Coproduction of health and wellbeing outcomes: the new paradigm for effective health and social care

Vidhya Alakeson, Antonia Bunnin and Clive Miller

March 2013

Contents

Background

While the contribution of clinicians to combating ill health has long been acknowledged, there is also a growing recognition of the role played by patients in achieving improvements in health outcomes.[1] The importance of bringing together the *learned expertise* of professionals with the *lived experience* of individuals underpins the emergence of concepts such as shared decision making and coproduction in health, and more widely across public services. This applies across the spectrum from preventative activities, such as healthy eating and exercise, through to managing and reducing the impact of long term conditions on people's daily lives.

The role that patients play in the NHS is now recognised in policy drivers such as Choice and 'no decision about me, without me.'[2] It is also reflected, at a practitioner level, in a range of parallel developments which in different ways seek to empower patients to take control of their health and have an equal say in deciding the supports they require and how they should be delivered. Examples include: shared decision making, the Year of Care and the use of personal health budgets. Whilst these approaches have been developed independently, they all recognise two types of expertise – *learned* and *lived* – as critical to achieving health outcomes.

This paper draws on a roundtable discussion hosted by OPM in 2012 with leading edge practitioners and researchers (see Appendix 1) to explore the connections and linkages, as well as differences, between these approaches to involving and empowering patients. This paper reports the results of that discussion. In particular it discusses the two central concepts in this area: shared decision making and coproduction, and: highlights their shared principles as well as their differences; identifies practice initiatives in these areas and how they relate to each other; and proposes a way in which the set of key developments could be implemented as an integrated portfolio to produce radical improvements in health outcomes. It is in the nature of exploratory work such as this that many other linked developments could also be cited. We acknowledge that there will be gaps and omissions, and hope that these will be identified through responses to this paper.

Shared decision making and coproduction

Shared decision making and coproduction are concepts that are increasingly used in the context of managing long term conditions. Both recognise that improvements in health and wellbeing outcomes cannot be driven by health professionals alone, but require the active involvement of individuals and families. This is because, firstly, the effective management of long term conditions is largely dependent on what people do day-to-day for themselves, rather than on professional clinical interventions. Secondly, only an individual can know his or her own priorities and preferences, and for care to be effective, it must be shaped around these.

---

[1] Dentzer, S. Rx for the 'Blockbuster Drug' of Patient Engagement, *Health Affairs* 32:2, February 2013.

[2] Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making, Department of Heath, 2012

Shared decision making and coproduction are often used interchangeably. While they do share common ground and have more in common with each other than with traditional, professionally-led NHS practice, they also have marked differences. The rest of this section discusses the two concepts and the related concept of 'recovery' used in mental health services.

Shared decision making

'*Shared decision-making is a process in which clinicians and patients work together to select tests, treatments, management or support packages, based on clinical evidence and the patient's informed preferences. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and a system for recording and implementing patients' informed preferences.*'[3]

Defining features of shared decision making are:

- patients and clinicians act collaboratively to make decisions together, each recognising the (differing) expertise of the other;

- the decisions can be about tests, treatment options, management of conditions, self management and support – any aspect of care where the situation is not immediately life-threatening, and the patient has the mental capacity to make a decision;

- decisions are based on both clinical evidence and the patient's informed preferences;

- patients (and indeed, clinicians) have reliable, accessible, evidence-based information that explains care and treatment options, potential outcomes, risks and uncertainties to inform decision-making;

- an individual's lifestyle, needs, preferences, aspirations and attitudes to risk are recognised as important factors in the decision making process;

- clinicians ensure that patients have effective decision-support through conversations with a clinician or health coach – ideally someone trained in shared decision making support and communication skills. In addition, decision aids may be used; these can take a variety of forms (e.g. information sheets, leaflets, videos, DVDs, websites, interactive computer programmes) but crucially are designed to support people in understanding the evidence and thinking through the options available;

- decisions are systematically recorded and implemented, and communicated to all who need to be involved; this includes ensuring that records of decisions and care plans are accessible to patients, not just clinicians.

The government's mantra for its health service reforms: 'no decision about me, without me' should fit well with the ethos of shared decision making. In May 2012, the Department of Health issued *Liberating the NHS: No decision about me, without me - Further consultation on proposals to secure shared decision-making*. However, this document positions shared decision making in a narrower way, and focuses mainly on giving people more choice of

---

[3] *Making shared decision-making a reality: No decision about me, without me,* Angela Coulter and Alf Collins, King's Fund, June 2011

provider (in line with agendas such as Any Qualified Provider and Choose and Book), and over the time and place that they receive treatment and care.

The principles of shared decision making have been disseminated for many years, but implementing and embedding it in health care systems has been slow. The Health Foundation is currently working through the MAGIC programme (Making Good Decisions in Collaboration) with NHS and academic partners in Newcastle and Cardiff to explore how shared decision making can be embedded into everyday clinical practice.

Coproduction

Shared decision making originally developed in the context of clinical decision making, but has become more broadly interpreted (by the Health Foundation and others) to encompass all aspects of patient involvement in their own health and care. As a result, shared decision making has come to be associated with the concept of coproduction.

Coproduction explicitly recognises the value and benefits that derive when people who use services work together with those who provide services, to achieve positive social outcomes (i.e. outcomes which are 'co-produced'). The concept of coproduction was developed in the context of improving social outcomes and exploring the impact of public services in general.
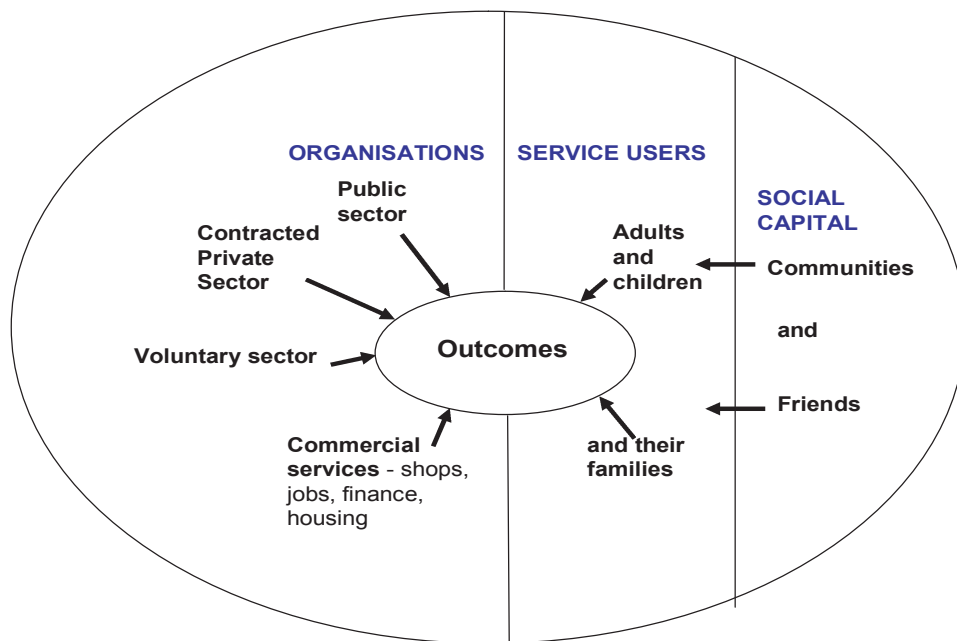
> *'Services do not produce social outcomes; people do. Recycling happens because of the people involved. Householders separate waste, compost some of it at home and put the rest out for their local council services to collect and recycle. The police and the courts could not apprehend and prosecute criminals were it not for members of the public; it is they who are the major detectors of crimes. Schools provide education but it is parents who support their children's learning. In each case, what we are seeing is social outcomes – a sustainable environment, community safety and educational attainment – being co-produced through the joint efforts of service users and services.'* [4]

