perhaps surprising is that some of the strongest advocates for this huge cultural shift are practicing clinicians. **Dr Alf Collins**, a consultant in pain management, captures both the progress achieved by modern medicine, and its limitations when faced with working with people who have long–term or chronic conditions:

> Doctors have been trained in bio–medicine – a taxonomic system which seeks to understand the basis for physiological dysfunction – pathology – in order to define a treatment. Steeped in scientific method, medicine is a reductionist, deterministic model which speaks the language of deficit and illness. The legacy, the inevitable by-product of medicine is that we now have an ageing population who live with multiple complex conditions that medicine cannot cure.

Not only does modern medicine face limitations in terms of providing a cure for people with long-term conditions, but – according to **Juliet Bouverie – it also devalues our human capacities and experiences:**

> A culture bound by technical expertise that is at ease with targeting treatment at body parts has often failed to **acknowledge the personal and social experiences of the person to whom the body part belongs.**

The medical model is still entrenched in the NHS, but **Alf Collins** believes it is important to think about **new ideas, paradigms, and philosophies** that could provide an alternative vision of the future:

> Now is the time then, to **look beyond bio–medicine** to ways of working with people – particularly people who live with long-term conditions – that supports them to keep well and to adapt to changing life circumstances. **This doesn't mean rejecting medicine as a philosophy – it means refining it or complementing it to meet the needs of our population in the 21st century.**

Adrian Sieff made similar comments:

> To be truly transformative, co–production necessitates a new relationship and different roles: clinicians changing from being fixers to facilitators, using their expertise to enable; patients changing from being passive recipients to active partners. It also requires the service infrastructure that constrains or enables the new relationship making self–management support their organising principle.

The majority of our contributors share this idea about the importance of changing **the culture of the NHS**. But **Paul Corrigan** remarks that **many clinicians are unconvinced** by co–production because:

> When they interact with medical staff most patients are at their most dependent. This means that if a medical professional sees 15 patients in a day, many of them will be experienced as very dependent for the time they are with the professional. This is not the easiest time to see people as containing assets.

However, as **Paul Corrigan** notes, co–production is about clinicians and patients working together, rather than leaving the patient to manage their own care on the one hand or completely taking over their care on the other.

Ian Wylie reflects that **there is a disjuncture between what is expected from us in everyday life, and what is expected from us by the health service.** He compares booking a restaurant online with getting a hearing test:

> I could actually contribute quite a bit to the outcome of my health problem were I allowed to do so.... Had I been asked to take [that great] responsibility I would have had the satisfaction of contributing to the fact–gathering and would have been better able to engage with the diagnosis, treatment options and outcomes.

This 'disabling' of the patient impairs clinical processes and outcomes. **Juliet Bouverie** points to the 70–75 per cent of breast cancer recurrences that are detected between routine hospital appointments. So it is crucial for clinicians and patients to work together in new ways, both during the diagnosis phase, and during aftercare.

Zoe Reed believes co–production is absolutely fundamental to the future of the health service, though recognises how many clinicians resist it:

> [Each] clinical encounter ... needs to generate in the patient a sense that they are valued and valuable and have a contribution to make to their own care and society at large. A co–production ethos and approach is the missing 'how' in a currently well trained and evidenced 'what'.

Changing practice...

Training and evidence are central to clinicians' professional identities and practice and and adapting these elements will be crucial to the success of co–production. **Glyn Elwyn** makes a strong argument for encouraging doctors to focus on what patients want in a consultation, rather than diagnosing what they think they need:

> Many doctors aspire to excellence in diagnosing disease. Far fewer aspire to the same standards of excellence in diagnosing what patients want... **there are wide gaps between what patients want and what doctors *think* patients want**

Nigel Mathers argues that an important first step is to get clinicians to **recognise that there is a problem:**

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

And **Sue Roberts** argues that it is crucial to engage with how clinicians think and feel about co–production. She points to a series of failed attempts to 'train' clinicians to adopt new, patient-centred approaches in the past:

> When system components such as sharing test results with people before the care planning 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

Najabat Hussein, a GP from Stockport, lists some of the barriers and concerns colleagues have raised, but stated that:

> I have no easy short-term answers, but I have found that spending time to allay each fear and tackling the governance issues as well as demonstrating long-term benefits has helped to convert some of my clinical colleagues.

Professional appraisal and re–validation systems need to pay more attention to the ability of healthcare professionals to activate patients, particularly those who have low levels of health literacy, argues **Chris Drinkwater.**

Chris also suggests a that doctors should work more closely with and learn from the **voluntary and community sector** in order to better understand the needs of patients and

what the sector has to offer. In particular he sees a role for local people with long-term conditions as peer support workers, health champions, link workers, navigators and health trainers at local and neighbourhood level. However, **Mark Platt and Amanda Cheesley** argue that such initiatives will flounder if we fail to invest in **primary care** and specifically the role of nursing, which continues to be the main point of contact for people with long-term conditions.

Changing organisations...

It is important not to underestimate the challenge of changing culture in the NHS. Indeed, according to **David Dawes** the main difficulty is that Boards operate according to a **short-term command and control mentality**, but fail to make any real inroads into the culture of clinicians. Furthermore, he argues that front–line innovation is often quashed by managers who are responding to targets and short-term financial measures and reporting pressures:

> Senior medical staff...will have a dozen different Chief Executives and even more Boards throughout their career and can simply outwait any new top down initiative of new management programme that they do not support, particularly if they use their extensive networks to slow it down.

So, is culture change impossible? Not according to **Lynne Maher,** who points to **skill development** as a good place to start:

> Staff particularly need to be supported with new skills. This includes listening, not for symptoms to link with a particular diagnosis, but listening for new insights, new ideas and expertise that patients bring, not only from their experience of healthcare, but also from their own life/job skills in whatever form.

How services are commissioned and evaluated can also change in ways that promote co-production. **Paul Jenkins** points to the need for:

> Commissioners to work proactively in managing the market in a way which eases transitions and facilitates the arrival of new market entrants. One important strategy is to work with service users and carers at the collective level and not just see co-production as a manifestation of individual choices and preferences.

Beverley Collett calls for:

> Commissioners... to work proactively with people in pain and with professionals, to ensure that co-production can occur as a positive and enhancing step for every patient.

Stewart Mercer points to the importance of clinical teams working together *as* **teams**:

> No man is an island and staff work in teams and teams have leaders and managers and all of these people must be signed up for true co–production. Both staff and patients will need to go the extra mile.

And **Jim Thomas** argues that we need to look beyond clinical teams or even services to ask how practitioners can work together **across organisational** and **professional boundaries** in order to achieve co–production:

> If we spent less time inducting people into a particular professional group and more time examining the skills that individual workers require to deliver the right local outcomes we may find that co–production happens naturally.

Cat Duncan–Rees draws from her experience of co–production in Stockport to argue that new forms of facilitation and conversation are required both across existing organisational boundaries, and also within organisations, if co–production is to be scaled.

Kate Michi Ettinger, highlights a number of examples of **organisational change**, made possible through new types of curriculum and teaching, new ways for clinicians to work

with the community, and the use of a range of online tools that enable patients to engage with both their peers and clinicians in unconventional ways.

Don Redding, thinks about how to capture the value of co-production, through **business cases**, and other forms of social value and the importance of translating this into policy and practical action. He also argues that it is crucial to make the case for change on a number of fronts, including to commissioners, patient groups, clinicians and research organisations.

Conclusion

Working with rather than doing to...

Co-production **competes** against many other policy terms and concepts. Indeed, a number of contributors felt that the term was too **technical** and impersonal, and preferred phrases such as shared care or partnership. For others, co-production was important, because it explicitly valued the work doing being by the patient in **producing** their health outcomes. Clearly, for some people the term co-production served to open up new possibilities for practical action, for others it acted as a hindrance. It was noted that arguments over language reflected the reality of a health service in flux, and emerging conflicts between the bio-medical model and the aspirations and desires of patients.

There was overall agreement that co-production was about a new set of relationships with patients, new forms of practice from clinicians, and new forms of organisational change. None of this is easy to achieve and there was a realisation that co-production continues to be the exception rather than the norm, isolated to small pockets of practice. For this reason, a number of contributors argued that **systemic change** requires work on a number of fronts. This has to include working with clinicians to engage with how they think and feel, and the culture of the teams and organisations that they work in, as well as the introduction of tools, methods, and strategies to shape practice and organisational culture. Co-production needs to be promoted at all levels in the system; from top down policy and Health and Well-being Boards, to networks of radical clinicians and, of course, demand from patients for co-production with their clinicians.

Contributors highlighted a number of practical solutions such as the CARE approach, Care Planning, Year of Care and learning from the Health Foundation's Co-creating Health programme. It was also clear that there is plenty of scope for more radical innovation and experimentation, learning from international examples, and supporting existing and new health providers with cultures, models and metrics.

Creating a co-productive workforce and culture is an ambitious and complex endeavour, but we hope that the ideas presented here, based on the accumulated practical experience of the authors, will support further innovation and impact in this field.

Next steps...

Working for co-production is one of a series of products which will include further insights from People Powered Health and other practical tools and methods for practitioners and policymakers.

If you would like to join in this discussion about workforce and culture for co-production you can get in touch on **pph@nesta.org.uk**; or you can tweet at #PPHealth.

Dr Simon Eaton, Consultant Diabetologist and Clinical Lead, Year of Care Partnerships, Northumbria Healthcare NHS Foundation Trust

Dr Ajay Khandelwal, Nesta

CONTENTS

Co-production in everyday life, versus co-production in health: some reflections

Ian Wylie, Chief Executive, Royal College of Obstetricians and Gynaecologists
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I have an appointment letter from Imperial College NHS Trust on my pin-board as I write, giving me a precise time to attend a hospital clinic for a hearing problem. This outpatient booking is now referenced by my name and three unique numbers: the hospital number, my NHS number, and a unique booking reference number.

The only things asked of me are that I turn up (preferably by public transport as I will need to pay parking fees if I drive); that I tell the clinic if I'm not going to turn up; and that I remember the name of my GP. As my GP has already written a referral letter (which I haven't seen), this latter information seems to be an unnecessary duplication.

Although I got off to a good start as I chose the appointment online with my GP through the 'choose and book system', in reality, I am already a passive player in this process. Sadly, that early activity has now died away as the weeks have dragged on.

Last night I booked a restaurant online for the end of the week. My expectation is that my visit to the hospital clinic will be much less satisfying than my restaurant trip. This is not because of the length of time between booking and event (my problem is chronic not acute), but because I expect the restaurant will manage to deliver what it promises, namely that my choices of food and drink will be met during the evening of my visit. Unless a set of tests on my problem ear are ordered in the next few days, it is very likely that the outcome of my hospital visit will be another hospital visit. We don't see this as surprising, although it is rather odd. It is the equivalent of choosing my meal at the end of the week and being asked to come back a week later to eat it.

I could actually contribute quite a bit to the outcome of my health problem were I allowed to do so. My GP and I have explored my hearing loss quite thoroughly and from his summary and online questionnaire (using best practice guidelines) could probably identify further tests needed to identify the likely problems. I could have been asked to complete these tests in time for the results to be analysed by the specialist before my appointment. Had I been asked to take that responsibility I would have had the satisfaction of contributing to the fact-gathering and would have been better able to engage with the diagnosis, treatment options and outcomes.

