



Co-producing services - Co-creating health

Acknowledgements

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The purpose of this guide

This guide has been produced to enable healthcare organisations and their teams to successfully implement a series of interventions to improve the safety and quality of care that their patients receive.

It is recommended this guide is read in conjunction with the following:

- How to Improve - The guide for reliable and sustained improvement
- The 1000 Lives Improvement Service Quality Improvement Guide
- Learning to use Patient Stories for Improvement

These are available from 1000 Lives Improvement.

Contents

1. Preface	4
2. Defining Co-production	6
<ul style="list-style-type: none"> Context What is co-production? What is impact of co-production? Co-production in Health and Social Care Co-production and improving Quality Together 	
3. Co-producing services	12
<ul style="list-style-type: none"> Introduction Step 1: Identify and build your initial team Step 2: Define and share assets - what can be built on Step 3: Co-create the vision - develop will Step 4: Co-designing the solution - build ideas Step 5: Co-delivery - building execution Step 6: Co-evaluation - measure the impact of change Step 7: Share the evidence and celebrate success 	
4. Co-creating Health	27
<ul style="list-style-type: none"> Introduction Step 1: Share knowledge - evaluate known information Step 2: Have conversations, build partnerships - health interactions Step 3: Additional Information Step 4: Shared Understanding of options Step 5: Agreement of way forward Step 6: Facilitation of agreed action(s) and choice(s) Step 7: Evaluation of outcomes Step 8: Clinical Audit Step 9: Continuous Improvement 	
5. Getting Started	38
<ul style="list-style-type: none"> Introduction Training and support A selection of organisations using co-design in health and social care Reading list 	

1. Preface

There is much discussion about the role of co-production as part of the response to the current challenges to the delivery of public services. There are many articles and documents describing co-production and many aspects to what it encompasses and how it is undertaken.

This guide serves as an introduction to some of the thinking behind the interest in co-production, how it fits with current NHS thinking in Wales and introduces some of the techniques and processes that are used. It aims to stimulate interest and ideas about how and where co-production can support services design, delivery and evaluation and how the principles can be applied at an individual patient level to support management of long term conditions.

It also shows how co-production can support the delivery of person-centred care, which prioritises putting patients, their families and carers at the heart of all decisions and plans about health care. It sees patients as equal partners in planning, developing and assessing care to make sure it is most appropriate for their needs.

Person-centered care aims to be patient focused, to promote independence and autonomy, provide choice and control and be based on a collaborative team philosophy. It takes into account service users' needs and views and builds relationships with family members.¹ It requires both safe and effective care and an expectation of a good "experience".

The delivery of person centered care should result in a good experience for the patient. NHS Wales identified the need to be able to describe the key determinants of a "good" experience as a guide to assessing how patients feel when they receive care and services.

A key lesson from the public inquiry into the Mid Staffordshire NHS Foundation Trust, chaired by Robert Francis QC (the Francis Report)², the Department of Health review and response to Winterbourne View Hospital³, and the review into the quality of care and treatment provided by 14 hospital trusts in England led by Professor Sir Bruce Keogh⁴ is that service providers need to develop more equal partnerships with people who use services, together with their families and carers.

To support a focus on improving patient experience, a National Service User Experience Framework⁵ for NHS Wales was launched in 2013, based on national and local published evidence. It includes the following three domains which describe the key determinants of a good patient experience:

First and Lasting Impressions - which includes:

- Being welcomed in an appropriate manner.
- Being able to access services in a timely way.
- Being treated with dignity and respect.

Receiving care in a Safe, Supportive, Healing Environment - which includes:

- Receiving care in a clean, clutter free environment.
- Receiving good, nutritious, appropriate food.
- Having access to drinks.
- Having rigorous infection control practices in place.

Understanding and Involvement in Care - which includes:

- Receiving appropriate, timely, accessible information.
- Being communicated with in an appropriate, timely manner.
- Being involved in decisions about choice of treatment options and care plans, including discharge.
- Involvement of carers and families in decisions, especially about discharge/transfer.

A range of methods are available to gain user feedback, including surveys and patient stories. Information gained from patient feedback is helpful in shaping priority areas for improvement and to be successful, an approach based on the principles of co-production will ensure full patient and public involvement in improvement activities and in tracking the impact they have on the patient experience

2. Defining Co-production

NHS Wales, like all public services, faces severe challenges including increasing demand, changing expectations, increasing burden of chronic disease and the health needs related to an increase of very elderly people in the population.

These challenges are made more urgent by the impact of the current economic situation. Although the NHS in Wales with its structure of integrated Health Boards and responsibility for public health is well placed to meet the increasing challenges it seems unlikely that sustainable improvements in services and health and well being will be delivered simply through restructuring services or efficiency drives. A new way of working is needed with NHS staff, patients and the community seeing their roles differently and behaving in a different way.

There is a growing consensus that co-production is such a way forward, a view supported by the Health Minister, Deputy Health Minister and Chief Medical Officer⁶. In response to an open letter from Co-production Wales (All in This Together)⁷ in May 2013, advocating the widespread adoption of co-production principles at the heart of public services in Wales, the First Minister replied that he and Ministerial colleagues see increased co-production in the design and delivery of public services as an imperative⁸.

The First Minister also confirmed that co-production will be central to the forthcoming Social Services and Well-being (Wales) Bill. The Bill aims to promote “the empowerment of service users by giving them a stronger voice and greater control over services” and will, when introduced, transform the way in which many public services in Wales are delivered and experienced.

The Welsh Government Quality Delivery Plan⁹ for the NHS in Wales sets out the clear vision for a quality-driven NHS Wales. This is to achieve the triple aim of:

- Providing the highest possible quality and excellent experience.
- Improving health outcomes and helping reduce inequalities.
- Getting high value from all our services.

This means providing services that are safe, effective, accessible, affordable and sustainable - reducing harm, variation and waste. It means delivering person-centred care to all our patients and re-designing and delivering services to achieve this aim.

This can only be truly achievable in full and equal partnership with the people using the services, other organisations, including the third sector, and the wider community. If this is done consistently and effectively this will ensure that all sectors of the community are included, supporting the NHS in fulfilling its duties under the Equality Act 2010¹⁰.

The Equality Act 2010 brought together and replaced the previous anti-discrimination laws with a single Act. The Act includes a new public sector equality duty (the ‘general duty’).

The aim of the general duty is to ensure that the NHS and other public authorities and those carrying out a public function consider how they can positively

contribute to a fairer society through advancing equality and good relations in their day-to-day activities. The duty ensures that equality considerations are built into the design of policies and the delivery of services and that they are kept under review. It is therefore vital that the NHS in Wales assesses the likely impact of proposed, reviewed or updated policies and practices.

A co-production approach to health and social care will ensure that the requirements of the Act are met and that development of an Equality Impact Assessment becomes an integral part of the process.