It is amazing that so few services take account of coproduction in either their strategic or operational development. There are however, some exceptions. In health, for instance, the Expert Patient Programme recognises, enhances and uses the expertise of patients to help one another. Some schools have taken active steps to help parents to support their children's learning (although it must be said that many fall back on token 'home school contracts' that once signed, are then filed and forgotten). But these and similar examples are the exception rather than the rule. Where they do exist, they are often seen as 'useful extras' alongside the core business of professional service delivery, rather than as being central and essential.

What can be done to take coproduction and the use of social capital into account in the further development of public services? First it is important to realise that coproduction has always existed but the contributions of service users and social capital have largely gone unrecognised. Figure 1 helps us see what must be taken into account.

---

[4] 'Co-production and social capital: the role that users and citizens play in improving local services', Jude Cummins and Clive Miller, OPM, October 2007

Figure 1: Coproduction

ORGANISATIONS   SERVICE USERS

Public sector

Contracted Private Sector

SOCIAL CAPITAL

Adults and children

Communities

and

Voluntary sector

Outcomes

Friends

Commercial services - shops, jobs, finance, housing

and their families

In the past, the focus has been on the left hand side of the diagram, the organisational resources that are used to achieve outcomes. The view of those resources has sometimes been quite narrow. For example, we have tended to focus on a single public service while neglecting the crucial role that the private sector plays in making basic living resources such as food, clothing and financial services available to people. Meanwhile, the right hand side of the diagram – the personal resources of service users and the social capital on which they draw – has largely been neglected. As we have seen, this is partly because of narrow interpretations of what constitutes a 'service'. Where the personal resources of service users *have* been taken into account – for example, in community work and in personal services such as health and social care – our tendency has been to focus on people's deficits and to try to fill these gaps with services.

Accepting the logic of coproduction leads to a view of people who use public services as also having assets and capabilities that can be harnessed to improve social outcomes. Coproduction emphasises the development of connections between people to bring about change, and the creation of opportunities for self help and reciprocity. Finally, it shifts the role of the state and service providers from doing things for people, to facilitating them to act for themselves in pursuit of their own goals.

The practical implications of both shared decision making and coproduction are that services will need to be redesigned, but coproduction demands a more radical shift of current NHS practice. This must also include finding ways to change the current service ethos, which is based on a provider-consumer relationship. Coproduction recognises that in reality there have always been two sets of (complementary to a greater or lesser degree) providers: individuals who use services and those responsible for providing services, with the former meant to be the ultimate beneficiaries.

Recovery

The notion of 'recovery' has much in common with coproduction but has developed separately within mental health services.[5] Recovery is not focused on recovering from illness but recovering a life: supporting and enabling people to lead flourishing and fulfilling lives as part of their communities. Achieving recovery for a greater number of people is the second of six objectives in the Government's mental health strategy, *No Health Without Mental Health.*[6] There are three central components to recovery: agency, opportunity and hope.[7]

- Agency - gaining a sense of control over one's life and one's illness. Finding personal meaning - an identity which incorporates illness, but retains a positive sense of self.

- Opportunity - building a life beyond illness. Using non-mental health agencies, informal supports and natural social networks to achieve integration and social inclusion.

- Hope - believing that one can still pursue one's own hopes and dreams, even with the continuing presence of illness. Not settling for less, i.e. the reduced expectations of others.

Today's mental health services are organised around the three Cs: cure, care and containment. The primary focus of services is one of cure: the reduction/elimination of symptoms or problems. Unless and until a person's problems can be eliminated they are 'cared for' and, should they be a threat to their own health and safety or that of others, they are 'contained'.[8,9] This focus does not recognise the basic goals that most individuals have for their lives: to have meaningful activity; to have meaningful relationships; and to have a place to call home.[10] Just as shared decision making and coproduction require a degree of culture change from established practice, recovery tests the culture, values, practices and organisation of mental health services.

First, like shared decision making and coproduction, recovery-focused practice requires recognising two sorts of expertise: professional expertise and the expertise of lived experience. The challenge for mental health services is to move from attempts to ensure compliance with 'expert' professional prescriptions, to a process that brings together these two types of expertise, with the individual in the centre of the service system. Second, recovery necessitates a move away from the centrality of clinical treatment as the only valid

---

[5] See, for example, *On Our Own: Patient-Controlled Alternatives to the Mental Health System*, Chamberlin, National Empowerment Center, Inc. Massachusetts USA, 1977; Recovery: the lived experience of rehabilitation, Deegan, *Psychosocial Rehabilitation Journal*, 11, 11-19; M. (1993); *Stopovers on My Way Home from Mars*, M. O'Hagan, London: Survivors Speak Out, 1993

[6] *No health without mental health: a cross-government mental health outcomes strategy for people of all ages*, Department of Health, Feb 2011

[7] *Making Recovery a Reality,* Shepherd, Boardman, and Slade, Sainsbury Centre for Mental Health, London, 2008

[8] UK mental health policy development: A counter-argument deriving from users' experiences. Perkins, (2012) in *Working in Mental Health: Practice and Policy in a Changing Environment ,* Phillips, Sandford, and Johnston (Eds), Routledge, Oxford, 2012.

[9] Recovery in England: Transforming statutory services?, Perkins and Slade (2012) *International Review of Psychiatry,* 24(1): 29–39

[10] *Lost Lives: The paucity of quality in human services,* Nerney, Centre for Self-Determination, Michigan (www.centerforself-determination.com)

route to wellbeing. In a recovery-oriented mental health system, professional treatment is balanced by other approaches and priorities, and its value lies in supporting self-care and the pursuit of individual ambitions.

Third, supporting people to rebuild their lives means breaking out of the existing service silos of the NHS. It means placing greater emphasis on services that help people to rebuild their lives such as housing, education and employment, alongside clinical care and treatment. The success of mental health services within a recovery paradigm should be judged according to the changes they achieve in people's lives and the extent to which they enable people to achieve the goals they set for themselves, not how well they manage people's symptoms.

Shared decision making and coproduction in practice

We have identified a number of developments in health and wellbeing that appeared to have the concepts of shared decision making and coproduction at their centre, although often using quite different terminology. These developments are summarised below.