Taking this level of responsibility for my healthcare is the same level of complexity as many daily living choices and much below the complexity of choosing a job, a partner, a child minder, or a place to live. Such responsibility could have brought about a swifter, cheaper and better outcome than the one that patient no. 0002299211SM is likely to receive at the end of July.

Co-production and mainstream healthcare: an uneasy alliance?

Dr Alf Collins, Consultant in Pain Medicine, Taunton and Somerset NHS Foundation Trust (peter.collins@tst.nhs.uk)

As you read this paper, thousands of people we call patients are meeting up with thousands of other people we call clinicians in encounters we call consultations. During the few minutes they spend with each other, some of those patients will be told by their doctors that they are dying whilst others will be told that have a trivial condition that's easily treatable. And in those encounters, each party has an expectation of the other; patients expect to be treated (if possible) and doctors expect to treat them. It's a deeply held cultural belief about our respective roles that is, in Daniel Moerman's view[2], key to how and why patients who see doctors (sometimes) get better.

Doctors have been trained in biomedicine – a taxonomic system which seeks to understand the basis for physiological dysfunction – pathology – in order to define a treatment. Steeped in scientific method, medicine is a reductionist, deterministic model which speaks the language of deficit and illness. The philosophy has proven to be remarkably resilient; medicine has helped us find specific causes for many diseases that can now be prevented or cured. However the legacy, the inevitable by-product, of medicine is that we now have an ageing population who live with multiple complex conditions that medicine cannot cure.

Now is the time then, to look beyond biomedicine to a way of working with people – particularly people who live with long-term conditions – that supports them to keep well and to adapt to changing life circumstances. This doesn't mean rejecting medicine as a philosophy – it means refining it or complementing it to meet the needs of our population in the 21st century.

Perhaps then, co-production is an idea whose time has come. The question is: can the philosophy of co-production complement or help us adapt and refine the medical model? Well, I think there are many challenges ahead.

Authentic co-production is more than just supporting people to keep well and to adapt to changing life circumstances. It's about recognising people as assets and supporting them to build on their own range of capabilities. It's about supporting them to recognise, engage with and develop their own sense of resourcefulness and resilience – as individuals and as communities. For many people who work in public services, it's an entirely alien way of working. This is because:

- The medical model predominates. It is a way of working that focuses on diseases and not on people and it aims to reduce disability rather than build on capability.
- Our assumptions about what the NHS is for are informed by the medical model; the NHS is currently an NIS– a National Illness Service.
- All of our national public service policies, systems, processes and relationships are predicated on the medical model.
- 'Being ill' is currently our ticket into the system.

The medical model is now our predominant cultural and institutional model for how to understand and manage health. The medical model and co-production flow in different directions and given this, we might well struggle to take genuine co-production into the mainstream other than in a dilute form (which we might call 'working in partnership').

Does this matter? Well, it matters profoundly because medicine has caused the problem of long-term conditions and we are currently making the category error of applying the medical model to manage the problem it brought about.

So, is there an answer to this?

Well, it seems to me that we need to employ the medical model when people become unwell or when they initially develop a long–term condition; people should know about the best possible treatment options and be supported to make informed decisions about the right choice for them (shared decision making).

What should also happen is that there should be a parallel service to the medical service designed to support people to keep well and to adapt to changing life circumstances. This service would be the mainstay of a 21st century health service – the illness service should only kick–in when the health service has done all the work it can.

So, there we have it. A National Health Service informed by the principles of co–production and designed to 'do what it says on the tin' and a parallel National Illness Service designed to treat people when they fall ill. The challenge is how to achieve this, given that we currently seem genuinely trapped in an illness/treatment paradigm.

Co-production: A slippery yet essential concept in health

Zoe Reed, Executive Director South London and Maudsley (zoe.reed@slam.nhs.uk)

Co-production is a slippery concept – hard to describe, hard to retain accurately in the mind and even harder to implement in public services.

Nesta and **nef** lead a piece of work which arrived at a six point definition. This is what we aspire to use as the operating system across the Lambeth Living Well Collaborative – one of the six pilot sites in People Powered Health.

The Nesta/**nef** work on co-production was probably most interesting in generating a paper on what co-production isn't. There is a good grid included which clearly defines both the 'co' and the 'production'.

From this analysis it is clear that co-production isn't a number of things, including:

- Partnership working between different parts of the NHS.
- Patient and public involvement.
- Consultation and engagement exercises.
- Having service users at a meeting or an event.
- User-led services.
- People with long-term conditions being denied access to services.

Co-production is in danger of becoming seen as universally applicable in all health settings – the answer to all our problems. I got short shrift when trying to persuade an intensive care consultant that it was a valuable concept in his work! Pushing the logic of applicability too far is probably not helpful at this stage – although ultimately of course it is applicable in all settings!

However, co-production in long-term conditions management [LTC] is an extremely valuable construct and we do need to take it from margins to mainstream. It will require services to be provided from a fundamentally different mindset and starting point. It is about the NHS having a fundamentally different view on where the boundaries of its work are and the issues it should be involved in. It is about a different definition of what health services are.

At every clinical encounter it is about offering well developed skills and evidence-based advice in a manner which generates in the patient a sense that they are equal players in the management and improvement of their LTC. It needs to generate in the patient a sense that they are valued and valuable and have a contribution to make to their own care and society at large. As public servants it is entirely appropriate for clinicians to be seeking to improve the health and well-being of the patient in front of them and the wider society at the same time. Co-production ethos and approach is the missing 'how' in a currently well trained and evidenced 'what'.

As a system, health needs to see it as entirely appropriate to use its power and position to trigger health and well-being behaviours in communities and to therefore support community-based organisations that encourage the development of reciprocity and taking an asset-based approach. A move away from traditional volunteering is to be encouraged as this only reinforces a dependency *"I am fortunate and have – you aren't and don't."* between volunteer and recipient.

Service systems that support the co-production delivery approach require clinicians to be comfortable at communicating in group settings and thinking about how to lever and ensure rather than do to. Clinicians and managers need to be constantly thinking who else could be delivering different parts of the healthcare system – people who could benefit from the sense of value and worth they themselves get from delivering it e.g. in large part the current recipients of their clinical advice. Peer support needs to become just that, i.e. every patient being asked to give something back. Whilst there is a place for the professionalisation of people who have used services to help others through similar distressing times, that should not be in the place of the massive injection of assets and improvement in well-being which the health service could release if it were to take this approach as standard.

Why co-production can seem absurd from a health practitioner viewpoint

Professor Paul Corrigan, Independent Consultant (paul@paulcorrigan.com)

One of the main barriers to the ability of medical staff to co-produce is that they hear the idea of co-production as one which removes health professionals from the scene. Often when co-production is said, they hear alternative medicine which belittles all of the activity they are involved in and trained for. This does not then become an issue of self-justification, but in their day-to-day experience of the NHS it becomes absurd. Most medical professionals see patients most days that have very high levels of acuity and the idea that these patients could 'look after themselves' is absurd. Actually day-to-day medical professionals work with very, very dependent people and they hear co-production say that they are not necessary in these interactions. This strikes them as absurd (and they would be correct if that was what co-production was saying).

When they interact with medical staff, most patients are at their most dependent. This means that if a medical professional sees 15 patients in a day, many of them will be experienced as very dependent for the time they are with the professional. This is not the easiest time to see people as containing assets. Almost more than any other moment in their lives, the patients present as having less to give. Again, seeing patient after patient in that situation means it is very hard at the end of the day to see 'patients as having a range of assets to work with'.

In terms of training and culture, medical professionals are trained in communication to listen (receive communication) for symptoms and to talk (give out communication) with diagnosis. This means that everything they hear from a patient adds to the disease and does not add to the rounded view of that person. And the communication back to the patient is about very, very complex and important things concerning the condition the patient has.

The role of the doctor: to diagnose and prescribe, or to co-produce?

Dr Najabat Hussein, GP and MH Lead Stockport CCG (najabat.hussein@nhs.net)

As a GP with 20 years' experience I have seen terms such as 'patient empowerment' but have never fully committed to the principle. I have sat on PCT meetings with token lay members and service users but I have doubted how much influence they have had on decision making.

The reality is that the NHS is 'medicalised' and the greatest influence in service provision comes from the clinicians, whose training is based upon establishing a diagnosis and prescribing appropriate remedies, which in most cases is medications. When those medications take effect the clinician believes that the patient is in recovery and hence their job is done.

This in a nutshell is the biggest problem and the greatest barrier I have had when dealing with clinicians and to some extent commissioners when trying to persuade them of the value of co-production and the long-term benefits that it has in the health economy.

The other issues raised are:

- Clinicians' insecurities—undermining their status/role/job.
- Issues of confidentiality and risk management/litigation.
- Lack of belief in the ability of peer support.
- Afraid of challenging patient-dependence.

I have no easy short-term answers, but I have found that spending time to allay each fear and tackling the governance issues as well as demonstrating long-term benefits has helped to convert some of my clinical colleagues.

As for roll-out on a grand scale, I believe that the concept of co-production has to be introduced at the undergraduate level so that future NHS workers see patient management in a different light. In the short term, the Department of Health could pressure commissioners to engage in this approach.

The challenge of overcoming ingrained health and social care workforce cultures and attitudes

Juliet Bouverie, Director of Services, Macmillan Cancer Care
(JBouverie@macmillan.org.uk)

The workforce of any health and social care organisation is a living embodiment of its culture. However, the growing obsession in the world of business and service delivery with change management tools promising easy fixes, have all too often lost sight of the fact that it is people, not things (policy, strategy or system), that come to define an organisational culture.

So powerful is this influence that staff behaviours that compromise or undermine the official 'sales pitch' or brochure – the stated organisational vision and values, can nevertheless spread rapidly and weaken the intent and application of a plethora of policies and strategies. New unofficial straplines and associations prevail that replace or weaken that which was so carefully constructed.

The challenge of scaling-up co-production in the design and delivery of health and social care services is the challenge of overcoming ingrained health and social care workforce cultures and attitudes. Reorganisation of structure and system should only ever be seen as secondary to achieving this goal.

The 'Dr knows best' paternalistic culture of the NHS is as prevalent today as it was when the NHS was first established. The rhetoric of a patient-centred NHS seems a bit hollow and the 'nothing about me without me' rallying cry far too aspirational.

The prevailing discourse and culture around cancer management, treatment and medication has been crafted by a number of talented professionals that have worked tirelessly to introduce a biomedical revolution to treat a disease. These innovators have inspired future generations of staff to also play their role in this biomedical revolution and strive for clinical excellence. Thus a certain type of culture has prevailed.

Treating a disease has become the primary policy, clinical and strategic priority, one which certainly rings true for cancer. A culture bound by technical expertise that is at ease with targeting treatment at body parts has often failed to acknowledge the personal and social experiences of the person to whom that body part belongs.

A culture that facilitates such a dehumanising approach may not always recognise the patient as an active contributor that has the expertise and right to co-produce their treatment and care plan.

The biomedical revolution has therefore instilled a culture of unequal relationships that are purely transactional rather than reciprocal. The consequences of such unequal power dynamics can be clearly illustrated during the follow-up phase of cancer treatment.

After initial treatment, cancer patients currently enter what is called the 'follow-up' system. This involves regular surveillance to check that the cancer has not returned. There are gaps in this system between best and common practice. Patients do not always feel sufficiently empowered to express their needs, and rarely are they given the choice to be involved in co-creating the personal care and support requirements necessary to manage their condition. This gap is costly and ineffective and fails to meet patient need:

- **Costly and ineffective –** follow-up fails to spot recurrence early. One study found that between 70 and 75 per cent of breast cancer patient recurrences are detected between routine hospital appointments.