The recent 1000 Lives Improvement white paper, The Listening Organisation¹¹, described how a range of feedback sources and methods could be used by health boards and trusts in Wales to ensure services were delivered safely and effectively and that the patient experience was continuously improved. The white paper also noted that listening, and involving communities, patients, families and carers is at the heart of co-production.

What is co-production?

Co-production is an approach to public services which involves citizens, communities, and the professionals who support them, pooling their expertise to deliver more effective and sustainable outcomes and an improved experience for all involved.

NEF (the New Economics Foundation)¹² and NESTA¹³ (National Endowment for Science, Technology and the Arts) define co-production as ‘delivering public services in an equal and reciprocal relationship between professionals, people using services, their families and their neighbours’.

They argue that where activities are co-produced in this way, services and neighbourhoods become far more effective agents of change.

In co-production, citizens and patients have rights and responsibilities as equal partners. This can be at an individual or community level and can involve the public sector, the third sector and other agencies.

The co-production process begins with the question ‘how do you want to live your life?’ rather than ‘what services are you eligible for?’ This starting point recognizes that citizens and service-recipients are experts by experience and can identify what is important to them, and they also have rights and responsibilities as equal partners in the process.

In a co-production scenario, service-users and their communities are involved in defining the need or problem, designing the solution, delivering it, and evaluating it, either with professionals or independently, or anything in between. This approach demands longer-term engagement by service-providers but leads to profound and sustainable change.

Co-production is also based on the sharing of information and on shared decision making between service users and providers¹⁴.

Co-production encourages participation, mutuality and respect for others, valuing the experience, skills and knowledge that each participant brings and providing opportunities to extend their skills and knowledge. It aims to change 'traditional relationships of power, control and expertise' and the relationship between state and citizen. This is quite different to other engagement activities

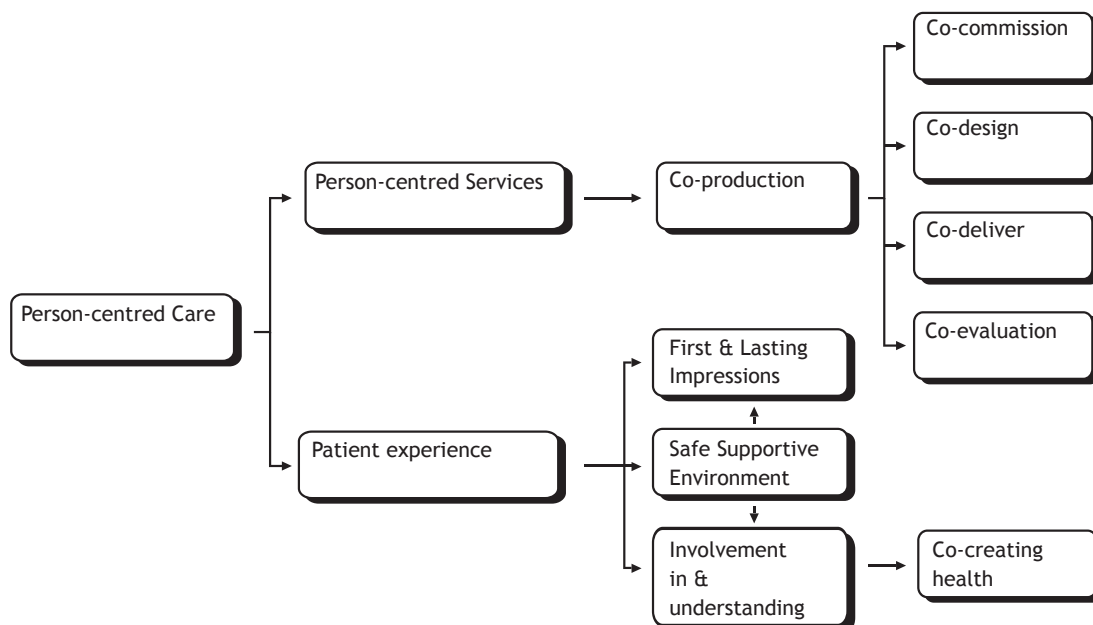
There are different levels of co-production. At its most effective, transformative co-production, it involves a permanent shift in power and responsibility from service providers to citizens and their communities, aiming to change the way that public services are commissioned, procured, designed, delivered and evaluated¹⁵. The goal is shared power and shared responsibility.

Part 2 of this guide uses the term co-production to broadly describe the development, improvement and delivery of services. This encompasses co-commissioning, co-design, co-delivery and co-evaluation. The term co-creation is used in Part 3 to describe the interaction with individual patients in terms of improving and maintaining health and preventing ill health.

This approach can also support the co-creation of health in communities. This facilitates a shift from the prevention of illness to the promotion of wellness by recognising the assets that are available to enable people to have good health. This approach is described in the Betsi Cadwaladr University Health Board Executive Director of Public Health's Annual Report 2013¹⁶.

The ethos of shared power and equality and many of the issues discussed in this chapter are key to both, although we only refer to co-production for easy reading.

The way that these two approaches fit with the concept of person centered care is shown below.



Co-production introduces a range of terms to describe the recognition of the experience, capabilities, knowledge and time that individuals bring to the process. Additional information can be found in the reading list at the end of this guide.

The impact of co-production

Co-production requires a shift in power from service providers to citizens. This results in a need to re-think what we mean by professionalism and leadership in health and social care, and a re-examination of risk management and professional boundaries.

For government and commissioners, co-production requires a move to a holistic approach to planning based on outcomes for individuals.

Organisations or departments also need to move beyond their own boundaries and work in genuine and generous partnership with others. This can raise issues over funding, i.e. who is paying for a particular service that is being delivered by someone else, and governance, i.e. who is responsible for making sure services are delivered to the right standard, on time and budget, and in the right place.

People taking part in co-production are being asked to change too. The capacity of individuals and communities to make a contribution is affected by a host of variables - income, education, confidence, knowledge, previous experience, as well as by more pragmatic issues around family circumstances, time, and physical or cultural barriers.

At an operational level, public service providers and community organisations will need to work together to provide information, advice, advocacy and support, to help build a context which truly enables and empowers citizens.

Embedding co-production requires shifting resources to the front line and to communities, to prevention and early action. At a strategic level, this will require recombining the medical model, which focuses on diagnosis and treatment, with the social model, which recognises that other factors, such as discrimination, can have as much significance as a disability or disease itself. This in turn requires acknowledging and improving the inter-relationships between health, social care and wellbeing.

Co-production in health and social care

The use of co-production as a means of developing more equal partnerships with people who use services has been used in a wide variety of organisations delivering social care¹⁷. The requirement to develop equal partnerships, shift resources and redesign services requires a culture change and persuasive evidence of the benefits. NESTA has funded work to demonstrate the benefits of co-production in health care and the ways in which it can be used.