Co-creating Health

Co-creating Health is a large scale demonstration programme funded by the Health Foundation designed to enable people with a long term condition (LTC) to 'improve their health and have a better quality of life by taking a more active role in their own care.'[11] This in turn will enable better clinical outcomes and use of NHS resources. Phase 1 (2007 -10) of the programme built skills and evidence. Eight sites were involved, each focusing on one of four LTCs - chronic obstructive pulmonary disease, depression, diabetes, and musculoskeletal pain - in a mix of primary and secondary health care settings. Sites were provided with an initial £150,000 and a package of integrated support. Following an evaluation[12] Phase 2, (2011 - 12), focuses on sustaining and spreading the approach.

Rationale

Co-creating Health builds on the evidence of what works in supporting self management which in turn leads to improved clinical outcomes. It requires 'a fundamental change in approach from health professionals and from the health system as a whole.' This is because it means moving away from the traditional relationship between 'passive patients' and 'expert health professionals' to one where both parties work together as active partners.[13]

Key elements

The programme has distilled the evidence about what works in enabling self management into a set of skills and practices that can be taught to both people with LTCs (the Self Management Programme - SMP) and clinicians (Advanced Development Programme – ADP). Both programmes were spread over a number of sessions and co-facilitated by a person who was successfully managing their LTC and a clinician. The programmes focused

---

[11] Health Foundation web site http://www.health.org.uk/areas-of-work/programmes/co-creating-health/

[12] *Co-creating Health: Evaluation of first phase*, L.M Wallace et al., Health Foundation, 2012

[13] Health Foundation website *ibid.*

on three enablers: goal setting; shared agenda setting and goal follow up. Support was also provided to the sites, via the Service Improvement Programme (SIP), to improve the way their services are designed and operated to better support self management.

Outcomes

The SMP was completed by 882 people. They reported 'statistically significant changes in positive engagement in life, adopting a more constructive attitude and approach to their condition, having more positive emotional well being and using self management skills and techniques'. The ADP was completed by 437 clinicians (doctors, nurses and other allied professionals). 'Clinicians commonly report an increased motivation to improve their practice and greater belief that improvement is possible, increased job satisfaction, and a greater sense that they are now 'helping people' in a way that reflects why they came into healthcare'.

Year of Care

Year of Care is a pilot project aiming to improve the care of people with diabetes, giving them more control through: personalised care planning; a collaborative relationship between people with diabetes and their clinicians, and effective local commissioning. The Year of Care prototype has been tested with 12 additional diabetes communities, people with other long-term conditions such as COPD, and people with multiple long-term conditions.

In 2007, the Healthcare Commission published *Managing Diabetes: Improving services for people with diabetes*, which revealed that although 95 per cent of people had diabetes checks at least once a year, fewer than half discussed ideas about the best way to manage their condition with their clinician, and even fewer discussed their goals or agreed a plan for the next 12 months. The Year of Care for diabetes was launched in 2007 (funded to 2012) at pilot sites in three areas: Tower Hamlets PCT; Calderdale and Kirklees PCTs (in West Yorkshire); NHS North of Tyne (North Tyneside and West Northumberland PCTs).

Year of Care was piloted through a partnership between the pilot sites, Diabetes UK, the Department of Health, NHS Diabetes (formerly the National Diabetes Support Team), and the Health Foundation. They worked with the Royal College of GPs, who developed a guide to help GPs introduce care planning into their work with people with LTCs, and are developing professional standards for care planning to be incorporated into training.

What does Year of Care entail?

The Year of Care Programme found that effective care planning consultations rely on three elements: an engaged, empowered patient working with healthcare professionals (HCPs) committed to a partnership approach, supported by appropriate/robust organisational systems. The Year of Care's Care Planning House Model - with its walls, roof and foundations acting as a metaphor and a checklist - emphasises the importance and inter-dependence of each element – if one element is weak or missing the service is not fit for purpose.

Year of Care proposes a two-visit model for care planning and annual health reviews. Care planning might include sending people their test results ahead of an annual review, with supporting information to help them interpret it (e.g. the person's blood pressure will be given as well as guidance on what it means). This allows people time to think about their condition, discuss it with family and carers, and decide their specific goals for the coming months. Care planning will also involve agreeing shared goals during the annual review, finding

common ground between everybody's aims, then working out actions to help meet them. Under this approach, it is fundamental that the goals are specific to each person, for example they could include things like "I want to lose weight before my brother's wedding" or "I want to stop smoking before my holiday". The actions to help meet these goals could be for the service or the individual to carry out.

Figure 2: The Year of Care's Care Planning House model

Personalisation

The term 'personalisation' was coined in 2004[14] to describe a range of developments aimed at empowering people who use public services by changing the relationship between professionals, service providers and users to one of coproduction. Much of the early work on personalisation focused on disabled adults campaigning for the right to determine the support they needed through the use of Direct Payments; this eventually led to the introduction of personal budgets in adult social care.

Personal budgets and self directed support in social care

Personal budgets are an important element in the personalisation of adult social care. In December 2007, *Putting People First*[15] proposed that all (state funded) social care users should have access to a personal budget, with the intention that they should be able to use it to exercise choice and control to meet their agreed social care outcomes. The

---

[14] Personalisation through Participation: a new script for public services, Charles Leadbeater , Demos, 2004

[15] *Putting People First: a shared vision and commitment to the transformation of adult social care*, Department of Health, Local Government Association, Association of Directors of Adult Social Services, December 2007

implementation of personal budgets was initially driven by a national target for 30 percent of all people who use (state funded) social care in each local authority to have a personal budget by April 2011. Local authorities subsequently made a commitment that by 2013, 75 percent of adults using community-based social care services would have a personal budget.

A survey by the Association of Directors of Adult Social Services (ADASS) found that at the end of March 2012, an estimated 432,349 people in England had a personal budget, with 61% going to older people. This means that of the 818,700 people supported in the community by local authorities on a week-by-week basis, just under 53% received a personal budget. The total amount of money spent on personal budgets in 2011-12 was £2.597 billion.[16] The first National Personal Budget Survey, published by the Think Local, Act Personal partnership (TLAP) in June 2011, found that personal budgets were having a positive impact on most people's lives.[17] However, the survey also found that people who managed their support through a direct payment were better able to exercise choice and control than those with a council-managed personal budget and, therefore had a more positive experience.

These findings reflect differences in implementation across the country, with some people being offered a personal budget in name only and experiencing very little change in the services and supports they can access and, consequently, in their quality of life and their ability to achieve meaningful outcomes. This highlights the gap between theory and practice in the implementation of genuine coproduction.[18]

Importantly, *Putting People First* recognised that personalisation required a wider set of changes than just the introduction of personal budgets:[19]

- *enabling people with support needs and their families to develop and make best use of their own resources* - led by the work of In Control,[20] 'self-directed support planning' helps people and their families focus first on their own *resources* rather than their needs. This is also central to developments such as the use of family group conferencing.

- *enabling people with support needs to both draw on and contribute to their local communities* - people with support needs often become isolated from their communities with sparse networks of friends and neighbours. They may be subject to harassment or suspicion from others and are less likely to take part in community activities. Personalisation aims to enable people to develop friendship networks and become positively involved in their communities - participating in, and contributing to, community activities.[21]

---

[16] *Personal Budgets Survey March 2012*, Association of Directors of Adult Social Services, June 2012

[17] *National Personal Budget Survey*, Think Local, Act Personal Partnership, June 2011

[18] Longitudinal study of Personal Budgets for Adult Social Care in Essex Final report, Sanah Sheikh, Tim Vanson, Natasha Comber, Rich Watts, OPM, September 2012

[19] Putting People First: Transforming adult social care, Transforming adult social care programme board with help from the Make It Easy Group, Department of Health, 2008.