- **Failing cancer survivors –** approximately one in five people living after treatment for cancer will develop significant long–term emotional, psychological and physical problems that seriously affect their quality of life (e.g. depression, incontinence, psychosexual problems, new cancers).

To close this gap, the dynamic between people who use services and those who provide them needs to be transformed.

However, there is little focus on key cultural shifts required to make the assessment and care planning approach a positive experience, premised on co–creating care with the patient. This requires a different approach from how professionals engage with patients; itself a broader National Cancer Survivorship Initiative outcome – 'different ways of getting professionals to engage'.

Often the patient must wait for an automatic routine appointment before they can discuss potential concerns, anxieties or report signs and symptoms indicating suspected recurrence. If however, the dynamic between the person using services and those who provide them was equalised and less professionally dominated, patients would not only be able, but also feel confident, about accessing support when they themselves have any concerns and would find professionals who are receptive to them.

Without such a transformation of culture and practice, patients will continue to receive impersonal 'one size fits all' care. The consequences of current widespread practice can be serious: routine follow up appointments can delay 'the right kind of discussion' which in turn can lead to late presentation, impacting upon the ability of a specialist cancer team to effectively treat the cancer or manage the complications of recurrence or the consequences of treatment. This could have a detrimental effect on the patients' quality of life and an extreme but real example is the case of spinal cord compression following treatment for prostate cancer where a late intervention could lead to paraplegia.

Recommended further reading:

From vision to action

When doctors and patients talk: making sense of the consultation

Helping people share decision making

Donaldson, A., Lank, E. and Maher, J. (2011)The collective voice: bringing practitioners together to influence policy and practice. 'Community Practitioner', November 2011, Vol. 84. No. 11.

Supporting staff to deliver better and more patient-focused care

Mark Platt, Policy Advisor, Patient and Public Involvement and Amanda Cheesley, Long-Term Conditions Advisor, Royal College of Nursing
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Nursing and care staff are key to delivering patient–centred and co–produced care, but to do it they need to be properly resourced and supported, and individual services need to have the correct numbers of staff and mix of skills.

More specifically, staff need to be supported and provided with suitable IT equipment and given the necessary training to use it. More investment needs to be made into community services and staff, both in terms of numbers and equipment. This is especially vital in relation to specialist nursing staff, e.g. cancer, MS, and Parkinson's nurse specialists. These nurses are often the main and trusted contact for people living with long–term conditions and their carers and families, and can play a pivotal role in supporting them to design the best care 'eco–system' to deliver the outcomes desired by the patient, and arrived by use of shared decision making.

As well as individual–level co–production, nursing staff also have a role to play in the development of existing or new services, and so need to be involved at the earliest stages of service changes and reconfigurations, so that they can bring their knowledge and understanding of how patients use services, and their insights into how improvement can best be secured, for instance through initiatives such as the Productive Ward programme.

In support of our memberships, and the wider nursing family, the RCN has developed a set of principles, entitled the Principles of Nursing Practice. These are nine high–level statements, illustrated with case studies, which set out what patients should expect from the people who care for them. Two principles are particularly relevant: Principle D, which highlights the need for nursing staff to promote and provide care that puts people at the centre; and Principle G, which highlights the need for nursing staff to work closely with their own team and with other professionals to make sure that patients' care and treatment is co–ordinated, is of a high standard and has the best possible outcome.

Looking to the future, the 'Nicholson Challenge', to make £20 billion of cost savings by 2015, is already putting significant additional pressure on frontline nursing and care staff, and on their ability to deliver high quality care, especially in those areas where they are also being faced with significant service reconfigurations. Our RCN Frontline First reports have shown that there are already many instances where organisations have resorted to cutting staff, and in particular those who are perceived to be the most expensive. Unfortunately these are often the specialist nurses who have the very skills required to support the implementation of patient–centred care.

The RCN believes if allowed to progress unchallenged, these 'slash and burn' approaches will in fact impede the increase of initiatives such as self–management, and approaches to increasing patient–centred care such as shared decision making, and may ultimately lead to an increase in health costs, as the demand for services is incorrectly or ineffectively managed.

Links:

- RCN Principles of Nursing Practice **http://www.rcn.org.uk/development/practice/principles/the_principles**
- RCN pamphlet, 'Specialist nurses, Changing lives, saving money.' **http://www.rcn.org.uk/__data/assets/pdf_file/0008/302489/003581.pdf**

Cross-boundary team building for co-production

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The process of professional training is about inducting new recruits into the culture, values, beliefs, customs, attitudes and behaviours of that profession (Hall, 2005). If we are going to overcome workforce and cultural barriers in developing co-production, we need to understand these professional cultures and work to develop a culture of co-production, whose values, beliefs, attitudes and behaviours are shared interprofessionally and interorganisationally – taking precedence over traditional unitary professional values, attitudes and beliefs. To create the environment for co-production to flourish we have to enable the workforce to acknowledge their differences as well as the things that they have in common.

At a strategic level, workforce commissioning and workforce scenario planning have an important role to play in developing co-production. By understanding the local environment, its demographics and its care and health workforce data, we can begin to explore how the population of a particular area is changing and what the workforce change requirements are likely to be in the future. At an operational level, cross-boundary teambuilding remains an essential element in facilitating co-production. Using these workforce approaches in tandem can make a significant difference to outcomes.

By taking a skills-led approach to co-production and asking what knowledge and experience do you already have and what knowledge and experience do you require to contribute actively, we can begin to create different approaches and different outcomes for people in their homes and in their communities.

Skills for Care's work on skills around the person takes this idea in a practical way to the next level. It is surprising how much knowledge and experience people do not realise they have unless it is pointed out to them. If we spent less time inducting people into a particular professional group and more time examining the skills that individual workers require to deliver the right local outcomes we may find that co-production happens naturally.

Reference:
Hall, P. (2005) Interprofessional teamwork: professional cultures as barriers. 'Journal of Interprofessional Care.' Vol.19. P.188-196.

The principles of workforce redesign **http://www.skillsforcare.org.uk/workforce_strategy/workforceredesign/workforce_redesign.aspx**

Learning from Innovation **http://www.skillsforcare.org.uk/workforce_strategy/workforce_innovation_programme/workforce_innovation_introduction.aspx**

Community Skills development **http://www.skillsforcare.org.uk/workforce_strategy/neighbourhood_and_community_skills/neighbourhood_and_community_skills.aspx**
Interprofessional Care.' Vol 19. P188–196.

Methods and tools to achieve co-production

Lynne Maher, Director for Innovation and Design, NHS Institute for Innovation and Improvement (lynne.maher@nhsinstitute.nhs.uk)

The new NHS Constitution says; *"The NHS belongs to the people"* (DH 2012). This must signal a need to move from the traditional model of healthcare delivery which is based on an expert or paternalistic mode of care to a position where patients and family members are enabled to be much more involved not only in their own care pathway but in the overall design of health services. This constitutes a shift to a partnership approach where the skills and expertise of staff, patients and family members are all recognised and used together to co-produce health services.

The paternalistic model is often still accepted as the norm or 'right way' by both staff and patients although there are an increasing number of examples of co-production. This gradual change can be linked to the public's increasing interest in healthcare service provision. For example, more people now seek information before seeing a healthcare professional and often want to have a discussion about what the information means for them. People are also more aware of what constitutes good service and this in turn has influenced increased feedback about the public's expectations of healthcare service delivery.

Essentially, moving to a model of co-production constitutes a change from what has been the norm in terms of the more traditional model of service delivery. A level of resistance usually accompanies any desire or plans for change and we need to draw upon our knowledge of effective change leadership as with any other change/improvement work.

The terms co-production, co-creation and co-design are often used interchangeably and this causes confusion for both staff and patients. Firstly we need to really help people to understand what co-production means, how it can be used and what benefits it can bring.

For example:
Co-production is not the same as consultation, surveys, annual focus groups or other types of tokenistic participation of people who use services which do not result in the patient and family being actively involved in redesigning those services.

Co-production means more active involvement and decision making by the person using a service, and puts more emphasis on 'relational' rather than 'transactional' approaches to delivery.

In a recent research report commissioned by the DH and NHS Institute which aimed to identify 'What Matters to Patients'[3], it was clear that the 'relational' aspects of services provision were highly important to patients. For example:

- Feeling informed and being given options.
- Staff who listen and spend time with me.
- Being treated as a person, not a number.
- Being involved in care and being able to ask questions.
- The value of support services, for example patient and carer support groups.
- Efficient processes.

Empowerment

To act as partners together, both patients and service providers need to be empowered. Co-production is based on active and collaborative relationships and this requires more empowered frontline staff who are able and confident to share power with users

and accept user expertise. In addition, patients and family members also need to feel empowered and equal in this relationship.

Skills

Staff particularly need to be supported with new skills. This includes listening – not for symptoms to link with a particular diagnosis but listening for insights, new ideas and the expertise that patients bring not only from their experience of healthcare but also from their own life/job skills in whatever form.

Staff often need to use a greater range of interpersonal, relational, facilitative skills – rather than a delivery/clinical focus being predominant.

Time

Involving people more directly in shaping services does require time, especially initially while skills are being developed and confidence grows. Of course the importance of evaluating the benefits and impact of this work is critical and must include celebration of achievements.

System incentives

The Government has made it clear that the patient experience is a crucial part of quality healthcare provision. The NHS Constitution, the Outcomes Framework 2011/12 and the NICE Quality Standards for Experience and Mental Health Experience all reinforce the need for patient–centred care. This helps in terms of signalling strategic intent but translation to what this means in practice needs to happen.

There are a number of opportunities for commissioners to build the need for positive patient experience into the vision, strategy, systems and structures for commissioning. Commissioners should work in close partnership with providers to ensure that their expectations are understood and to ensure that there is support for providers to deliver a positive patient experience and track that experience along patient pathways as well as by individual service.

There needs to be a range of mechanisms that can capture direct feedback from patients, family members and wider communities. This data can be used alongside information on clinical outcomes and other data sources to inform quality improvements and reshaping of services.

References and links

DH (2012) NHS Constitution. Accessed via: **http://www.dh.gov.uk/health/search?q=NHS%20Constitution%20**

Robert, G. Cornwall, J. Brearley, S., et al. (2011) 'What Matters to Patients; Developing the evidence base for measuring and improving patient experience.' Accessed via: **http://bit.ly/NKNVJj**

DH (2012) Public Health Outcomes Framework. Accessed via: **http://www.dh.gov.uk/health/2012/01/public-health-outcomes/**

NICE (2012) Patient Experience in Adult NHS Services **http://guidance.nice.org.uk/CG138/Guidance/pdf/English**

Also look at:

Transforming Patient Experience Web pages from the NHS Institute **http://www.institute.nhs.uk/patient_experience/guide/the_patient_experience_research.html**

Patient Feedback Challenge Web pages **http://www.institute.nhs.uk/innovation/spread_and_adoption/nhs_patient_feedback_challenge.html**

Royal College of General Practitioners and care planning – co-production of health

Nigel Mathers, Vice Chair RCGP

The RCGP strongly supports the principles for the co-production of health identified by the Richmond Group of leading charities, which prioritise care from the patients' standpoint:

- **Co-ordinated care:** people feel that the care they receive is 'seamless' because it is organised around them and their needs.
- **Patients engaged in decisions about their care:** all patients and carers can take an active role in decisions about their care and treatment because they're given the right opportunities, information and support.
- **Support in self-management:** People with long-term conditions can manage their condition appropriately because they have the right opportunities, resources and support. *(Ref: 'From Vision to Action: Making patient-centred care a reality'. Richmond Group of Charities. King's Fund, 2012).*

The RCGP published a policy document on 'Care Planning' in September 2011 which summarised the lessons learnt so far by initiatives such as Co-creating Health, people powered health and the Diabetes UK 'Year of Care' project. *(REF: Improving the lives of people with long-term conditions; Mathers, Roberts, Karet and Hodkinson. RCGP 2011. Available through the RCGP website).* In this document a "care planning approach" was defined as a "set of attitudes and structures which transform the nature of the professional-patient relationship and enables the delivery of such a vision."