People Powered Health¹⁸ was a programme to support the design and delivery of innovative services for people that are living with long term health conditions. This programme included co-production approaches such as peer support groups, time-banks¹⁹, self management support, group consultations, narrative based assessments, service co-design, service navigators, motivational interviewing, innovative uses of personal budgets, social prescribing, staff and patient training and support and multi-purpose service centres.

NESTA has published an overview of the business case for 'People Powered Health'²⁰.

The programme showed approximately 7 per cent reduction in the cost of delivering healthcare. Costs are reduced through reducing the number of A&E attendances and hospital admissions, reduced length of hospital stay if patients are admitted and decreased patient attendances in primary care.

Given these savings, it is estimated that putting the People Powered Health model of co-production into practice would save the NHS £4.4 billion across England.

Supporters of co-production claim that the benefits can be demonstrated in social and monetary value. As examples:

1. A qualitative study of over 90 co-production practitioners²¹ asked participants to identify the benefits of co-production - for themselves, for their organisations and for service-recipients. The most frequent responses were:
 - for practitioners: greater job satisfaction, effectiveness and ownership. Staff felt empowered, trusted, and fulfilled - able to make a difference in people's lives.
 - for organisations: service relevance and effectiveness, flexibility and shared learning and opportunities for collaborative working. Co-productive organisations are considered to be more robust in meeting their mission, more responsive, more trusted and more sustainable.
 - for service-recipients: empowerment and influence, and the increase in confidence and wellbeing that comes from being listened to and valued. This finding chimes with the results of a recent cross-national survey which suggested that 'the most important driver of co-production is self-efficacy: the feeling that individual action can have an impact upon political and social change'²².
2. Exeter University evaluated a community-led co-production initiative in Falmouth over a 3-year period, focusing on indices of deprivation. Among other things, they found that child-protection rates were down by 42 per cent, post-natal depression down 70 per cent, childhood asthma down 50 per cent and unwanted teenage pregnancy had dropped to zero²³.
3. The SUN peer-support group in Croydon is run for and by people with severe emotional and behavioral problems. After only 6 months participation, members' A&E attendance was down by 30 per cent and the need for hospital admissions reduced by over 50 per cent²⁴.
4. In the USA, the Nurse-Family Partnership programme pairs up nurses with first-time mothers in high-risk groups. Child abuse and neglect have reduced by 48 per cent with a significant return on investment for the project as a whole²⁵.

Co-production and Improving Quality Together

To take a transformative step towards working in a different, co-produced way, all NHS Wales staff need to understand what is meant by co-production and where to find the skills and expertise to support it. There needs to be a robust method of transferring the awareness, knowledge and skill across all its organisations and staff, preferably using a common toolkit of methods and using common terminology.

The Quality Delivery Plan 2012 mandated a common and consistent language and approach to improvement to be led by the 1000 Lives Improvement Service. The consistent methodology chosen is Improving Quality Together (IQT)²⁶. This is a standardised framework of core improvement skills for all NHS Wales' staff and contractors, which builds upon recognised local, national and international expertise.

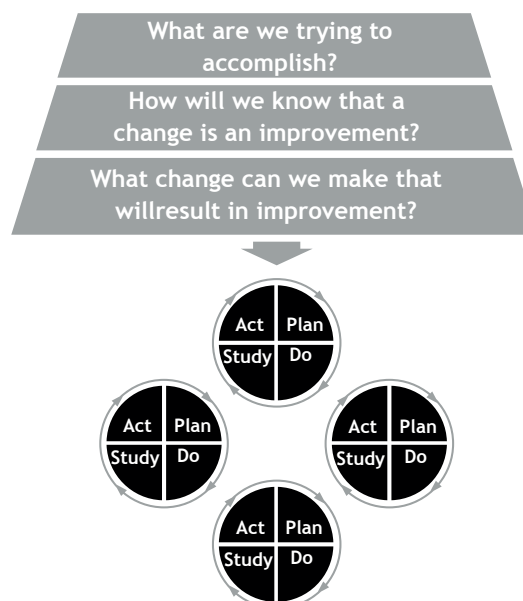
IQT allows staff to develop their skills and gain accreditation in quality improvement methodology at three levels, Bronze, Silver and Gold, with an additional Board level programme. The content of the framework has been developed on a national level, is delivered locally by NHS organisations and incorporated into existing organisational development programmes.

The programme focuses on a person-centred approach and the core set of skills is based on the Model for Improvement, which provides a framework to structure improvement efforts.

The model is based on asking three key questions, known as the thinking components:

1. What are we trying to accomplish?
2. How will we know that a change is an improvement?
3. What change can we make that will result in improvement?

These questions are then used in conjunction with small scale testing, the 'doing component' known as **Plan, Do, Study, Act (PDSA) cycles**. The combination of the three questions with PDSA cycles in the model for improvement is shown below.