[20] What is self-directed support, In Control, 2011, http://www.in-control.org.uk/support/support-for-individuals,-family-members-carers/what-is-self-directed-support.aspx

[21] See evidence and practice examples at: http://www.thinklocalactpersonal.org.uk/BCC/about/

- *personalisation of universal state funded services and commercial services*[22] - inability to access universal services such as leisure, libraries, public transport, public toilets and primary health care, and commercial services such as banks, cafes and shops, can undermine people's independence and make them more reliant on scarce targeted services. Personalisation goes further than removing barriers to access, by also transforming these services so that they are designed for *all* people rather than the 'average' service user or customer.

- *personalisation of purchased targeted services that are not individually purchased* - only some of the targeted services that people with support needs require will be purchased via personal budgets. Other services, notably many aspects of secondary health care, will remain outside the scope of personal budgets. These too require personalisation as exemplified by developments such as Co-creating Health and the Year of Care.

- *extension and use of personal budgets and personalisation of targeted services*[23] - personal budgets enable more equal coproduction within the process of decision making about support needs and how they should be met.   This also needs to be reflected in the relationship between service users and those who provide the services that are purchased. Hence work is also being focused on personalisation of the targeted services purchased via personal budgets.

This agenda[24] is now being taken forward by Think Local, Act Personal (TLAP), the sector improvement partnership for adult social care.

Personal health budgets

Personal health budgets (PHBs) build on personal budgets in social care by extending the approach into the NHS. At its simplest, a PHB is an amount of money provided by the NHS that is spent on meeting the health care and wellbeing needs of an individual - generally someone with a long term illness or disability.[25]

PHBs give individuals and their carers greater say over the ways in which their health and wellbeing needs are met. This can include needs that have traditionally not been met by the NHS such as rebuilding relationships with family and reconnecting to the community. PHBs transfer control of public resources to individuals rather than having the state commission services on their behalf. PHBs do not include GP services, pharmaceuticals or emergency care but outside of this, they can be used in flexible, innovative ways, including to pay for care and services not traditionally provided by the NHS.

At the heart of a PHB is a care plan or support plan developed in partnership with a health professional and often with the support of an independent broker. The care or support plan is

---

[22] 'Personalisation of universal services: 1. Bus travel', Clive Miller OPM, 2010 and 'Personalisation of universal services: 2. Library and information services', Clive Miller OPM, 2010 at: www.opm.co.uk

[23] 'Progress for providers: checking your progress in delivering personalised services', http://www.progressforproviders.org/progressforproviders.pdf

[24] A sector-wide commitment to moving forward with personalisation and community-based support, TLAP, January 2011, http://www.thinklocalactpersonal.org.uk/_library/Resources/Personalisation/TLAP/THINK_LOCAL_AC T_PERSONAL_5_4_11.pdf

[25] See http://www.personalhealthbudgets.dh.gov.uk/About/faqs/#item2

the basis for a different conversation between an individual, those who support that person, and clinical professionals, in which each shares information and expertise to coproduce better outcomes.

PHBs were proposed in the 2008 Darzi Review with a national pilot programme launched a year later alongside an in-depth evaluation. Around 70 Primary Care Trusts (PCTs) were involved in piloting PHBs in the three years to 2012, with 20 taking part in an in-depth evaluation. Pilot sites have developed PHBs for people with mental health and substance use problems, individuals receiving NHS Continuing Healthcare, and people using maternity services, end of life care, stroke services and those with diabetes. The evaluation report[26] found PHBs to be cost-effective, particularly for people who get NHS Continuing Healthcare and those who use mental health services. It showed that:

- Where people had a higher budget, savings were made for the NHS as well as people's quality of life improving. This was partly due to people choosing to meet their health needs in different ways that cost less - such as training their care staff to carry out health tasks like changing dressings.

- Some of these new ways meant that people bought care and support which the NHS doesn't offer - NHS commissioners will need to plan for this.

- In-patient costs fell for people with a PHB, suggesting that people receiving PHBs had fewer stays in hospital, and might be adopting more preventative approaches to care.

The government has made a commitment that everyone receiving NHS Continuing Healthcare will have the right to ask for a PHB from April 2014. The Department of Health is supporting nine 'Going Further, Faster' sites to move ahead with larger scale implementation, and demonstrate how PHBs can be extended beyond NHS Continuing Healthcare. In addition, Clinical Commissioning Groups (CCGs) will be able to decide locally to offer PHBs to others that they think might benefit.

People Powered Health

People Powered Health is a programme from NESTA, working with Innovation Unit (a social enterprise), to enable more effective coproduced approaches to be developed with people who experience long term health conditions.[27] The overall approach has six key features:

- 'Recognising people as assets

- Building on people's capabilities

- Promoting mutuality and reciprocity

- Developing peer support networks

- Breaking down barriers between professionals and users

- Facilitating rather than delivering'

---

[26] Evaluation of the personal health budget pilot programme, Julien Forder, Karen Jones, Caroline Glendinning, James Caiels, Elizabeth Welch, Kate Baxter, Jacqueline Davidson, Karen Windle, Annie Irvine, Dominic King and Paul Dolan, Discussion Paper 2840_2, Department of Health, November 2012

[27] http://www.nesta.org.uk/areas_of_work/public_services_lab/people_powered_health/assets/features/about_the_programme

The aim is to scale up coproduction recognising that this is a disruptive approach that challenges how current professionally led health and social care systems are organised. The project provides £100,000 to each of six project sites along with up to 20 days of non-financial support from leading experts in the fields of coproduction, service design, economic modelling, health economics, change management, leadership, commissioning and procurement. Examples from three of the project sites are:

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

Lambeth: Lambeth Living Well Collaborative –'is working to enable people with severe mental illness and complex life problems by producing a greater supply of low and medium level services in the community, for example an information and referral "navigator" service, a choice of services like talking therapies, peer support groups, exercise groups, health and wellbeing activities and a network of mutual support provided through time banks.'