The co-production of health

The RCGP intends to develop a joint strategic approach to health improvement, based on the concerted implementation of care planning in General Practice within the context of multimorbidity and in partnership with a range of disease-specific organisations; e.g. cardiovascular conditions, respiratory conditions.

This intent has been chosen to promote shared decision making using a care planning approach – this is central to the delivery of care to people with long-term conditions but recognises the need to strengthen the evidence base by action research and robust evaluation supporting a model of integrated care.

The aims of the RCGP care planning programme are to embed care planning into usual General Practice and to incorporate the development of care planning skills into the GP training curriculum. The objectives of the care planning programme are to establish communities of practice within and across health communities, to develop leadership and facilitation in care planning and to bring together members of primary healthcare teams from existing networks (e.g. Federations of Practice) and other stakeholders, to provide continuing learning and to roll out best practice. A further objective of the RCGP care planning programme is to develop learning and teaching resources as well as engaging in improvement research. Partner organisations are currently being sought to develop and implement this programme.

Overcoming cultural barriers to co-production

Although some improvements have been seen in recent years, the traditional training of doctors in the acute sector has not generally included the development of the core knowledge, skills and attitudes appropriate for patient-centred care. One key issue which needs to be addressed is that many doctors already feel they are delivering patient-centred care – unfortunately that is not what patients generally report. The challenge, therefore, is to raise the consciousness of doctors about the issue and to facilitate the development of the appropriate knowledge, skills and attitudes which support shared

decision making, care planning and the co-production of health. Each Practice has its own subculture which may be either internally or externally focussed. Broad processes for patient care within Practices may be classified as either relationship-based (with a focus on flexibility, individuality and spontaneity) or mechanistic type processes (with a focus on control, order and stability).

Within this matrix of processes and focus, Practices may have adopted[4]:

- **A clan culture** which is cohesive, participative, with a leader and mentor and bonded by loyalty and tradition.
- **A hierarchical culture** which is ordered, uniform, with the leader as administrator and bonded by rules and policies.
- **A developmental culture** which is creative, adaptive with the leader as risk-taker, innovator and bonded by entrepreneurship.
- **A rational culture** which is competitive, acquisitive with leader as goal-orientated and bonded by competition with an emphasis on winning.

Facilitators need to diagnose which type of culture a particular Practice has and work with that culture using a wide range of versatile skills and approaches. One of the most powerful facilitators of change in any professional group is the example of peers and the identification of 'Co-production Champions' in care planning will be necessary to cascade the programme through communities of Practice.

Implementing innovation in clinical practice: obstacles and solutions

A useful framework has been outlined recently by the Health Foundation which identifies a number of obstacles to introducing care planning/co-production into Practices and proposes some solutions[5]. These may be summarised as follows:

Failing to convince people there's a problem (consciousness raising). This is a key obstacle to the implementation of co-production and the emotional engagement of practitioners is particularly important to implement shared decision making. People might not think that the solution is the right one for the identified problem or they may dispute the evidence and it is important for facilitators to be prepared to provide the evidence for practitioners when required.

There may also be an over-focus on projects and delivery and it is important not to emphasise timelines at the expense of the work itself i.e. sufficient time needs to be spent on planning, consultation, understanding local context (i.e. Practice culture) and clear communications. Data collection and monitoring always takes significantly more time and energy than anticipated.

Co-production facilitators need to avoid being over ambitious and have realistically achievable objectives and goals for implementation, which need to be aligned with the goals of the Practice itself to ensure a fit with the culture and the commitment from staff. It is also important to 'go with the flow' of the external context such as the current drive for clinical commissioning.

Finally it's important to clarify who owns implementation and the solution to problems and agree roles and responsibilities at the outset. It's also important to remember that all innovation and change may have side effects, and that although the co-production initiative may address one issue it may cause other problems, e.g. by increasing waiting lists for appointments, and this can cause people to lose faith in the initiative.

Stop the silent misdiagnosis: patient preferences matter

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Many doctors aspire to excellence in diagnosing disease. Far fewer, unfortunately, aspire to the same standards of excellence in diagnosing what patients want. In our recent publication for the King's Fund, *Patients' preferences matter: stop the silent misdiagnosis*, we presented an accumulation of evidence which showed that preference misdiagnoses are commonplace. In part, this is because doctors are rarely made aware that they have made a preference misdiagnosis. It is the silent misdiagnosis.

The NHS must break this silence. It must stop the silent misdiagnosis. When it does so, it will score three distinct victories. First, patients, who can suffer just as much from a preference misdiagnosis as a medical misdiagnosis, will get the medicine they would choose were they well informed – that is, if they had better information about treatment options, outcomes, and evidence. Second, the NHS's aspiration to create an 'internal market' will finally have a chance to achieve its full potential. Third, because patients choose fewer treatments when fully informed, the NHS could save billions of pounds.

The problem of the silent misdiagnosis is widespread. Several studies show that patients choose different treatments after they become better informed. In addition, there are wide gaps between what patients want and what doctors think patients want. Finally, there are dramatic geographic variations in care that can only partially be explained by causes other than the silent misdiagnosis.

The most important step the NHS must take in order to stop the silent misdiagnosis is conceptually straightforward: it must measure and report the incidence of preference misdiagnoses. It must also challenge a handful of entrenched but erroneous assumptions that are inconsistent with the mindset necessary to tackle the problem of the silent misdiagnosis. Those assumptions are: (1) that science alone determines need; (2) that variation in care is the problem; (3) that patient choice is about time and location; (4) that 'the market' can sort out healthcare; and (5) that commissioners can calculate need.

Furthermore, the NHS must support doctors in their efforts to make more accurate preference diagnoses. It must do so by providing doctors with more and better information about what patients want, and by providing patients with more and better information about options, outcomes, and evidence. To assess progress, the NHS should implement measures that indicate how much doctors and patients have learned.

To fully realise the agenda that we propose here, the NHS must recognise the need for new, dedicated teams focused on gathering and disseminating information. It must also aid commissioners in shifting their focus, from trying to calculate the need to trying to eliminate preference misdiagnoses, so that patients receive the care they need (and no less), and the care they want (and no more).

Extract adapted from: Patients' preferences matter: stop the silent misdiagnosis. King's Fund, London; 2012 by Al Mulley, Chris Trimble and Glyn Elwyn.

For the full publication go to: **http://www.kingsfund.org.uk/publications/patients_preferences.html**

Empathy is key

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Co-production of health was a term coined by Welsh GP Julian Tudor Hart in 1995 (famous for the 'inverse care law') and was put forward to counter the growing trend of seeing patients simply as consumers of healthcare, and thus for healthcare to be treated like any other commodity, based on free market logic. Julian saw (and still does see) the NHS as being a very important social institute based on mutuality and trust, with important effects beyond simple healthcare. I agree with him.

For co-production to work, both patient and healthcare practitioner must believe in it, and work together on the basis of respect and trust. This must be genuine, and such a trusting relationship develops over time. Thus co-production is most possible in areas of healthcare which have personal continuity, with general practice being the prime example. Informational continuity is not a substitute for real continuity – same doctor, same patient, getting to know each other over a series of consultations. Empathy is a key ingredient, as is time (consultation length). Short consultations with unempathic staff who are rushed and stressed is a recipe for disaster. My recent work (Mercer *et al.* (2012) in *BMC Family Medicine*) has shown that empathy is a pre-requisite for patient enablement.

Co-production requires staff to be skilled not just technically but interpersonally and the CARE Approach web-based tool is one approach to try to help. However, no man is an island and staff work in teams and teams have leaders, and managers, and all of these people must be signed up to true co-production. It is not about getting the patient to do what you tell them. Nor is it simply giving information and 'education'. It is about much, much more than that. Both staff and patient will need to learn to go the extra mile. The CARE Approach needs to extend to teams, so that teams get to know each other and work together with trust and respect. Currently we have silo medicine, and silo social care.

Co-production is not synonymous with self-management support. It is about much more than that.

Co-production in practice

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Co-creating Health and Year of Care are two programmes that have demonstrated how co-production can be put into day-to-day practice with people living with a range of long-term conditions.

Both recognise a fundamental problem with current models of care: the mental model that the patient is a passive recipient of expert advice, a rational being that makes long-term strategic choices on the basis of information given to us by people who hold clinical knowledge. But knowing the qualifying time for the 100m for the Olympic men's team was never going to mean I had a chance of qualifying; knowing there is a pot of gold upstairs will not help me if I am in a wheelchair and there is no lift; and knowing that my patient needs to lose weight to better manage their diabetes will not mean they will do it just because I told them and they now know. Gyms that charge annual membership and time share sellers make their money on the basis that we don't behave in the way that we say.

Both also recognise that what we do is far more shaped by our values and our vulnerabilities, by what feels possible in our real life situations and our capabilities than it is by what we know. WeightWatchers® works because it provides the encouragement and on-going support to help us translate our aspirations into action through achievable goals that I set, regular reinforcement and peer support.

The barriers to participation are built into the NHS. In order to diagnose a condition, a doctor needs years of training; they get my results sent to them and appointments are made around service convenience rather than my need. In order to manage their condition 24/7, 365 days a year, a patient receives some information and perhaps some training, often focused on self-medication rather than on self-management.

There is a growing evidence base that training programmes for people living with a long-term condition can help them gain confidence, knowledge and skills to be active producers of their care and treatment and that self-management can be reinforced through a different type of on-going relationship with services – one that provides support through three key techniques:

- Shared agenda setting enables people to prepare in advance the issues they want to explore and the problems they want to solve. It signals from the beginning that patients are active partners in their care. Giving patients an agenda setting sheet in advance of the consultation; sharing any tests results in advance; turning the waiting space where the patient sits passively into an active preparation area, are simple, practical ways in which health services can support people to set the agenda for their consultation.
- Collaborative goal setting involves the clinician supporting the patient in choosing small and achievable goals and agreeing an action plan as to how they will achieve them. The 'confidence ruler', a 1–10 scale against which the patient assesses their confidence of achieving the goal under discussion, provides confidence to both patient and clinician that the goals are realistic. And how about going further: replacing the traditional'prescription' – of medicines, information or exercise – with a contract, sent to the patient and copying it to other relevant clinicians involved in the patient's care and support?
- Timely goal follow-ups within a fortnight are more likely to succeed. An alcohol relapse prevention programme in Bolton sends regular texts with simple questions to check how they are feeling. The client's answer triggers a service response, the level of which depends on the answers given. A project in Newham is replacing routine follow-up outpatient appointments that don't require physical examination with web-based consultations. Patients report that being in their own environment helps them feel more in control.