3. Co-producing services

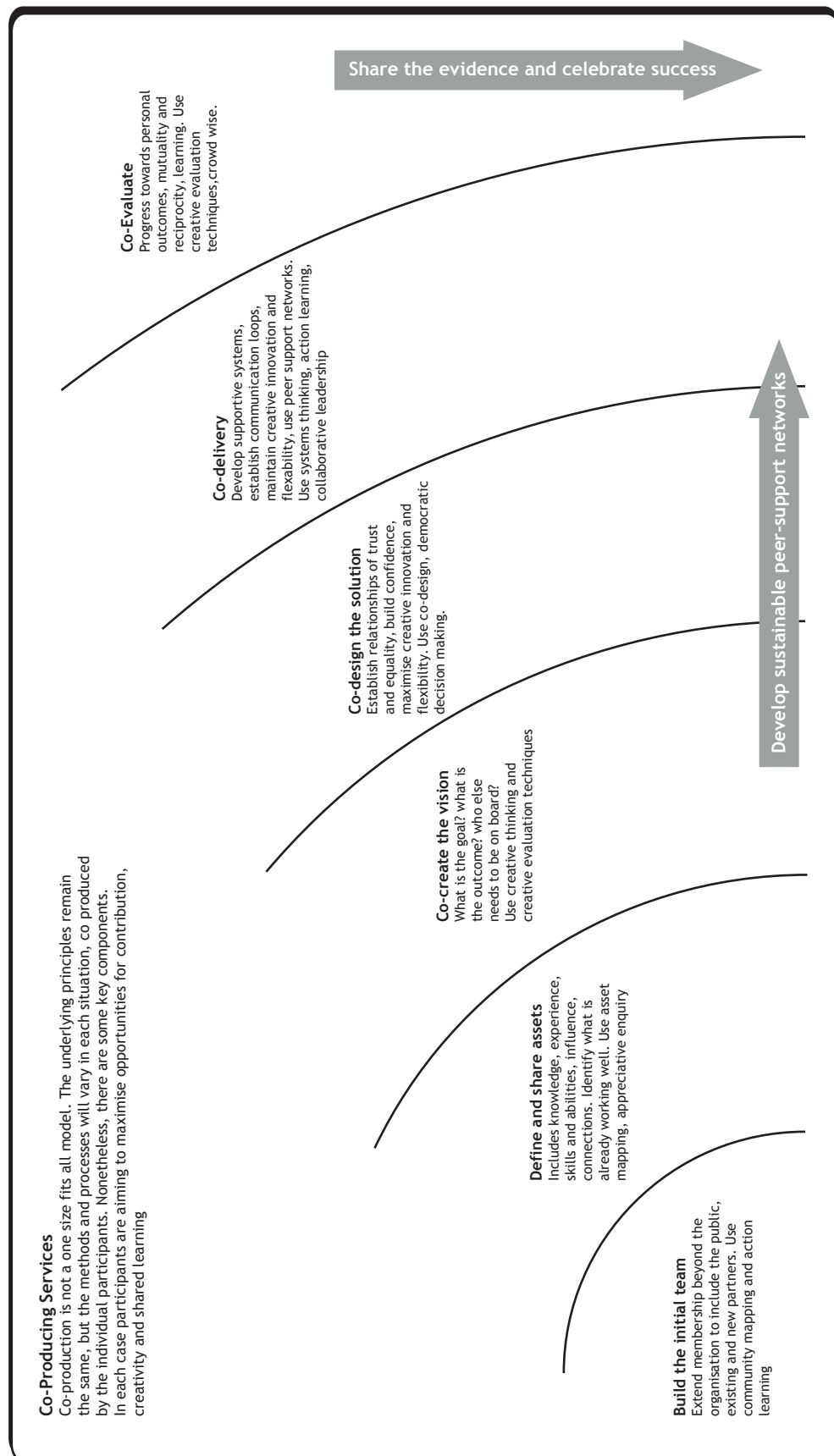
As outlined earlier, this guide uses co-production as a term to broadly describe the development, improvement and delivery of services. This encompasses co-commissioning, co-design, co-delivery and co-evaluation. The term co-creation is used to describe the interaction with individual patients in terms of improving, and maintaining health and preventing ill health.

By its nature, co-production cannot be a one-size fits all model. The underlying principles remain the same, but the methods and processes will vary in each situation - as it is co-produced by the individual participants. Nonetheless, there are some key components; in each case participants are aiming to maximise opportunities for contribution, creativity and shared learning.

Since some of the thinking needed and approaches used are new to healthcare professionals it is often helpful to carry out an initial self assessment of where an organisation, service or individual lies in terms of their practice and how it fits with co-production²⁷. This will help establish a baseline, identify gaps and areas for improvement and allow progress to be tracked.

The co-production self-assessment tool can be used to help individuals and organisations review what they already do in relation to the essential principles of co-production and identify good practice and areas of weakness. The tool can assess an individual's practice, evaluate a current service or look more closely at the way an organisation operates.

This section will map out a suggested framework as a guide, outlining the different steps and some of the tools which will help the co-production of services.



Step 1: Identify and build your initial team

In this phase the aim is to build an initial team to take the work forward. This can be quite time consuming and needs detailed consideration, but is a key step to achieving co-production. By ensuring engagement of all parties that are or could be impacted or affected by a change in the system or contribute to its development co-production can be achieved with equality as its core principle.

This initial stage should not be rushed and every appropriate step should be taken to identify and involve all relevant stakeholders, including:

- Considering people who are directly affected by the service, now and in the future and to adopt a wider community approach.
- Considering people who may have a valuable role to play going forward as well as people who are currently involved.
- Including people who have a high interest in what is being taken forward, but have a low amount of power in the decision making process.

The membership should be expanded within and beyond the organisation to include the public and existing and new partners. It may be that the team becomes quite large. It is important that at an early stage the participants establish democratic and inclusive ways of working to ensure that all contributions are equally valued.

There are several tools available to guide the identification and assessment of stakeholders. For example, the former NHS Institute for Innovation and Improvement created a useful guide²⁸.

To maximise the impact of any actions taken, it is important that the individuals involved are motivated and committed. It is also essential that there is stakeholder buy-in from the beginning. For example, this could be achieved through holding information and training sessions for the people who have been identified to drive the actions forward. This will help to ensure they are fully aware of what is being undertaken, how it is going to be done and their role.

It will also be important, as this could be a lengthy process, to keep stakeholder interest throughout. This helps to ensure that actions are implemented and can also attract other stakeholders for possible future projects. Thanking the stakeholders for their involvement and keeping them up to date with progress is a simple way of doing this. Other options include organising a more formal celebratory event or official opening for the new service.

It is also important to recognise those individuals and groups who may be 'seldom heard' throughout any co-production process or whose influence may be disproportionately high. One approach to this is through Community Mapping²⁹.

Community Mapping creates an understanding of an area as seen by those who live there. It identifies key individuals, resources, networks and groups, which could be invited to take part in co-production. Because successful co-production relies on peer-support networks, these links need to be nurtured and extended.

A useful approach is to begin by listing those organisations, groups or individuals that there are already working relationships with - whether formally or informally. Then consider those whom you know about but have not established

relationships with; then those who are normally outside existing networks and spheres of influence.

This shifts the perspective to the ‘seldom heard’ groups. Through the Community Map you can begin to see how you could make connections to these groups through your existing network, and/or how you could build relationships of trust through intermediaries (a ‘six degrees of separation’ approach).

Community Maps can also include information about transport, public spaces and buildings, local clinics or advice centres etc. It can also be used to provide a baseline ‘snapshot’ of your community from which you can measure change or progress.

Community Mapping is best done with a variety of stakeholders. It can be produced electronically or by hand (the latter tends to be most engaging). It should be visually lively and flexible so that things can be changed around as networks grow.

In some cases the nature of the service being looked at will make it easy to identify those people who will be directly affected and therefore who need to be part of the co-production process. For example in the development of stroke services there will be a clear community of patients, families and carers who have been affected.

Case study

Life after Stroke

The needs of stroke survivors and carers cannot be met by any one group alone and there is a requirement for cooperation and complimentary working across health services, social care and the third sector.

The 1000 Lives Improvement Service Life After Stroke (LAS) programme needed to develop a framework that captured the key drivers and changes that would be needed to achieve the aim of enabling stroke survivors to achieve and maintain their optimum quality of life. The programme sought to achieve that aim by putting stroke survivors and carers in a stronger position of knowledge and self-determination whilst improving the responsiveness of services themselves.

Two listening events were held, covering North and South Wales (approximately 150 people) asking stroke survivors and their families and or carers what had impacted and what would improve their care and quality of life since their stroke (post secondary care).

The time since stroke varied from 20 years to a daughter whose father was about to be discharged. The events were facilitated and each table had a facilitator to ensure everything was captured and all had the opportunity to contribute. The Main Facilitator went through the table papers and in the afternoon fed back the key emergent themes to ensure what was captured reflected what had been shared.