Newcastle: Newcastle Bridges Commissioning Consortium, a pathfinder GP consortium –'aims to develop a single cohesive approach to social prescribing in primary care'.
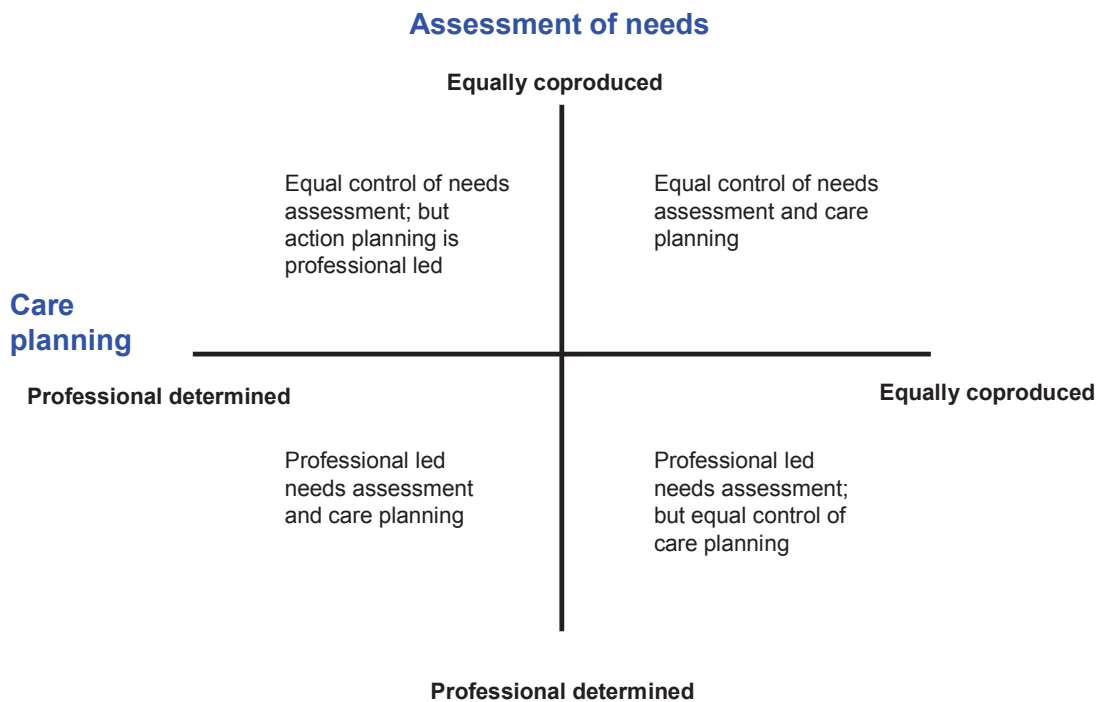
Common themes

Although the initiatives and approaches described above have been developed in parallel, they share several areas of common ground, which we discuss below.

Recognising two forms of expertise

At the core of these approaches is the recognition that patients and people who use services have a right to inform decisions about their care. This enables better outcomes to be achieved by drawing on two sources of expertise, the clinical expertise of professionals and the expertise of patients who understand what will work best for them. Patients and people who use services can make the links between decisions and their social circumstances, and are recognised as the experts when it comes to expressing their preferences and responses to risks.

Underlying all the approaches is a shift in the way individual health needs are assessed and care plans are developed. Grid 1 explores the shifts that the developments are aiming to make in the relationship between professionals and patients or service users. The aim is to shift practice to the description typified by the top right hand quadrant of Grid 1. It emphasises that individuals have an active role to play in both assessing their own needs, and deciding how best these needs can be met.

Grid 1: Assessment of needs and care planning

Assessment of needs

Equally coproduced

Equal control of needs assessment; but action planning is professional led

Equal control of needs assessment and care planning

Care planning

Professional determined

Equally coproduced

Professional led needs assessment and care planning

Professional led needs assessment; but equal control of care planning

Professional determined

The Co-creating Health pilots, for example, enable professionals to shift from behaviours described by the bottom left hand quadrant, to those in the top right, by providing training to both professionals and patients in how they can contribute equally to these processes. Patients contribute knowledge of their own lived experience and what makes it more or less difficult to manage their condition, and therefore what they might find most supportive. Professionals provide information on the condition, what is known about what makes it work, and what can be done to manage it. Together they then produce a care plan that the patient is able to work with, and which helps them deal with their most pressing concerns. Personal budgets and personal health budgets use the self-directed support planning process to enable the same change in relationship.

Remodelling care planning

Making use of patient expertise requires clinicians to both ask for it, and act on it. This involves changing the relationships and working culture between patients and clinicians. Thus central to all of the approaches described is a remodelling of the care planning process to enable this new equal two-way engagement. To do this effectively, care planning should be treated as a process not a single one-off event.

'Part of the effectiveness of coproduction comes from developing a joint plan that comes into action when you need it – having time for discussion. It's the planning process that is really key.' (roundtable participant)

Personalised care planning is in essence an example of shared decision making. To do personalised care planning well, at least three things need to be in place that are essential features of shared decision making:

- Reliable and evidence based information about options and likely outcomes.

- Professionals to be expert in providing decision support through non-directive or motivational interviewing. This involves helping people to think about alternatives which match their individual values and circumstances, rather than simply telling patients what to do or giving recommendations.

- A written plan and a commitment to implement it. Coproduced decisions need to be recorded and easy to access, review and update. The outcomes of the decisions also need to be aggregated to track effectiveness and demonstrate value to commissioners. This will require IT systems development.

Changes may also be required to the structure or the care planning process, as well as the interactions to give patients who are not used to being engaged in joint clinical decision making the space to do so. Year of Care introduced an interim step in the process to enable people to get to the place where more effective coproduction becomes possible.

'The YoC programme is attempting to change the infrastructure of how diabetes care is delivered – currently patients take part in an annual review. With YoC this has been turned into a two-step process. Rather than expecting patients to make decision with little time for preparation of reflection, in our approach, we first bring people in for an information gathering session with a health assistant, the session is de-cluttered. Then there is a second session to have a really good discussion about what they thought, adding the clinical perspective. We have found that health care professionals are not used to working in this way.' (roundtable participant)

The notion of care planning can sometimes give the impression that coproduction approaches can only be used in situations where crises are not commonly expected to occur. However it is possible to flex the approach to deal with crises.

'We have been working to change culture in the field of crisis care – people in Norwich are using personal budgets for crisis management. At the point of crisis they are able to be treated in their own homes, having greater links with the community and this is making a real difference to their recovery. Norwich Mind is working with health and social care professionals helping people to avoid spending a long time in wards, using a direct payment but being creative about how you use it e.g. respite support in a crisis. This is really working for people.' (roundtable participant)

Changing service delivery

Whilst all the approaches emphasise the need to remodel care planning, they also emphasise the importance of embedding the use of joint expertise into the practice of service delivery. This can lead to further changes, such as what services are delivered and how. For example, in diabetes care, the Year of Care has found that pathways for the provision of insulin were not sufficiently flexible to allow patients options such as staying on tablets. Other pathways, such as palliative care, are being redesigned by bringing together budgets and multi-disciplinary staff teams to rethink service delivery in line with changing patient requirements. Sometimes the requirement is for low cost but highly personalised service changes. For example, finding out how people who experience mental ill health want to be

treated when they are unwell. This led to one person being able to walk on the beach during periods of mania, which enabled her to be calmer and reduced the need for medication.

Patients' willingness to engage

For the remodelled care planning process to work effectively patients must be willing and able to contribute their own knowledge and expertise. This often leads clinicians to raise questions about whether, aside from a few really engaged people, there is an appetite amongst patients and people who use services to be more fully involved in their own care.