To be truly transformative, co-production necessitates a new relationship and different roles: clinicians changing from being fixers to facilitators, using their expertise to enable; patients changing from being passive recipients to active partners. It also requires the service infrastructure that constrains or enables the new relationship making self-management support their organising principle. Supporting patients to develop the skills, confidence and knowledge through a self-management support programme and reframing the consultation around agenda setting, goal setting and goal follow up are practical changes that can make co-production real.

Co-production addressing health inequalities

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Inequalities in health outcomes and health literacy are not often discussed in the context of co-production for long-term conditions. Long-term conditions fall more heavily on the poorest in society: compared to social class I, people in social class V have 60 per cent higher prevalence of long-term conditions and 60 per cent higher severity of conditions[6]. This tallies with the Marmot review which reported that the poorest people die on average seven years earlier, but more importantly, they have on average 17 years of disabled living before they die.

Social determinants, such as poverty and educational failure are responsible for these poor outcomes but the common intermediary is health literacy which has been defined as the ability to make sound health decisions in the context of everyday life – at home, in the community, at the workplace, in the healthcare system, the market place and the political arena. It is a critical empowerment strategy to increase people's control over their health, their ability to seek out information and their ability to take responsibility.[7]

A variety of studies quoted in the above document have identified that people with low health literacy:

- Are more likely to use emergency services.
- Are more likely to be hospitalised.
- Are less likely to take medication correctly.
- Are less likely to use preventive services.
- Incur higher healthcare costs.

This is an enormous challenge which one study has estimated costs the American economy $73 billion per year[8]. At present we are tinkering at the edges with a lot of rhetoric about transforming health professionals from the default position of viewing patients with long-term conditions as passive and incompetent, to viewing them as active and engaged citizens willing, with support, to take responsibility for their own health.

This shift will only be achieved if we move from our current model, where expert health professionals are responsible for health production influenced from the outside by consumer voice and choice, to a model where co-productive engagement between health professionals and health consumers at the point of service delivery becomes the norm. This will mean taking a serious look at current drivers for workforce behaviour and at how we incentivise different ways of working.

Current drivers for workforce behaviour include the following:

- Managerial and time-based approaches looking at productivity and flow through systems e.g. four-hour waiting times.
- Competency based around expert knowledge and hard skills with high value placed on specialist expertise. This has tended to result in a complex hierarchical system with a multiplication of niche roles and responsibilities.
- Reward systems such as QOF and Clinical Excellence Awards which tend to reinforce patterns of behaviour around hard evidence and expert knowledge.
- NICE Guidelines and current professional competence to practice systems which again reinforce expert knowledge at the expense of soft skills.

All of these mean that moving from an expert–based system to a co–productive system will be challenging but places to start this change could include the following:

- Professional appraisal and re–validation systems need to pay more attention to the ability of healthcare professionals to engage with and activate patients, particularly those who have low levels of health literacy. This should include service user in–put, video consultations and post consultation questionnaires about whether or not patients feel more confident about managing their own condition.
- Roll out of care planning training for front-line health and social care professionals, using the model developed by the Year of Care Partnership, which is about experiential training and continuing facilitation and support to develop workplace systems that reinforce and embed professional behaviour change[9]. The RCGP should ensure that care planning training is part of professional registration and accreditation as a general practitioner.
- Focus on ways of supporting and facilitating better connections between general practices in disadvantaged areas and their communities so that they can better understand the social context of their patients' lives and identify and help to develop local community assets. The Links Project, with practices in disadvantaged areas, is one such example[10].
- Work more closely with and learn from the voluntary and community sector in order to better understand the needs of patients, what the sector has to offer and how to build trust and relationships with disadvantaged groups.
- Develop effective systems which provide information about non–traditional services provided by the voluntary and community sector. ALISS developed by NHS Scotland which is an open–source system with curators has enormous potential[11].
- Further develop the role of local people and people with long–term conditions as peer support workers, health champions, link workers, navigators and health trainers at local and neighbourhood level. This needs to build on local assets by developing what is working locally[12].
- Ensure that national and local system leaders such as the Commissioning Board and Health and Well–being Boards support this approach.

Addressing workforce and culture: lessons from the Year of Care programme

Sue Roberts, Chair Year of Care Partnerships (sue.roberts@gofo.co.uk)

Since what you think affects what you do – co-production is best thought of as an attitude of mind!

Of the various levels in modern society where co-production is envisaged, this contribution concentrates on the individual encounter between the service user and the healthcare professional. Changing the unequal power relationship which accepts the clinician as holder and controller of expertise and the patient the passive recipient, is what co-production is all about, and the logic must be that everyone's mindset needs to change. But the starting point is always 'where we are now'; and the beliefs and consequent behaviours of those who deliver care are currently the most powerful determinate of 'patient' experience and the potential for co-production.

The good news from the Year of Care Programme (YOC) is that focussing on the workforce not only gets to the heart of the problem for co-production, but improves the experience and outcomes for 'patients', job satisfaction for staff, helps to contain costs and promotes organisational changes which are ultimately essential if the NHS is to remain viable as the population ages and the prevalence of long-term conditions (LTCs) increase.

During the last ten years as the policy agenda has moved through 'patient-centred care' to 'personalisation', and then to 'co-production' service users and their representatives have articulated ever more strongly the case for change and what good should look like. In response, the service has prioritised improved access, speeded up delivery, oiled pathways, developed new information sources and decision aids, used technology differently, and set targets. But co-production remains stubbornly isolated to a few examples of good practice. Doing more of the same, addressing the processes and 'technology of care', however imaginative or innovative the examples, is no more likely to be successful than in the past.

The traditional approach starts with tools and structural changes, and then trains or performance-manages staff to use them. This paper contends that for co-production to move from the margins to the mainstream, the focus must be reframed around the workforce, and the lived experience of clinical teams, often the Cinderella of policymaking. The changes in structure and organisation that will inevitably be needed must be built around the new behaviours and relationships that grow from new ways of thinking and working, rather than as attempts to shape and drive them. The general public and service users will also need to develop a different mindset, and set of expectations about their role in the design and participation of the services they use in the 21st century. New thinking on everyone's part will help to make the reality of co-production more likely. In summary we must think differently before we can work differently, before we can organise the service differently and before we can map incentives, metrics and financial flows to what needs to be in place.

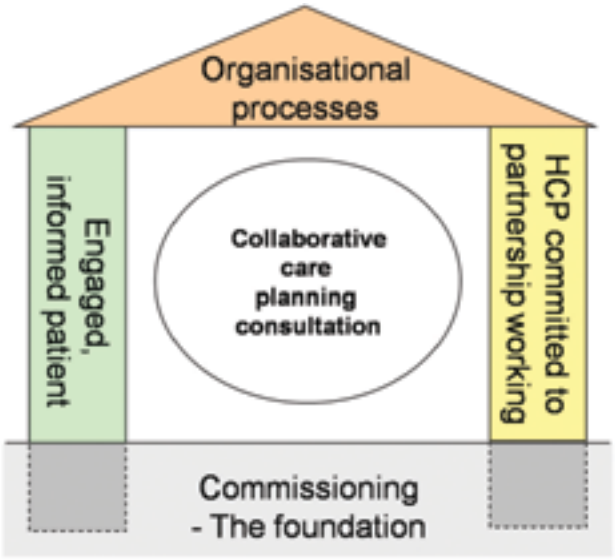
Taking this approach, the Year of Care programme has successfully shown how to introduce and embed collaborative care planning into mainstream practice using diabetes as an exemplar. Care planning is a systematic approach to co-production as part of routine care for people with LTCs based on a new sort of 'consultation/conversation'. This is transformed into a meeting 'between experts' (the person with the condition/s and the healthcare professional) to share expertise and knowledge from their differing perspectives, define the priorities and the agenda for action, enabling the individual to develop their own goals, action plans, and need for further support in a systematic way. Having decided, agreed and owned how their condition is to be managed, the desired outcome is that the person develops the knowledge, skills and confidence to manage their condition day-to-day and adds to their previous store of personal and community assets.

Working with three diverse pilot sites, and starting with a new mindset and skill set for clinicians, the YOCP identified the infrastructure and systems of care needed to enable this new way of working. They developed a practical model for implementation with components that can be understood, articulated, measured and transferred and then interpreted according to local need. This prototype has been spread in depth and breadth to 12 other sites and other LTCs such as cardiovascular disease, COPD and health checks and more recently those with multiple co-morbidities.

This 'House' model (Figure 1) provides both a checklist and a metaphor emphasising that effective and collaborative care planning consultations rely on four elements working together in the local healthcare system; an engaged, informed patient working with healthcare professionals committed to partnership working, supported by appropriate and robust organisational systems and underpinned by responsive whole-system commissioning.

This flexible and reproducible model was developed with a training and support team in an iterative way; learning from each round of training was fed back into the programme as a whole and identified key issues for the workforce.

Figure 1: The Year of Care 'House'



Key issues for the workforce.

The metaphor of the House as a structure with key parts, all of which needed to be in place to enable care planning as co-production to occur, was reinforced by observing the effects of introducing one element at a time as a 'quick fix'. When system components, such as sharing test results with people before the care planning consultation were introduced without addressing the fundamental philosophy of the programme and mindset of the staff, this proved ineffective in 'engaging', 'empowering' or 'activating' people. Where clinician training, especially badged as 'behaviour change' or 'motivational interviewing' was used as the focus of skills training to support self management (SSM) without addressing beliefs about roles in a co-production process this led to cynicism, and disengagement.

For many senior clinicians especially in primary care, a patient-centred consultation has been a core skill throughout their professional lives. Getting to grips with their new role and extended skill set as co-producers in SSM is hard for those who feel 'we do this already'. But acknowledging that the person with the condition is the key decision maker in relation to the actions they take day-to-day to manage their condition, is the first step to using their considerable skills to work with the person to support them to make the best plan for themselves, rather than to do this for them. 'Thinking differently' became the mortar which held the components of the House together and led to the quality-assured approach to training which addresses attitudes, skills and infrastructure together, to achieve the improved outcomes that the YOC programme reports.

YOC observed that as they began to work with other health communities there were less well recognised issues that emerged for staff taking on a co-production role. Staff acquired skills quickly and confidently if they understood their own role and where they fitted into the whole

picture of care delivery. Whilst in theory a co-production relationship could take place anywhere, in practice the context and working assumptions about roles and tasks were important barriers and may be one reason why policy imperatives have failed to gain traction. People with LTCs are seen everywhere in the NHS, for different reasons, and the role of the clinical 'expert' and the nature of the issue/s the person brings as well as the environment all need to be taken into account. The philosophy, the mindsets and the basic skill set to SSM may be similar everywhere but the co-production 'House' will look very different in acute settings, for community teams and in primary care. Workforce training needs to be team based or bring together similar teams, and include those with the power to make the changes that the team identifies are needed to support them, to enable a new way of working to become an everyday reality.

Professionals also identified themselves and their behaviours by their traditional professional role; 'doctor', 'nurse', 'dietitian', sometimes with a specific qualifier such as 'GP' or 'specialist nurse'. They rarely saw themselves in relation to the task or role required by the encounter. For some staff the range of roles they are expected to carry out may be limited; but others may have multiple potential roles such as 'prescriber',' information giver', 'diagnostician' as well as 'supporter', 'care planner', 'coach', or ' navigator'. Many of these cut across traditional professional identities. The new mindset for professionals must include the recognition that reflection on role and task enables them to engage more fully in co-production.