Eight key themes emerged and the event helped to build the consensus and support for what is required and where there are examples of success.

There will also be other organisations that will be able to contribute to a successful co-production process. Support for identifying potential participants and engaging them is available through the NHS Wales Partnership and Integration Team and the Welsh Council for Voluntary Action.

The Partnership and Integration Team supports and promotes co-production within Wales to help deliver better health and social care services to those who need them through a more cost effective, efficient and person-centred approach to service delivery. The team supports NHS Wales in developing its skills and capacity in relation to partnership working between organisations and with citizens. The three broad work programmes of the team include:

- Developing approaches to citizen engagement.
- Supporting the delivery of integrated services.
- Supporting and promoting co-production within Wales.

The work programme also continues to develop the tools and skills required by NHS Wales to effectively undertake continuous dialogue with local citizens to support service change and improvement.

Wales Council for Voluntary Action (WCVA) represents, campaigns for, supports and develops voluntary organisations, community action and volunteering in Wales. It represents the third sector at UK and national level. Together with a range of national specialist agencies, County Voluntary Councils, Volunteer Centres and other development agencies, it provides a support structure for the third sector in Wales.

The WCVA has 3,000 members, and is in touch with many more organisations through a wide range of national and local networks. Across Wales there are county voluntary councils (CVCs) and volunteer centres (VCs) acting as a network of support organisations that help people who are inspired to make a positive difference to their communities. They work with charities, voluntary and community groups, social enterprises, trustees and individual volunteers. WCVA works at a national level, while CVCs/VCs work at a local level. The WCVA and CVCs should be key contacts when establishing a co-production programme as a means of accessing citizen stakeholders.

Forming and working with groups with a wide range of participants can be challenging for those used to working within a formal organisational structure and support guidance is available from the Partnership and Integration Team and the WCVA.

It is important that events are accessible to all and that barriers to communication are identified and addressed. There may also be expertise within organisations that is not normally aligned to service improvement that can be of help.

Case study**Patient Groups**

In Cardiff and Vale University Health Board a link has been formed between the MAGIC Shared Decision Making programme³⁰ and the patient experience facilitator who has the responsibility for encouraging and supporting the development of patient and carer groups.

The facilitator has developed guidance for clinical teams and services to support the establishment and successful operation of groups and this material will support clinical teams in involving patients in the implementation of shared decision making. The facilitator also has close links with the Equality Adviser for the organisation and carers groups.

Step 2: Define and share assets - What can be built on?

A key component of co-production is building on existing resources and expertise. In this phase participants start to define and share the individual and community assets that are available to them. These will include knowledge, experience, skills and abilities, influence and connections. It is also crucial to identify what is what's already working well. This phase will lead on to an identification of where the gaps are and how they can be filled.

In order to determine how to develop services to meet current and future needs there is a need to be aware of what the current service looks like. With a picture of the current service and what it feels like to participate in it, we are able to build on good practice, using and build on any assets we have available to us.

Obtaining information from a variety of sources gives a full picture of the current service. The 1000 Lives Improvement white paper, The Listening Organisation³¹ lists potential sources:

- Patient Feedback including patient stories, surveys etc
- Compliments
- Patient complaints
- Current pathways
- Staff experiences

Stories for Improvement are a rich source of information to inform areas that could benefit from a co-production approach and as a way of gaining insights into how services could be designed and delivered, and as a means of evaluation. The 1000 Lives Improvement "Tools for Improvement" Guide *Learning to use Stories for Improvement*³² is a good source for anyone wishing to embark on collecting and using stories for improvement.

Patient and Family Shadowing is a method that allows healthcare professionals to shadow a patient and their families through their entire healthcare experience. This process offers insight into what the actual experience of a system is from the eyes of those we care for.

Shadowing should be undertaken as a team effort and prior consent must be obtained from the patient and their family.

This simple method provides a unique opportunity for members of the team to assess how a system is functioning and its impact on patients and their families. It allows them to better understand the various touch point and information sources within a pathway and to effectively identify possible changes that could have a big impact. By putting the professionals in the eyes of the patients and their families it helps them to look at their environment in a new and fresh way, providing a great starting point for delivering person-centred care.

1000 Lives Improvement has showcased a method developed by Dr Anthony DiGioia who has developed a six steps methodology to support frontline staff embark on a shadowing experience for service improvement. Support materials are available on the 1000 Lives Improvement website³³.

Asset Mapping³⁴ is an engaging and visually lively way to map the assets of a community: places and spaces; resources; people - knowledge, skills, abilities, experience; and activities. Coloured post-its, coloured pens, stickers and cut-out shapes are all useful: they can be added randomly or used to make a 'picture' - a landscape, seascape or cityscape. Production can continue over several days, with different groups contributing at different times. The result should be both creative and energising, displayed in the community itself as a reminder of the positive potential of the community and its members.

Case study

The Vanguard Method³⁵ in Social Care

Staff working in social care are committed to supporting individuals but they, like many others, can be constrained and, in some cases prevented, from providing this support by the system within which they work.

Social Care staff in Monmouthshire and Carmarthenshire County Councils spent time following work through the system from the perspective of the citizen. In six days they had identified several underlying problems in the system. They discovered multiple assessments that disempowered people, multiple referrals between professionals leading to enormous quantities of bureaucracy, and performance indicators driving dysfunctional behaviour.

The underlying issue learned was that the system is underpinned by the assumption that citizens want a service. As they have a menu of services they could offer, these dedicated individuals found themselves assessing the citizen to fit into a menu of services. They were also forced to treat each request for help as a single transaction, without being in a position to understand and help the person solve the underlying problem for themselves.

Once they realised this, they were in a position to challenge the logics that had led to the design of the current system. This is crucial if a sustainable move to co-production is to be made. Without this fundamental reappraisal of the underlying logics that cause problems in the system, organisations find it extremely difficult to undertake co-production.

Unless the frontline is freed from policies, procedures, IT systems and specialist functional design, co-production remains a 'nice to do' rather than the core of the organisation. This freedom comes from changing our logic about how work should be designed and managed

It is often helpful to be able to express complex ideas and aims in a simple way to ensure that the key messages are heard and understood. An Elevator Pitch is a short summary which can be used to quickly and simply define something such as a service, potential development or initiative and identify why it should be of interest to those receiving it. It reflects the idea that it should be possible to deliver the summary in the time span of an elevator ride, or approximately thirty seconds to two minutes. In this context the pitch should be able to describe the assets that are available and how they can be used to support the proposal.

Step 3 Co-create the vision - Develop Will

In this phase the team starts to identify and agree the aim and outcome. The team needs to identify who else needs to be on board and part of the process.