The national evidence shows that there is. In one survey 75 per cent of respondents said choice was either 'very important' or 'important' to them. Older respondents, those with no qualifications, and those from a mixed and non-white background were more likely to value choice, challenging the assumption that choice is the preserve of the better off and better educated.[28] However, despite government policy that backs patient involvement, repeat surveys have shown no overall improvement in the ability that patients feel to influence their care. The Year of Care for example, found that people with diabetes do not feel involved in setting goals and action planning with their GPs. This points to an unmet demand for change to clinical practice to enable greater engagement.

> *'National in-patient surveys ask 'were you involved as much in decisions about your care as you wanted?' On this measure we've had no improvement despite umpteen policy documents. I believe this is because there is not enough being done to change how professionals work.'* (roundtable participant)

Professionals often assume that some types of patients, for example those who experience mental ill health, will not have the capacity to become involved in shared decision making. This is not the case; rather, different kinds of patients need different types and levels of support. People using mental health services may need more support to inform decisions and coproduce care. One approach is to delay the decision until when they are well, another is to discuss what they would want to happen when they next get unwell.

> *'Using personal budgets, we are exploring ways of people being able to take more responsibility at a pace that makes sense to them. There is also the need to offer a range of ways for money to be held that enable service users to retain control and a range of different support and information options.'* (roundtable participant)

It can be difficult for people using mental health services to challenge clinicians. Shared decision making inevitably involves both professionals and people themselves being challenged about how best to meet a person's needs; this requires people to be appropriately assertive in engaging with professionals. Whilst this sounds eminently reasonable it can lead to problems when applied in mental health settings where compulsory treatment or the threat of it is a possibility. Assertive behaviour and challenging others' decisions can be interpreted by clinicians as a sign that a person is unwell. There are power relationships and dynamics between mental health service users and professionals that need to change, perhaps more fundamentally than in other areas of healthcare, to enable shared decision making.

---

[28] Dixon et al, Patient Choice: How patients choose and providers respond, London: The King's Fund, 2010

Culture change

The successful implementation of each initiative described here depends heavily on culture change. This includes changes in:

- who is expected to do what;

- what counts as valued knowledge and expertise;

- who takes what responsibility for risks and their management; and

- the balance of planning and decision making power between patients and professionals.

Professionals, individuals and families must all make changes to what they do and how they work together. Culture change needs to be led by the Department of Health and become widespread across the whole health and social care realm, including professional bodies, commissioners, NHS trusts, primary care providers and active patient groups.

Professionals

Culture change cannot be effected simply by asking people to sign up to new approaches and putting the infrastructure in place to support it - things would not get better. Instead it requires lots of sustained work on skills, philosophy and attitudes.

Professionals are trained for a long time to be the people who are expected to manage risk and take decisions. Through both their training and day to day practice they have developed deeply ingrained behaviours and ways of working. Hence, for example, many nurses involved in shared decision making say that in order to do it well, they had to unlearn what they were trained to do. Under the new paradigm, professional expertise is no longer about telling people what's best for them; rather, it is about recognising people's own expertise and sharing the power to influence decision making with them.

It should therefore come as no surprise to find that doctors and nurses often raise numerous objections when they are introduced to the new approaches. They will explain: why they don't like them; that they don't understand them; and that they have been explicitly trained not to work in the proposed new ways. Professionals have strongly held concerns about risk in relation to these new approaches. They are trained to manage risk and often feel that giving more choice and control to individuals leaves people more vulnerable and clinicians more open to litigation.

This concern about possible litigation can be overcome by enabling professionals to realise that whilst the new approaches do require a shift in power to people, they also shift responsibility. People and professionals share the risks by understanding and taking responsibility for the upsides and downsides of different options

Professionals need retraining to enable them to change their working culture. This cannot be achieved through a one-off session. To enable a shift in deeply ingrained behaviours continual coaching is required. The Health Foundation has shown the value of retraining through the use of multi-disciplinary groups of professionals, rather than tiered training for different clinical groups. They have also demonstrated the effectiveness of patients as trainers.

Patients and people who use services can be very effective change agents, by enabling professionals to recognise that there is a demand for increased involvement in decision making and sharing of power. They can also be effective in enabling professionals to

understand what shared decision making looks like from their point of view and, by coaching professionals in changing their behaviours and attitudes.

'Professionals sometimes don't know how they are coming across. An example from a CCG engagement forum is the GP lead for mental health, who talked at people but believed that he was engaging them.' (roundtable participant)

Individuals and families

Shared decision making and coproduction require as much of a culture shift from people using services as from professionals. In common with the thrust of government policy, they ask the general public to have a different relationship with state services. Accordingly, we need to invest in things that will shift the public's thinking.

'Some might prefer to sit back but that is because that is all they have ever known. However, in most instances patients are actually ahead of professionals. We need to train and incentivise staff and the public will appreciate it.' (roundtable participant)

Some people have already made the shift - many through being part of disability rights and mental health survivor groups whose lobbying gave rise to these new approaches. Others find the new coproductive approaches of interest, but difficult to grasp or engage with. Some people remain happy with professionals staying in control.

'Our work found that not everyone wanted a personal health budget – but the majority did. Not everyone will change; culture change is a gradual process.' (roundtable participant)

Whilst giving individuals control of budgets can play a key role in enabling coproduction, it is not sufficient in itself. We need to focus on what we can do to help shift the power dynamic. We need a bottom up approach that requires a change in people who use services and patients - not a simple consumerist approach but a different kind of relationship.

'Delivering personalised care is such a variable task. Some patients are self-sufficient others need a health trainer. Some need support to get to a point where they can make a decision. You mustn't underestimate the work involved.' (roundtable participant)

Information, training and support for individuals and families will be an important component of this.

'Bringing power to conversations requires being savvy to language and knowledge of the condition. Professionals need to think how they can respond to this and to think about the advice and support systems that actually allow people to flourish and contribute to coproduction.' (roundtable participant)

Promoting peer network development alongside professional development is another.
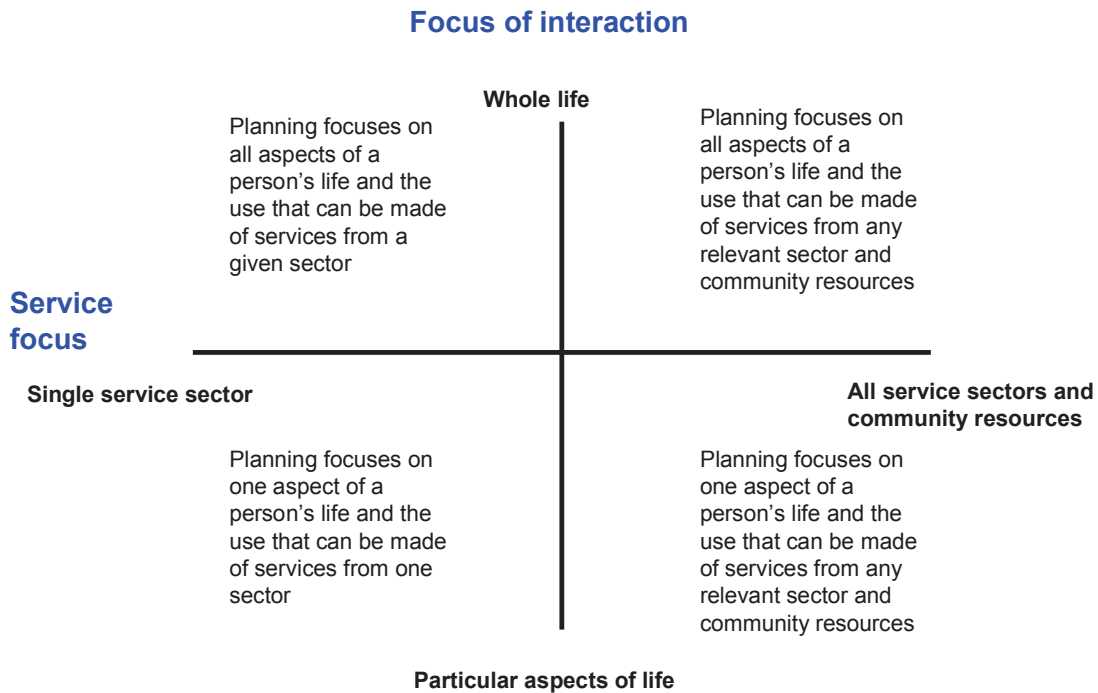
'Parents sharing experiences of not being adequately involved are powerful. They come from a place of real knowledge about how existing services don't meet their needs. We've given them the opportunity to share stories. They are a powerful movement. Working with doctors, over an 18 year period, I realise that I am the expert and need this different kind of support.' (roundtable participant)