Clinical Innovation and Research Centre. (2011) 'Care planning: Improving the lives of people with long-term conditions.' London: Royal College of General Practitioners.

As these issues were identified, the YOC training team redesigned their work to include preparation with local organisers emphasising the need to clarify care pathways, and identify roles, to ensure that people who attended training could relate the content to their real life working experience. The YOC team also emphasised the importance of ongoing support for clinic or practice teams to ensure that as their skills and experience with SSM developed following training, their requests for infrastructure support such as IT or additional skills training, could be met.

The programme itself was designed to address these issues in an integrated way and led to the key message of this contribution: that attitudes, skills and infrastructure must all be addressed together. While this has implications for traditional training and education it provides a practical demonstration of what is possible if the NHS reframes its approach to the workforce, building their structures and incentives around a new way of thinking and working. This learning could be at the heart of a transformation of care for people with LTCs with co-production at its centre.

Further information about the Year of Care Programme, including the final report, video extracts from participating patients and clinicians and other resources is available at: **www.diabetes.nhs.uk/year_of_care**

Further reading:

Doherty, Y., Eaton, S., Turnbull, R., Oliver, L., Roberts, S., Ludbrook, S., and Lewis-Barned, N. (2012) Year of care: the key drivers and theoretical basis for a new approach in diabetes care. 'Practical Diabetes 2012.' 29:183-6.

A co-production prototype

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I see barriers to mainstreaming and scaling co-production in health as a design challenge with rich opportunities for creative solutions once we understand the problem. Einstein said, *"If I had an hour to save the world, I would spend 59 minutes defining the problem and one minute finding solutions."* This response to *"how to overcome barriers to co-production in health"* sketches a frame to understand the problem, identifies design challenges and highlights innovative projects that support co-production in health.

A prototype sketch for co-production in health

Co-production in health seeks to shift the physician-patient relationship from a directive, passive dynamic into a partnership for health. To co-produce in health, patients and physicians need both tools and the capacity to collaborate effectively with each other. Co-production requires dialogue, shared decision making, ability to observe outcomes and ongoing modification of the care management plan.

In co-production in health, a critical layer of pressure arises from third party influencers. System pressures influence clinician interactions with patients; patients' personal context influences their participation in care management. To co-produce effectively, patients and clinicians also need tools and capacity to negotiate with these third parties.

Figure 1 shows a prototype sketch of the problem: How does this sketch fit with your experience and understanding? What's missing? How would you draw it differently?

Figure 1:

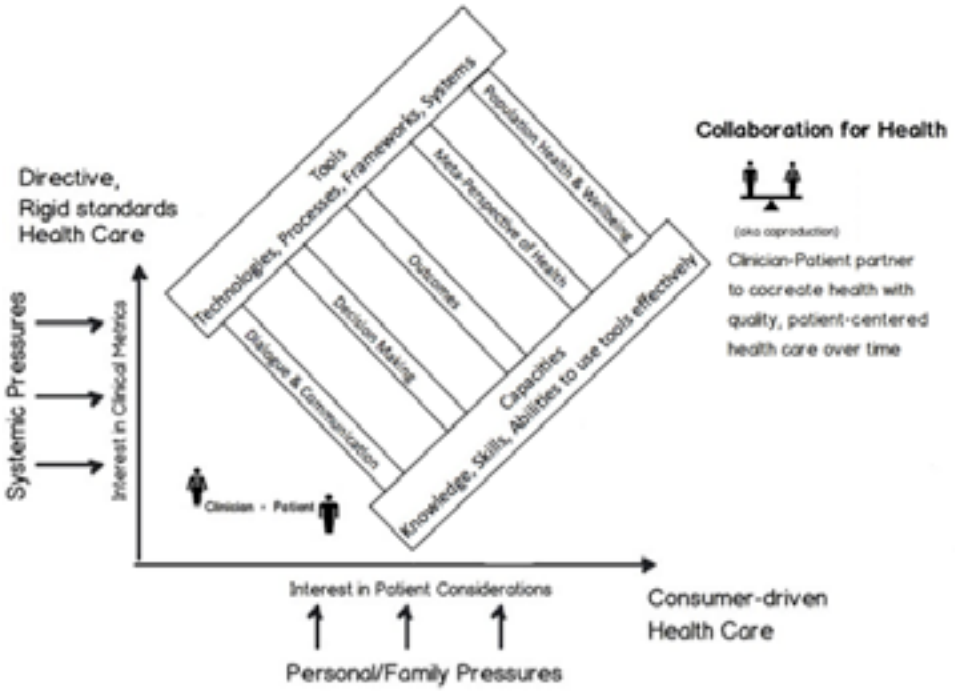

Figure 1 adapted from the Metacurrency Project.

Six design challenges in co-production in health

1. **How do we design to engage highly diverse users to co-produce?**
   - Patients' resources, needs, capacities, motivations vary as individuals, by condition, by geography, by age.

- Clinicians' skills, capacities, motivations vary as individuals, by disciplines, by specialty, by institution, by region.

2. **How do we design a meaningful interaction for both?**
   - Clinicians' needs and motivations differs from patients' needs and motivations.
   - Design restraint. How do we minimize the layers (people/technology) between a patient and their doctor unless it maximizes the value of their interaction.
3. **How do we design for adoption?**
   - Solutions must demonstrate utility and easily integrate into clinical practice.
   - Clinicians adapt their interactions to meet the needs of individual patients; if partnership is the goal, then tools/systems need to be easily customizable.
   - Patients have varying needs and resources; if partnership is the goal, then systems and standards need to have flexibility.
   - Support for building capacity to adopt tools needs to be integrated in tools.
4. **How do we design co-production to incorporate influencing third parties?**
   - The role of influencing third parties may not be visible or fully understood yet; incorporating them into the design of co-production is essential.
5. **How do we design capacity building to scale?**
   - Tools require the capacity to be used effectively. Efforts to scale need to ensure adequate support to building the capacity to support co-production.
   - Power dynamics in the healthcare system are a critical and potentially destructive force.
   - Concerns about patient privacy, confidentiality, malpractice and other ethical-legal issues need to be addressed to ensure adoption at a level of scale.
6. **How do we design to scale optimal care management strategies?**
   - Across communities with different and diverse resources.
   - Across specialties/institutions with different and diverse resources.

Innovative projects with promising elements to support co-production:

Example of capacity building for co-production:

- Foundations in Patient Care, UCSF School of Medicine*:
  - In 2009, a 'chronic care' patient who returns four times throughout the 18-month course was introduced to build capacity for developing outpatient and long-term partnership skills often missed in acute care settings.
  - With a faculty of 400 clinicians, this course provides medical students with communication and clinical reasoning skills while honing these skills among clinicians in the workforce to overcome the 'hidden' curriculum.

Examples of initiatives that support co-production:

- General Practitioners at the Deep End: GPs who provide care for the most socio-economically deprived in Scotland, formed a collaborative to address systems level issues for their patients and to partner with their patients and communities.
  - Example: A Deep End GP was represented in a community initiative to convert unused lots into green space within their patients' community.
- SHINE- Microenterprises in Social Care, International Futures Forum*: In Fife, this project facilitates connection between hospitals, social service workers and the

community to enable social and micro entrepreneurs to fill the gaps needed for isolated patients who no longer require hospital care to return home earlier.

- Positive Deviance: a method that empowers communities to partner with providers to build on the assets within a community to improve their health and well–being. Both a tool and capacity, Positive Deviance provides training for facilitators and facilitates application of the method in communities.

Lempp,H. Seale, C. (2004) The hidden curriculum in undergraduate medical education: qualitative study of medical students' perceptions of teaching. 'British Medical Journal.' 2 October. 329(7469): 770–773.

The context of culture change in the NHS

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The following are five factors which I believe explain some of the problems of introducing culture change in the NHS and also provide some context to the reality of the modern NHS.

1. The mosquito vs the elephant

Outsiders to the NHS often look at its organisational charts and assume that the Board and Senior Management Team have all the power and that they can issue instructions and policies in a 'command and control' style. This fails to recognise one of the major weaknesses in Senior Management Teams, highlighted by Sir David Nicholson (NHS Chief Executive) in the *HSJ* (January 2007), that the average NHS Chief Executive is in post for less than 700 days and a specific Executive Team of five Executive Directors is likely to be stable for less than a year.

In comparison, most medical and surgical consultants stay in the same post in the same organisation for an average of 30 years and General Practitioners tend to stay in the same practice in the same area for a similar time. What this means is that the senior medical staff in both primary and secondary care will have a dozen different Chief Executives and even more Boards throughout their career and so can simply outwait any new top–down initiative or new management programme that they do not support, particularly if they use their extensive local networks to slow it down.

The elephant can always outwait the mosquito no matter how much noise or irritation the mosquito produces.

2. Manchester United vs Chelsea

The larger the organisation, the more consistent the senior leadership focus needs to be for a longer period of time to enable genuine culture change. As shown previously, many frontline staff are on their third or fourth logo on their name badge and their sixth or seventh manager and if each manager had a different philosophy or management approach, then these will be ineffective and any change will be short–lived.

There may be tangible evidence that there has been a deliberate culture change at Manchester United after 25 years of leadership by Sir Alex Fergusson but there is little evidence that there has been a deliberate culture change at Chelsea after four managers in five years.

3. The reality of bath times

There is often a great deal of rhetoric about how services are designed around the needs of the patient or the wishes of the client. There needs to be recognition of the reality that the relationship between professional and patient and services is often organised around the needs of professional or the organisation. Two relatively trivial examples are as follows:

- Most adults choose to have baths in the evening at the end of the day whereas almost all patients are bathed in the morning to suit the professional workload.
- Most working adults never pass an open GP practice near where they live as they open after the commute begins and close before the commute ends.

4. Dealing with middle management dementors

Most of the literature around innovation shows that ideas about service improvements are often generated by the front–line staff in most contact with the users of a service. In the NHS, innovation tends to be driven from the top and the bottom of an organisation

and is slowed/blocked by the middle of an organisation. On the Nurse First programme, we spend considerable time trying to reconnect the top and bottom by enabling clinical staff to deal with layers of middle management, who spend considerable time and energy stifling any innovation. Like the dementors in Harry Potter, the effect of this layer can be to suck the happiness, the enthusiasm and the hope from front–line staff. This is not because NHS middle managers are inherently bad or against innovation, but their primary focus is often on cost–containment and achieving service targets.

5. The delusion of NHS culture change

There is almost no empirical evidence of intentional NHS culture change. Many NHS leaders will claim a policy change without any robust 'before' and 'after' measurement. This can be demonstrated by looking at the NHS Staff Survey which is commissioned every year. Over the last few years, most organisations would claim that they are improving the culture in the organisations and improving their management culture. The results of the latest NHS staff survey (2011) shows:

- The percentage of staff who would recommend their organisation as a place to work in fell from 55 per cent in 2009, to 53 per cent in 2010, to 51 per cent in 2011.
- Only 26 per cent said that communication between senior managers and staff is effective and less than a third (30 per cent) reported that senior managers act on feedback from staff.
- Less than half of all staff across the NHS (46 per cent, unchanged from 2010) felt that healthcare professionals and managers worked well together.
- Only 26 per cent of staff (27 per cent in 2010) felt that their managers involve staff in important decisions.
- Just over one–third of staff felt that managers encourage them to suggest new ideas.