In many cases this phase will naturally merge with the ‘Define and share assets - What can be built on?’ stage. Bringing together all stakeholders and scoping current activities and system design and what it actually feels like to access services will often naturally focus people’s mind and attention on what is the intended outcome of the change process.

However, we often work with stakeholders groups with competing priorities, with differing confidence and capacity to speak out or to engage. To make sure all voices are equally heard and all sides are represented it can be helpful to use some specific tools to engage all stakeholders in setting a defined aim with a shared sense of ownership.

Appreciative Inquiry³⁶ (AI) is a proven methodology that involves all stakeholders in a process of change and improvement, based on a co-production model. Unlike many other approaches, it starts from participant’s own experiences of what is working well, rather than identifying issues. It does not avoid tackling problems; it just frames them in a solution-focused way in terms of people’s aspirations for the future.

Because of this, AI avoids a blame culture and engages people from the start, generating real ownership of any action plans. The approach has a simple and clear process of application called the 5D model - Define, Discover, Dream, Design, Deliver.

AI has been used in a range of ways across Wales, the UK and beyond. This has included community engagement, organisational development and improvement, user consultation, thematic reviews (e.g. systems and processes) and culture change.

Case study

Gender Dysphoria pathway redesign

The Welsh Health Specialised Services Committee (WHSSC) is responsible for the joint planning of Specialised and Tertiary Services on behalf of Local Health Boards in Wales.

Among the services that WHSSC commissions is adult mental health, which includes gender dysphoria. Gender dysphoria accounts for less than 1% of the WHSSC mental health budget, but accounted for 45-55% of the time spent by the adult mental health team, primarily dealing with responses and enquiries about the policy from the trans community.

When WHSSC decided to revise the gender reassignment care pathway they took the opportunity to use a co-produced Equality Impact Assessment (EIA) process to engage with the trans community so that the views and needs of the service users could be incorporated into its redesign.

By using an EIA process, WHSSC ensured that they actively engaged with the trans community by setting up a working group which contained service users. Sub-groups of the working group were allocated work streams which allowed service users and clinicians to work together.

This approach enabled WHSSC to develop a more detailed and nuanced understanding of the people they were serving, and their diverse needs. It also provided WHSSC with more accurate data by accessing the knowledge, expertise and data held by the trans community (e.g. Trans Helpline data).

The collaborative approach of the EIA process has resulted in benefits to both WHSSC and the trans community. WHSSC have estimated that there has been a cost saving in reduced complaints alone. WHSSC has also seen a reputational benefit as well. Where previously they were seen very negatively by the trans community, their steps to engage with service users on the care pathway redesign has improved this.

For the trans community the EIA process was considered to be empowering. It demonstrated that by engaging constructively with WHSSC, their concerns would be listened to, and that they could influence the design of the service provided to them. The EIA process was also found to have inspired members of the trans community to become more positively engaged with the health service (e.g. volunteering to help deliver training to NHS staff on trans issues), and inspired them to become change agents.

Step 4: Co-designing the solution - Build ideas

Co-design is an innovation methodology that uses a collaborative design process to develop solutions that build on the expertise of end users, non-users and professionals. The methodology is flexible in length and application but a full co-design project will include phases of contextual research, analysis, idea generation and testing.

In the research phase, co-design employs small-sample qualitative methods such as rapid ethnography and guided interviews to gain deep insights into end users' context, wants and needs. Community consultations and focus groups are usually avoided because they provide limited insight into an end users everyday context.

Analysis of research and early idea generation is typically led by the design team and may not include end users. Ideas developed in these phases are then tested and refined (or discarded) through a phase of prototyping. Paper-prototyping involve getting users feedback to a walk-through of a service on paper, experience-prototyping could involve users taking part in a mock-up of a small scale service that runs for weeks or months.

To fully co-design a solution the team needs to establish relationships of trust and equality, build confidence, maximise creative innovation & flexibility and build on available and newly identified assets.

Case study

Beginners Guide to the Health Service - Welsh Ambulance Service

When the Welsh Ambulance Service engaged with learning disability groups, it became apparent that there was a lack of knowledge about the available NHS services and a hesitance in ringing 999. Research also showed that people with learning disabilities are more likely to access healthcare services as they have higher levels of ill health and much higher rates of premature death than the general population.

In response, the Welsh Ambulance Service has developed the first interactive learning programme of its kind in the UK, to help people with a learning disability understand the services that are available.

- The programme includes:
- Identifying what kind of situation is an 'emergency'.
- How to ring 999.
- What other services are available when it's not an emergency and how to access them.
- Information about how Welsh Ambulance Service staff can help them.

The learning programme uses a variety of techniques, including games, quizzes and flashcards and has been designed for independent and supported learning, making it suitable for a range of abilities.

People with learning disabilities were involved in the creation of the learning programme from the outset, with the design of the programme driven by their needs. It was made clear at the start how important their contribution was. The learning disability groups that worked with the Welsh Ambulance Services remained involved for the duration of the project and also tested the final version, including the feedback facility.

The most suitable methods of learning were chosen for the target audience, ensuring that they were suitable for a variety of abilities. Additional advice and support was provided by those working in the learning disabilities arena.

Feedback has been extremely positive with the majority of respondents marking the learning programme as excellent. Members of learning disability groups have increased confidence in ringing 999 in an emergency and in using alternative NHS services when these are more suitable. A number of learning disability groups want to use the programme and the first peer trainer has been identified.

Case study

New mental health unit, University Hospital Llandough

The Cardiff Adult In-patient unit is a large capital project to provide modern mental health services in a purpose built, up to date environment. The new Unit will replace many of the services currently provided from Whitchurch Hospital.

The development aims to improving the service users experience within a modern healthcare building. The development is using good practice guidelines from the Department of Health, Welsh Government, Royal College of Psychiatrists and others, including equality and disability standards to ensure that it provides a building that will enhance the service user experience and ensure privacy, dignity and safety.

A clinical project lead was appointed to ensure the service user voice is heard, listened to and acted upon. The clinical lead role requires all the elements of effective leadership skills at its core.

The project is a collaborative process that involves architects, NHS staff, service users and carers. Service users attend and contribute to planning groups with the health board to discuss how the new building should best meet the future needs of service users. There have also been meetings with service users and carers in both in-patient and community venues.

Service users have expressed a wish that the building exhibits a change in perspective of mental health issues and services. The space needs to express openness, safety, caring and recovery. The environment of the new unit needs to be comfortable, therapeutic and stimulating.

In order to inform the final design patient stories were used to understand the patient experience of in-patient care. Service users co-present consultation and question and answer sessions and are able to provide information to the Service user newsletter. Service users sit on the project team, provide feedback to Community Health Council (CHC) and are involved in independent reviews of the project.

There have been changes to the design due to service user feedback, and those involved have more understanding of the compromises that take place in designing environments.

Most of the working groups are exploring the issues raised by service users to ensure the University Hospital Llandough (UHL) site is integrated and offers opportunities for patients.