Critical differences

The previous section scoped the common ground between the various initiatives that relate to shared decision making and coproduction. However, as already discussed, the two

concepts themselves are different, although related. Therefore, it is to be expected that the initiatives also differ in important ways.

Grid 2: Scope of the coproductive relationship

Focus of interaction

Whole life

Planning focuses on all aspects of a person's life and the use that can be made of services from a given sector

Planning focuses on all aspects of a person's life and the use that can be made of services from any relevant sector and community resources

Service focus

Single service sector

All service sectors and community resources

Planning focuses on one aspect of a person's life and the use that can be made of services from one sector

Planning focuses on one aspect of a person's life and the use that can be made of services from any relevant sector and community resources

Particular aspects of life

Grid 2 examines two dimensions along which the scope of the approaches we have described can vary. These are: the range of areas of a person's life on which developments are designed to focus; and the range of services that they aim to mobilise to support individuals, patients or service users. On the focus of interaction dimension, this may vary from, at one end, a focus on one health condition - for example, diabetes – to, at the other end, the conditions and circumstances that give rise to diabetes and its knock-on effects on other aspects of the person's life - for example, depression. On the service focus dimension, at one end, the search for more effective coproduction is centred on a single sector - health - and remodelling and making best use of its services. At the other end, the choice of support is widened to include support from any sector, including informal support, that can enable a more effective outcome. It is important to acknowledge that approaches are moving towards the latter.

Given their positioning at different points on Grid 2, initiatives take a different view of the nature of evidence; range of services that can appropriately be used; and the breadth of outcomes that can be pursued.

Nature of evidence

The choices that service users wish to make can sometimes conflict with what is known about the effectiveness of a particular type of support or treatment, and with perceptions about the appropriate use of public funds. For example, should an individual be able to

purchase an alternative therapy from which they report deriving benefit, when the published evidence shows that it has no impact on health? Different initiatives adopt contrasting approaches to the existing clinical evidence base and questions about the value for money of making different choices.

While shared decision making tends to take place within the existing evidence base, other coproductive approaches such as personal health budgets challenge the dominance of existing evidence. Where information is available, it often states that in a given percentage of cases, a treatment is likely to be effective. Hence the personal health budgets approach tends to assume that there is legitimate room for people to choose other forms of support that they find best meet their own health needs.

> *'The Sun newspaper – reported negatively about how someone bought a theatre ticket with a PHB, but we need to look at individual circumstances to decide about appropriateness. In Continuing Health Care some sort of respite is vital for families and a day trip or football season ticket may be much more preferable and suitable than trips to a traditional day centre. The crucial thing is that as long as the whole package is not costing more, and recipients and family members and carers stand to benefit by having more choice, it is okay.'* (roundtable participant)

In many ways the national policy agenda around choice needs clarification. Choice can be taken to mean clinicians providing a series of options from which patients can then choose. It can also be construed as a consumerist version of the use of PHBs, where personal budget holders shop amongst a pre-set menu of services. Both of these interpretations fail to harness the power of patients' own expertise. What is really needed is a definition of choice that enables people to understand the range of available options that clinicians see as being appropriate and why, but also enables people to come up with their own ideas and be able to decide which suit them best. What choice involves, and how shared decision making and personalisation enable it to be used to greatest effect, needs to be explained.

Range of services

The different approaches to developing more effective coproduction are being trialled in different parts of the health sector. For example, shared decision making is being applied in all clinical contexts from primary to acute care. PHBs, however, are currently mostly being developed for long term health needs and are impacting on community health provision.

Whilst some approaches to coproduction have been focused on very specific health settings and sets of health services, the trend is to increase the range of services and sectors that they seek to mobilise. For example, shared decision making draws on health resources via referrals to existing health and other services. PHBs are used alongside referrals to other services, complementing them by providing people with budgets through which to directly purchase some or all of the other supports they require from within or outside the NHS. PHBs place few restrictions of what individuals can purchase to support them in achieving their health and wellbeing objectives.

One of the issues this raises is the impact that individual choice may have on commissioned services, if people choose not to use existing treatments and supports, and instead choose others that are not currently commissioned. This will mean that as PHBs become more widespread, money will be withdrawn from some existing services with the possibility of some being decommissioned. Where these services are provided on a group basis and require a given level of demand to remain viable, some services will be closed whilst some

people continue to demand them. In these cases, there will be a conflict in meeting the competing choices of patients. This is however not unique to the use of PHBs, but a result common to all approaches to resource reallocation that remodel the range of services available to patients.

Targeting outcomes

The common aim of all these approaches is to enable people to access services and support that improve their outcomes regardless of which sector supplies them, for example, purchasing education and training to enable social engagement and so reduce social isolation and depression. However, some approaches, for example PHBs, adopt a deliberately broad, whole person view of outcomes. Under these, individuals define their own health and wellbeing outcomes, and these could include returning to work and re-building important relationships with family and friends. Other approaches are more narrowly focused on improving health outcomes.

Evolving overlaps

Whilst the approaches differ, those involved in applying them report encountering similar barriers when trying to more effectively target health outcomes, and come to similar conclusions about the required improvements. For example, it is typical to initially focus any one of the approaches on a particular clinical pathway. However, this can limit the effectiveness of coproduction.

> *'Across the three pilot sites care planning is the norm. In the last six months we've been piloting the approach with COPD but our mission now is to look at LTC care more broadly – focussing on the fact that people have multiple conditions – why not bring them together in a single care planning process, rather than working in less helpful 'disease silos.'* (roundtable participant)

It is noticeable how the different approaches to improving coproduction are continuously evolving and increasing their overlap with one another.