If there is going to be a genuine culture shift that can be learned from, then there needs to be a level of transparency in what the culture was before and how it has subsequently changed.

Co-production from the margins to the mainstream: thoughts from National Voices

Don Redding, Director of Policy, National Voices
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Context: National Voices' current campaigns

Since February 2011 National Voices has been campaigning on two fronts, though they are linked.

The first is to push the case for integrated healthcare and social care. The second is to get 'patient involvement' understood and mainstreamed in the new NHS commissioning system. These twin aspects of care are those which our members – including over 130 national patient, service user and carer charities – consistently tell us are patients' biggest priorities for quality improvement.

The two are linked because a system of person-centred, co-ordinated care is the best framework to deliver the 'patient involvement' approaches that would see the culture of care shift from 'doing to' to 'partnering with' patients.

By patient involvement, we mean approaches that provide people with tailored and comprehensive information about their condition, how to manage it, and the treatment and support options available; offer people education for self-management; provide personalised care planning; and enable people to participate as fully as they wish to in decisions about their care and treatment.

We use the term 'patient involvement' because it is recognised in the Health and Social Care Act 2012, whereby commissioners are given a duty, in everything they do, to 'promote the involvement of each patient' in such decisions.

However, while integrated care is now earmarked for a significant national implementation drive, patient involvement remains at the level of policy rhetoric, with poor development of delivery mechanisms.

This, it transpires, is common across health systems in Europe:

> *"Patient involvement, in the sense of having patients at the heart of the healthcare process, seems poorly understood by many professionals and patients across the EU, with only limited concrete ideas and activities which substantiate the concept in real healthcare practices."*[i]

This is a missed opportunity, since patients who are engaged in their healthcare and treatment contribute value back to the system through better outcomes, better experience, and more appropriate use of healthcare resources.

We therefore seek to work both with programmes that are trying further to demonstrate the value delivered by 'co-production', such as Nesta's People Powered Health programme; and at the level of the policy leadership who could adopt and develop the tools for such approaches more widely through the system.

Clarity of definition

'Co-production' is currently used by DH to mean they use partners to help write guidance and policy.

More properly 'co-production' can mean:

i. The patient and the doctor or other professional working together to maintain/improve health ('patient involvement' as described above).

ii. Healthcare services working with groups of relevant patients to improve services.

iii. Commissioners working with groups of relevant patients to design services.

iv. Commissioners (and other leaders in the economy) using community development approaches to inform commissioning strategies.

We take the PPH approach to reflect meaning number (ii).

Connections/interdependence

It is important to note the potential connections or continuum between these modes of 'co-production'.

For example:

- Where commissioners work with patients to design services (iii), these are arguably more likely to engage patients better with their professionals to maintain health (i).
- Where commissioners develop community capacity to contribute to strategies (iv), these will bring forward groups of patients from the community to design the subsequently commissioned services (iii).

Confusion

The DH/NHS have struggled along over the past decade with a language of 'patient and public involvement/empowerment' (PPI/E) which tries to capture this continuum, but in fact only serves to muddle the practitioners by conflating all modes.

In large part this has been because traditional public service approaches have been led by legal requirements, a mentality which militates against co-production.

Law

Until now the only legal requirement in this area has been for NHS organisations to involve people in the consideration of significant changes to their services – 'whether by consulting or informing or by other means' (section 242 NHS Act 2006). This has been taken to mean consulting on decisions after they have been arrived at.

Such consultation has frequently been token (especially when ordered by the DH as a precursor to central interventions such as the 'Darzi centres' and AQP), lacked meaning and/or been poorly designed. Moreover NHS organisations have feared consultation, especially over any large scale reconfigurations or service closures.

World Class Commissioning Framework (WCC)

WCC was unusual in placing a demanding performance management framework around 'engagement', which must be 'proactive, continuous and meaningful', and was assessed via indicators. PCT leaders were expected to take Board-level responsibility; to act as leaders in their local economy; to engage with local communities; and to involve patients and the public. There is evidence that this significantly changed PCT behaviour, and that innovations in engagement were produced. However, structural reform and the abolition of PCTs curtailed it before any actual impact on services or communities could be assessed.

Health and Social Care Act 2012

This retains the S242 wording as a new duty to involve people, applying to commissioners. There is a slight change in that commissioners must 'involve' about any change, not having made a prior judgement as to the 'significance'; however the same danger of tokenistic consultation-only approaches applies.

There is also a separate duty to promote the involvement of 'each patient' in the process of their care ('prevention, diagnosis, care or treatment').

The draft Mandate to the NHS Commissioning Board

The draft Mandate, published in July 2012, is the mechanism whereby Parliament, through the Secretary of State, will hold the new Commissioning Board to account. It sets 22 objectives, one of which is around 'putting patients first'.

This objective is in three parts. Two focus strongly on implementation – of personal health budgets and of extended choice of providers. The other, on 'patient involvement', remains at the general 'enable' level. Our fear is that the imperative to deliver other forms of choice will marginalise the 'patient involvement' goal.

Commissioners or providers to innovate?

The 2010 White Paper and 2012 Act see commissioners as the engines of change and of involvement, working in a wider economy where health and wellbeing boards bring needs identification and commissioning strategies together. Providers are envisaged as a mixed market of competing suppliers, shaped by commissioners and not controlled from the centre.

However, taking the example of 'integrated care', most known cases of innovation currently originate with providers; while in both health and social care there is often provider frustration with commissioners who 'only procure' and are unable to redesign services.

The PPH approaches use providers as the locus of 'co–production', and part of the 'scaling up' question must therefore be about how to innovate in services in ways that produce a 'case of change' to persuade/convince commissioners.

Margins to mainstream

Where 'co–production' starts from a 'service line' approach to change, it must build the following connections:

➤ to senior clinicians and managers, upwards to Board and (for FTs) governor level	✔ support required for sustainability, application of lessons along the pathway, spread to other service lines, and prioritisation in workforce training, performance reporting etc.
➤ to patient/service user and community peer groups locally	✔ bring wider cadres into 'co–production', carry learning into support groups, spread awareness to GPs and commissioners, provide 'validation' for scaling up
➤ to research evidence and institutions	✔ bolster the case through research references, demonstrate the case by bringing in evaluators, improve the initial pilots by understanding lessons learned elsewhere
➤ to commissioners	✔ demonstrate genuine improvements for patients/service users, construct 'value' case, partner in spreading the innovation

The 'value proposition' is critical. Provider boards and commissioners will both demand rigorous evaluation; and will need what they see as a 'business case' for change. Cash for commissioning is in short supply (£25 per patient).

'Business cases' will be of two types:

- 'No cost/low risk' – "we, the provider, can institute these changes and absorb any risk, confident that it works" – but this is unlikely to go beyond the part of the pathway that provider controls.
- 'High cost/high risk' – "there is a case for changing whole pathways and the behaviours of more than one provider, as well as patients" – in which case the commissioner(s) must be convinced that there is a high probability of benefits being achieved, hence a high level of evidence from both research and evaluation.

There are limits to the ability of service line 'co-production' to demonstrate a high probability of 'at scale' success where value for money criteria are wholly dominant in commissioners' minds. The culture of care that is likely to arise from 'co-production' integrated/co-ordinated care, shared decisions about treatment, health coaching, supported self-management, etc., – does have a research evidence base for its effectiveness, but this is weak on value for money for reasons of research design and because of the difficulty of applying lessons from one health economy to another.

The 'value proposition' must therefore be different, and incorporate a sense of shared benefits, focusing on:

a. The value to patients in relation to their lives and lifestyles.
b. The value to patients in health outcomes.
c. The value to patients in relation to their experience of services.
d. 'Public value' as being the better use of resources (including a 'value for money' assessment but not limited to that.
e. 'Social value' as being the benefit to a wider social/community group, such as improving the lives of the families and carers of patients and service users; supporting people to stay in or return to work; increasing community assets by mobilising and activating patient leaders.

It is apparent that the proper spokespeople for at least a–c, and to some extent for all these aspects are the patients/service users themselves.

Convincing provider boards and commissioners is therefore only in one part about 'hard facts' from research, evaluation and financial risk prediction. It is equally a hearts and minds campaign that must capitalise on the 'co-production' process to develop, educate and support lay leaders who are capable of presenting their case in their words.

Conviction to action

For many practitioners and professionals, it will be a matter of seeing is believing – 'co-production' approaches will seem 'obvious' once they are demonstrated and both colleagues/peers and patients/service users speak in favour.

However, there will be resisters and the 'hard-to-convince', especially where 'established clinical practice' with an obdurate prioritisation of a traditional clinical evidence base is under challenge.

The connections outlined in the table above will help to bridge into a supportive culture that can develop the strategies, policies and practices that surround 'co-production' with a supportive infrastructure.

Within the innovative provider these may need to include:

- Workforce education and training – designing in-house training that is sufficiently generic to be used across departments and service lines, while being tailored to the needs and working conditions of a range of staff and different work patterns.

- Recruitment – re-examining the capacities for which people are recruited at various levels to ensure they are tested for their likely ability to adopt supportive, partnership-oriented relationships with patients and service users.
- Working practices – for example, changing consultation and clinic styles to enable some longer consultations with individuals, or to enable group consultations; or changing styles of rehabilitation and planning for hospital discharge to follow patients' needs and preferences.
- Use of new measures – finding, testing, developing and embedding new ways to measure outcomes and benefits; for example, by using patient experience, patient activation, and patient-reported outcome measures.
- Peer influence – freeing and supporting clinical and other professional champions of co-production to influence other actors in the system – whether in their own provider or in other parts of the care pathway (primary/community/social care).

Policy agenda

The assumption in the preceding discussion is that in scaling up we are seeking to move from the service line level to the point where innovative providers and their commissioners join in an endeavour to change the culture of care across a local economy.

In order for commissioners to commission both through and for co-production, they will need a range of guidance, tools and incentives to help re-engineer provision.

In our view these should be developed by the NHS Commissioning Board, working with others as appropriate (e.g. monitor on tariffs). This is what is envisaged for integrated care and patient involvement or co-production approaches should be twinned with this.

Hence we return to the importance of convincing policy leads – in this case, the new directors and other staff at the Commissioning Board – to mainstream 'patient involvement' in their strategy to transform care.

[i] (May 2012) 'Eurobarometer Qualitative Study on Patient Involvement, Aggregate report, European Commission, Directorate-General for health and Consumers.'