Equality issues have also been examined. For example, the new entrance plaza will now serve the whole hospital rather than solely the mental health unit, meaning all patients enter the hospital on an equal basis.

A number of organisations using co-design as an approach to address social challenges are listed at the end of this guide.

At the design stage there also needs to be clarity about the outcomes being sought. The Talking Points - Personal Outcomes³⁷ model is one way of achieving this.

Talking Points combines user and carer involvement with an outcomes approach to planning, delivering, evaluating and improving services. This approach has been developed by the Joint Improvement Team in Scotland which is a strategic improvement partnership between the Scottish Government, NHS Scotland, the Third Sector, independent organisations, and housing organisations.

Outcomes are defined as what matters to people using services, as well as the end result or impact of activities, and can be used to both plan and evaluate activity. Personal outcomes are distinct from outcomes for services, organisations or indeed nations. In taking forward an outcomes focused approach it is vital that outcomes for individuals are the primary driver for activity.

There are three components to the Talking Points approach which together aim to put the outcomes important to people using services at the heart of those services. So focusing on outcomes means:

- Engaging with the person to identify what is important to them in life and what they need to change, and planning how everyone is going to work together to achieve those outcomes. This means that the conversation is important, to work out what is important to the person and what needs to change. Often, being listened to and having the chance to think about their life from a different point of view will make a difference to people.
- Recording the outcomes in a support plan which is shared by everyone involved means that later on, the person, their family and staff can get together to check whether the outcomes have been achieved or if the plan needs to change. The outcomes can be measured for the person - 'did we achieve what we hoped'. By looking at lots of support plans and reviews, outcomes can be measured for the service - 'what is working well in our service and what needs to change.'
- Using the information that has been recorded about outcomes to ensure that what matters to people who use services influences service planning, commissioning and improvements.

Co-design can also work in a group context, assisted by creative thinking approaches and democratic decision making techniques. A wide range of Creative Problem Solving tools and techniques are available as free downloads: a good starting point is www.mindtools.com, which lists options under specific headings including 'decision making', 'communication skills' and 'team management'. Key features are to be non-judgmental during the creative phase and accept that all ideas are potentially useful, and to give everyone an equal opportunity to contribute.

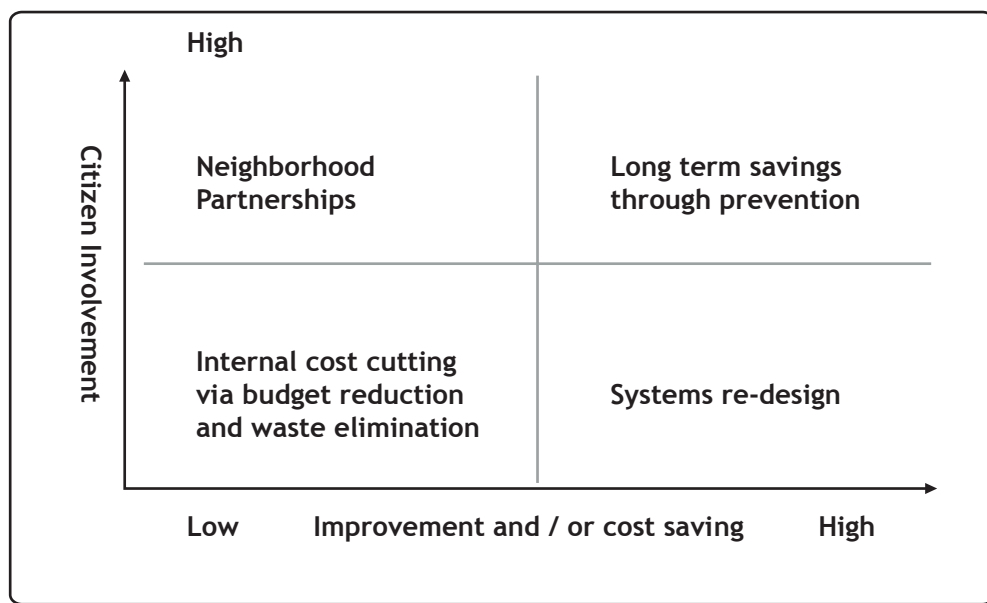
The term Creative Evaluation covers a range of innovative approaches to decision-making which have certain features in common. They are intended to prioritise rather than exclude, to extend the criteria for decision-making, to increase collective ownership of the outcome, and to encourage shared responsibility for progress.

Mind Tools is a good source (see above), as is www.debonothinkingsystems.com/tools. Perry Walker's Crowd Wise is an excellent tool for democratic decision-making with large groups. It can be used at face-to-face meetings/events or electronically via a free download at www.crowd-wise.org

Sometimes it can be challenging to prioritise the preferred solution from list of possibilities. Below is an example of a simple technique to help to distinguish priorities. 'Quick wins' (high improvement, high citizen involvement) are clearly identified and would be the best starting point.

Successes in these areas could act as a catalyst to future work, by attracting people who want to be involved and to be associated with success. On the other hand it will also highlight low improvement, high citizen involvement actions that should be avoided. These actions may be time consuming and heavily energy and resource dependant while producing little or no improvement.

Example of a Co-production Priority Matrix³⁸



Step 5: Co-delivery - Building execution

Transformational co-production requires new approaches to service delivery, using all available assets. This relies on the use of peer support networks, development of supportive systems, communication loops at all levels and for all stakeholders and the maintenance of creative innovation and flexibility.

To take a transformative approach to delivery, a whole system approach should be used. Whole systems approaches involve identifying the various components of a system and assessing the nature of the links and relationships between each of them³⁹.

A whole systems approach means that:

- Organisations must change at every level, from senior management to frontline staff, if they want to achieve meaningful participation.
- Participation should become part of daily practice, not a one-off activity.
- Participation operates at different levels.
- The co-produced change needs to become embedded as ‘the way we do things’ rather than as an optional extra or irrelevant tick box.

One useful approach is Action Learning⁴⁰, a successful problem-solving methodology for small groups which captures the best thinking of all group members and enriches their abilities to tackle important issues, take action and learn from the effects of that action. It encourages people to focus on what they can influence rather than what they can’t.

Action learning is a process of inquiry, beginning with the experience of not knowing ‘what to do next’, and finding that answers are not available through current expertise. When expertise fails to provide an answer, collaborative inquiry with fellow learners who are undergoing the same questioning experience is always available. To be effective, this learning partnership needs to be both supportive and at the same time challenging and questioning. Such partnerships actually create themselves when different people with different ideas engage whole-heartedly with each other to resolve each others’ problems.

In a nutshell action learning occurs when a group of 5 to 8 people meet for 2 to 3 hours on a regular basis. Working with a skilled action learning facilitator, and keeping within a specific set of guidelines, groups get to the heart of difficult problems and resolve real issues. There is no real meaningful learning unless action occurs.