> *'In the YoC project we found that people had needs that simply couldn't be met via health commissioners. So we did a piece of work with the VCS to deliver things that went beyond diabetes care and looked more broadly at health and well-being. We were commissioning things that couldn't traditionally be commissioned through health services. We found that personal health budgets could be a tool to enable that to happen.'* (roundtable participant)

The availability of different approaches inevitably raises the question of which is best, or given the increasing degree of overlap, will they eventually merge into one? Currently a more helpful perspective is to recognise the common ground and the evolving nature and flexibility of all of the approaches. This enables different approaches to be used at different times. For example, PHBs are currently focussed on meeting long term health needs, whereas shared decision making is being used in maternity, acute and primary care. It is therefore the ability to draw on the portfolio of models that will really make the difference.

Scaling up

Compared with their potential range, existing developments around shared decision making and coproduction are small scale and do not threaten existing budget allocations. Scaling up

will reveal the degree of change that they bring not only to practice, but also to pathways and services. This is likely to promote resistance unless time is invested beforehand in changing hearts and minds.

Shared decision making and coproduction are not currently on the radar of most commissioners. These developments need to be packaged and communicated so that it is easy for commissioners to understand what is involved and how they work. It will be important to explain the need to incur short term implementation costs in order to secure far bigger long term gains. These will come from releasing large savings from acute services as people become more informed and empowered and in control of their own health outcomes.

The system needs to change at the local and national level and amongst both commissioners and providers. Many want this to happen, but find their efforts thwarted by the system itself. Potential starting points could be alliances with integrated providers for acute and community services who can push the personalisation agenda, and influencing the focus of the Department of Health for more funded Year of Care type pilots.

Recommendations

This paper has highlighted the common philosophy that underpins the different approaches to coproduction and shared decision making, the similarities in the processes that they use, and the wide range of circumstances in which they are being applied, as well as their differences. The flexibility of the range of approaches available and their evolutionary nature means that whilst they aim to both challenge and transform current practice, they do not require the adoption of a one-size-fits-all approach. This is helpful to know for those engaged in transforming practice, as whilst sharing much ground, these different approaches provide a range of options for initiating change.

Based on the experience of the round table participants, a portfolio approach to implementing improved coproduction of health and wellbeing outcomes in trailblazer sites is recommended.

A portfolio approach

The coproduction portfolio would comprise:

- *Common philosophy* - the adoption of the common philosophy of the coproduction approach.

- *A range of coproductive approaches* - drawing on the range of practice that has been developed to transform practice (see Box 1).

- *Transforming existing targeted and universal services* - providers would draw on effective coproduction practice to transform their relationship with people within their current services to enable more effective coproduction.

- *Commissioning and providing new services* - commissioners and providers would also work together to identify services that need to be decommissioned and develop the new types of support that people find more effective.

- *Building social capital* – enabling people to contribute to, and draw support from their local community in ways that promote their health and wellbeing. This will include: enabling people to build connections with one another; promoting new forms of community activity; and ensuring inclusivity.

- *Enabling culture change* – the change programme would be supported by a continuing programme of multi-disciplinary group training and coaching involving people who use services as co-trainers.

- *Information, support and training for people who use services* – people who use services and have experienced the new approaches will be trained to support other people and provide information and advice alongside professionals. User led support organisations will be funded to enable continuing person-to-person support.

- *Information systems* – will be modified to enable people and professionals to access and share support plans and track progress. This data would be used at the aggregate level to inform practice development and commissioning.

- *Leadership* - the changes required to develop and implement the portfolio approach impact on all parts of all sectors whose activities impact on health and well being. They also require a fundamental change in culture, behaviour and relationships between professionals and people who use services. This will require a number of years to implement and will have to become the new paradigm that governs all front line practice and management from here on out.

- *Governance* – the scope of the services on which people will call to enable better outcomes will be far wider than those provided by the health sector. Hence it is essential that partner sectors are brought on board right from the beginning. For some partners, for example adult social care, this will be part of their existing transformation programme, for others it will be completely new, for example housing. Bringing the partners together, gaining the necessary agreements and brokering coordinated change will be the prime role of local Health and Wellbeing Boards.

Box 1: Portfolio of practice changes – an example

Primary care – a practice wishes to use a more coproductive approach to enable it to improve health outcomes for patients with particular long term conditions. To start with the aim is to enable patients to work out how to better self-manage their own conditions and to exercise choice from amongst the range of treatments and supports available within the practice. The practice could be enabled to do this through the use of shared decision making. It would focus on changing the relationship between practitioners and patients, enabling staff to support patients in making the changes that patients decide upon to their health management behaviour.

Management of sets of long term conditions – commissioners have identified that a significant number of patients present with a set of linked conditions, for example, diabetes, muscular skeletal and mental health problems. Currently each of these conditions is dealt with through a separate care pathway. This makes coordinated approaches to tackling the links between the conditions difficult to tackle. The commissioners decide to use two coproductive approaches together, Year of Care and the use of PHBs. The Year of Care has been used successfully to remodel existing care pathways and PHBs to enable patients to extend their range of supports outside of those that are typically available within existing pathways. A single, patient driven care planning process producing a unified patient centred plan is used to enable change.

Trailblazer sites

The evolution of effective coproduction approaches to improving health outcomes has now reached the stage where a portfolio approach can be deployed and tested. This would require trailblazer sites that would aim to:

- Use coproduction based approaches to more effectively and efficiently improve health and wellbeing outcomes.

- Identify ways in which more effective coproduction can be achieved through adopting a portfolio approach to improvement.

The trailblazer sites would have to commit to:

- Using the full range of coproduction approaches

- Being prepared to:

    o Enable changes in working cultures of both clinicians, other professionals and patients

    o Remodel consultation processes, care pathways and support systems

    o Make flexible use of resources within and across partner sectors and within local communities

    o Evaluate the impact of change on outcomes and resource use

- Enable others to learn from their work as it progresses

The trailblazer sites might best be:

- Focused on linked sets of long term conditions

- Built on existing good integration within heath and with social care and other partner sectors

- Driven by a demonstrable demand for more effective coproduction from patients and carers

- Backed by the local Health and Wellbeing Board and individual sector leaders who see more effective coproduction as the central driving force to produce improved health and wellbeing.

Appendix 1: participants at round table seminar

OPM hosted a round table in July 2012 to discuss these new approaches, and explore the similarities and differences between them. The participants were:

- Vidhya Alakeson – independent consultant

- Dr Alison Austin – Head, Department of Health personal health budgets team

- Laura Boothman - Policy Manager, Arthritis Research UK

- Rita Brewis - Consultant and MD at Clements Henderson Ltd

- Antonia Bunnin - Senior Fellow, Health and Social Care, OPM

- Angela Coulter - Senior Research Scientist, Department of Public Health, University of Oxford, and Director of Global Initiatives, Informed Medical Decisions Foundation, Boston

- Kaaren Cruse – Mind

- Vicki Ensor – Policy and Campaigns team, Mind

- Linnet Macintyre – Peoplehub

- Clive Miller – Principal, Health and Social Care, OPM

- Lindsay Oliver – National Director of Year of Care Partnerships

- Bridget Turner - Head of Policy and Care Improvement, Diabetes UK

- Tim Vanson – Senior Researcher, OPM

- Roger Webb - Project Manager Personal Health Budgets, NHS Dorset