Co-production, lessons from Stockport

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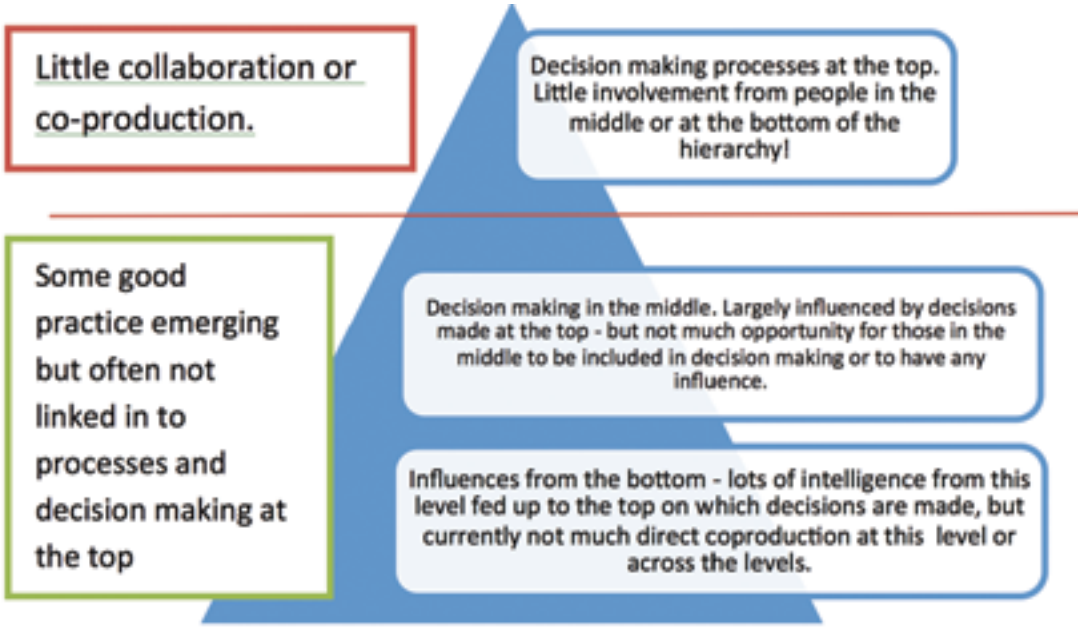
"The co-production model redefines health from something bought for money to something people do."

An Elderplan member says: *"The only reason I am as healthy as I am is that I'm so busy helping other people."*

> *"Co-production as a theorem asserts that the market economy needs the participation of the non-market economy, of families, of recipients, of the client community. And it further asserts that the market needs that non-market world, not as passive consumers with purchasing power, but as active co-producers"*
> *"Reciprocity is a core element of co-production. By definition it entails mutuality. We need each other. This is not just true of us as individuals, as human beings. It is also true of organisations and institutions. Fully embraced reciprocity gives rise to a commitment to provide the resources necessary to fund co-production."*
> **Edgar Cahn 'No More Throw Away People – The Co-production Imperative.' p150.**

- Stockport's learning around co-production has been on-going for a number of years, but most recently has been underpinned by the Nesta People Powered Health Programme. There are some good examples of co-production emerging that can be found on the Stockport page of the People Powered Health website. The challenges we now face are how we move the small pockets of good practice into the mainstream.
- The current environment in which we work is still very hierarchical in terms of decision making and service change and transformation. Co-production needs to happen at all levels to ensure that it is successful. Our current decision making structure may look something like:



- It is still very hierarchical as the concept of co-production is not yet fully understood. In Stockport there are many strengths in what we do in relation to how we involve and engage with people. However, we don't have a good understanding of reciprocity as a core value of co-production. We are also working to develop the understanding of

co-production across service areas, organisations and community groups in order to break down some of the structural and cultural boundaries to co-production. We can be averse to the perceived risks that this way of working might bring. We are learning though that more often than not it's worth the risk of having the conversations and trying something new! The creation of FLAG, a new kind of information and advice service, in collaboration with a range of voluntary and user-led organisations has opened up and continues to open up new possibilities in Stockport, and is one example of how things are changing for the better. The My Care My Choice adult social care website was also based on grounded conversations and co-designed with the people who would use it.

- Where we ideally want to be is more of a honeycomb. With a network of people and organisations who are all part of the co-production environment. Where the boundaries between groups, organisations and individuals are more connected, and less hierarchical, allowing people to work to their strengths and at different paces without obstructing progress due to the diversity of directions and contributions available to reach the solutions.

- A well-facilitated approach (in Stockport we use pinpoint facilitation methods), based around a grounded theory approach (a step beyond our current levels of 'consultation' and 'engagement') is needed to enable the conversations to take place across all levels, and co-define this different way of thinking and working.
- Having people within the organisation with the right skills and the commitment to facilitate these conversations, and who are willing to take the risks to enable new approaches to happen. The facilitated/grounded theory approach is proving to be very successful at helping to use the feedback that we get to co-define the issues and solutions as they actually are at all levels, rather than those at the top pre-defining or pre-supposing what those issues and/or solutions might be. This approach is being supported in other areas of the council, in health and other organisations and the conversations are joining up more. The result is that we are pooling skills and good practice models to ensure that co-production can become a viable and sustainable solution to many of the social and economic pressures that we currently face. While there is a place for external support from organisations such as **nef** or Nesta, external consultants are not always the best way to achieve this. A much more holistic and joined up approach can be gained from investing in this kind of resource internally, and is much more cost effective too. Maybe even a local bank of professional skills and assets to enable this to happen?
- We are working together to enable more local people to support their communities through participatory budgeting, and exploring ways we can harness assets within communities in a volunteer capacity. Developing our understanding of how time banks such as Timebanking Wales, and other similar models will enable this to happen is crucial.
- We need to celebrate success, share stories, and support everyone in understanding why co-production works and should be mainstreamed – including the financial gains to be made. Using social media, short films, care knowledge local content and creating a range of creative spaces to allow people to have the conversations, are all tools that we use to support this happening.

- The European projects that we have been and are involved with have identified other approaches that we can learn from. Their ability to work in collaborative ways and to harness the assets and contributions of volunteers to ensure people remain independent of healthcare for as long as possible, is much more progressive than in the UK. Stockport has worked as part of the Cities In Balance programme to develop intergenerational ways of working with seniors (older people). A recent exchange of senior volunteers from Stockport to Genk in Belgium to learn about the ways they support older people in their communities. Those volunteers are now working with us to explore ways we can improve support and care to seniors in Stockport.

There needs to be a clear understanding of what co-production is about. Not just another way of doing consultation and from this there needs to be a commitment to redefine the way we do business with individuals and communities. The key to success is the organisations that are involved having a clear understanding of their role (at all levels) in terms of ensuring sustainability – by providing a solid infrastructure on which co–production can happen.

Taking co-production from the margins to the mainstream

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The concept of co-production has received increasing recognition as a more effective approach to supporting disabled people to achieve their goals in life. However, despite this, it remains remote from the everyday lives of many disabled people receiving services from the state. Why is this the case and what can be done about it?

The biggest obstacle is, without a doubt, professional attitudes. Professionals can feel threatened by co-production both in terms of the challenges it can bring to their authority and power and to the value of their expertise. It is wrong to fail to recognise this and engagement and communication with the professional workforce will be key to progress.

While everyone always has their element of self-interest, for good professionals the compelling argument on co-production will be the evidence that it makes a real difference to outcomes and the reassurance that their professional expertise can continue to have a value, even if in a different manner. Another driver for change could be the emergence of a greater number of 'peer' professionals who intuitively understand the experience and issues of service users.

The second obstacle is anxiety about market change. For a variety of reasons co-production and the exercise by service users of choices about what kind of support they want and where they get it from can be destabilising for existing service providers. In some cases that might be a good thing, if existing provision does not fit with service users needs and aspirations. However, unmanaged change can destabilise providers which meet the majority of service users' needs but whose existence can be threatened by quite small changes in funding. The problem may be increased by the lack of alternative provision leaving some service users with no effective choice at all. All of this is harder in an age of austerity where it is harder to afford the spare capacity which is required to facilitate genuine choice.

There is no easy answer to this but it points to the need for commissioners to work proactively in managing the market in a way which eases transitions and facilitates the arrival of new market entrants. One important strategy is to work with service users and carers at the collective level and not just see co-production as a manifestation of individual choices and preferences.

The third obstacle is about accountability and risk management. How, in a system of co-production where individual budget holders control a significant amount of public money, does one ensure a reasonable level of assurance that public funds are achieving? How can we protect the reputation of the system of co-production from the impact of cases, which will occur even if in very modest numbers, of blatant misuse of public funds or more important, avoidable harm to vulnerable people? We have to remember that the *Daily Mail* will be on the look out for when things go wrong.

The answer does not lie in excessive bureaucracy, which would of course be the default reaction of many public authorities, but there does need to be a reasonable system of accountability and a sense that with a greater level of control comes greater responsibility. I have been encouraged to hear of regimes which manage to achieve this in a straightforward and relatively light handed manner.

In the end I am confident that we can go through a normal process of change. For me we are clearly past the stage of early adoption but it will need sustained policy focus and energetic champions on the ground to get to the tipping point. It's an old adage that we always overestimate what can happen in two years and underestimate how much change can happen in ten. Co-production, I believe, will be a case in point.

Working for co-production in healthcare

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Pain affects 7.8 million people in the UK. People with pain sometimes consult their General Practitioner, sometimes a general hospital specialist and sometimes a Consultant in Pain Medicine, most of whom work as part of a wider multidisciplinary team.

Acute pain is due to trauma, surgery or an illness. Chronic pain is pain that persists after healing has taken place or in conditions that do not heal. Many patients develop persistent changes in the spinal cord and the brain and treatment of the underlying cause will not relieve the pain. This means that both doctors and patients will be frustrated by failed attempts to totally or even partially relieve pain and should view chronic pain as a long-term condition.

This requires a culture change for both doctors and patients but does give opportunities for co-production and a chance to improve the range of management strategies available for patients.

Currently, services for people with chronic pain are of inconsistent standard and quality and are not always available for those who need them. This is particularly true for centres specialising for children with chronic pain. This gives exciting opportunities for a fresh look at service delivery within new local and specialised commissioning frameworks.

The strength of the recent Pain Summit 2011 was the involvement of people with pain at every step from planning, execution, and report writing to the forthcoming implementation. Their views are pivotal to planning, commissioning and implementing improved pain services in primary, community and secondary care.

Greater clarity is needed on what co-production means in practice for both healthcare professionals and for patients. How do you change the philosophy of both the patient and the healthcare professional? How do you motivate patients and healthcare professionals to change? What innovations need to be put in place to embed co-production in a patient pathway? Is co-production the way forward for every patient? Are there exemplars that can be studied to inform practice change? Is there one model or several? Commissioners need to work proactively with people in pain and with professionals, to ensure that co-production can occur as a positive and enhancing step for every patient.

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Endnotes

1. For Nesta's definition of co-production and 20 case studies see http://bit.ly/Pfbs1u Find out more about the People Powered Health Programme here: http://bit.ly/NePcoh The background to the programme is covered in three research reports: http://bit.ly/Q4fq1J
2. See: Moerman D. (2002) 'Meaning, medicine and the placebo effect.'
3. Robert, Cornwall, Brearley *et al.* 2011.
4. Marshall, Mannion, Nelson and Davies. 'BMJ.' 2003; 327: 599–602.
5. Woods, M. University of Leicester and the Health Foundation, revised by Marshall, 2011.
6. http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Healthcare/Longtermconditions/tenthingsyouneedtoknow/index.htm
7. http://www.ilcuk.org.uk/index.php/publications/publication_details/navigating_health_the_role_of_health_literacy
8. www.ama-assn.org/ama/pub/about-ama/ama-foundation/our-programs/public-health/health-literacy-program/assessing-nations-health.page
9. http://www.diabetes.nhs.uk/year_of_care/about_us__year_of_care_partnerships
10. http://www.scotland.gov.uk/Publications/2012/05/1043/0
11. http://www.aliss.scot.nhs.uk
12. See: 'Thanks for the Petunias.' at www.diabetes.nhs.uk/year_of_care