When members of a project, initiative, community, or organisation apply this formula of focusing, reflection and action, to the principles of co-production they can witness extraordinary results.

Case study

The home renal dialysis service in Abertawe Bro Morgannwg University Health Board

The development of a night time home renal dialysis service for patients with chronic kidney disease has reduced the need to travel to hospital for treatment and made a big difference to patients' quality of life.

Nocturnal haemodialysis is well established worldwide, but there are only limited programmes in the UK.

The first nocturnal service at home was piloted by an experienced home dialysis patient in Swansea who had been receiving treatment for five years.

The pilot was a success with benefits including more independence and flexibility around the treatment and a higher dialysis dose achieved while asleep.

Hayleigh Isaac, 25, from Swansea, has had kidney failure for 14 years and said the new service has improved not just her life but that of her family too.

She said, "I have a three year old son and was finding it difficult because before this service I had to travel to the hospital for dialysis three times a week. Now that I can have dialysis at home while I'm asleep it means I'm there for my son, my partner can now do more work and I'm enrolling on a college course because I now have the time."

Ten patients have now been trained to use home nocturnal haemodialysis making the programme in the health board the biggest in the UK.

Step 6 - Co-evaluation - Measure the impact of change

The process of evaluating progress in a co-productive way relies on similar approaches to those which were used to develop the solution. It will include evaluation of progress towards personal outcomes, assessment of the quality of relationships, evidence of mutuality and reciprocity and a review of the learning.

A key feature however is the need to measure the impact of the changes against the priorities set during the initial stages.

We must measure how effective the process has been against what truly matters to the stakeholders. For example a change in care delivery for elderly people should be measured against the actual changes to older people's life.

Many of the scoping tools described in the 'Define and share assets - What can be built on?' section will be valuable evaluation tools and a combination of those can be a great solution to measure impact.

Clear measurement strategies must to be considered and agreed from the onset of the project. Measuring the impact of any change should not be an afterthought but an integral part of the process.

Staff working in NHS Wales organisations can draw on the advice of the Improving Quality Together (IQT) Lead in their organisation will be valuable in developing the measurement strategy. These highly skilled individuals are able to help and advise NHS Wales staff on all aspects of improvement methodology.

4. Co-creating health

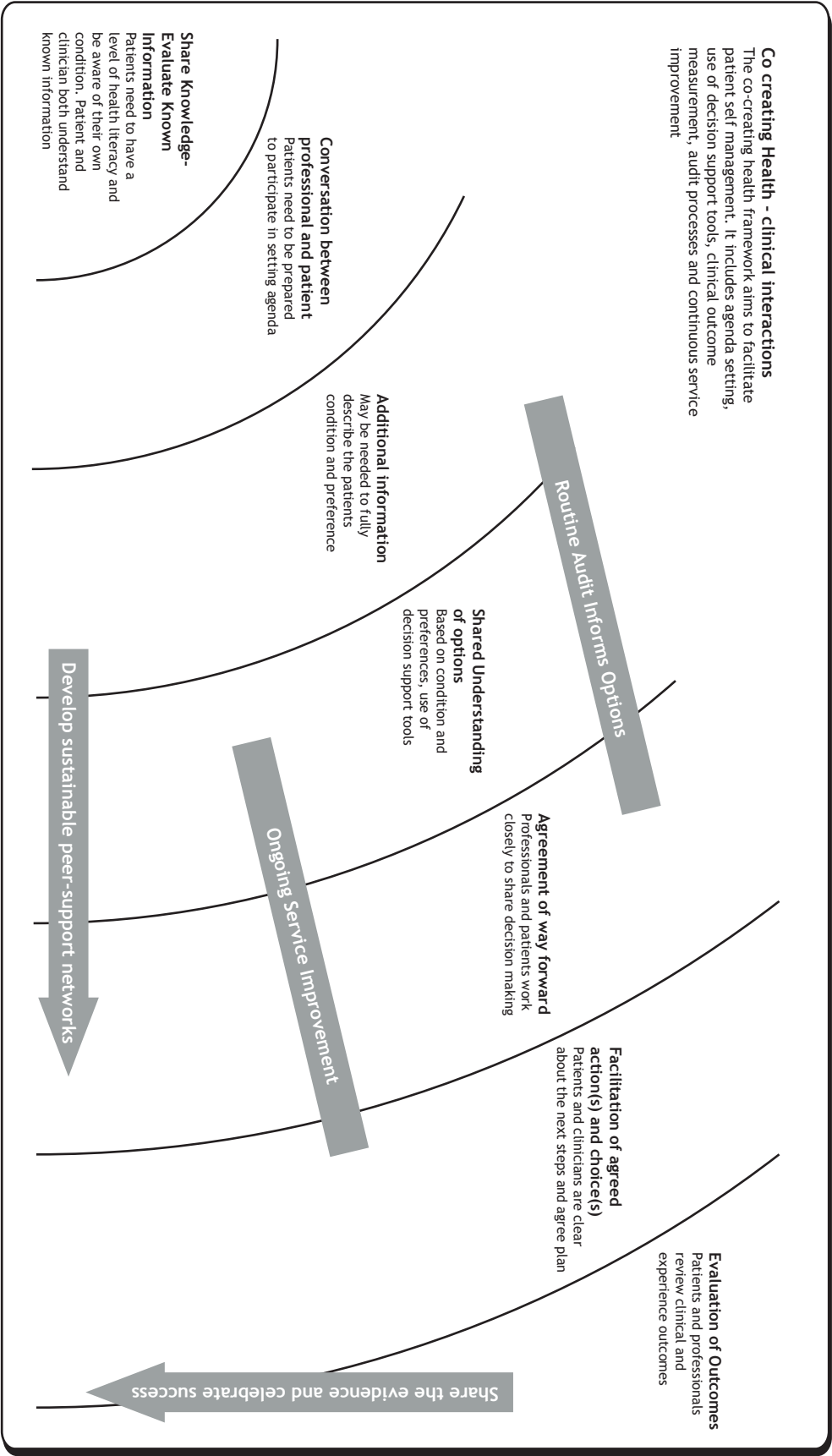
Co-creating health describes a framework in which clinicians and patients interact together. It is especially relevant in the care of the significant number of people in Wales with a long term condition such as diabetes, depression, heart disease or arthritis.

We know that people with a long term condition can improve their health and have a better quality of life by taking responsibility for their own health, care and wellbeing. But to do this people need self-management skills and access to information about their condition. They also need skilled coaching support from their clinicians, and healthcare systems.

From 2007 to 2012 the Health Foundation funded a large-scale demonstration programme called Co-creating Health⁴¹. This programme aimed to embed self management support within mainstream health services across the UK and equip individuals and clinicians to work in partnership to achieve better outcomes. Co-creating Health focused on three equally important factors which determine how much individuals are able to play an active role in managing their own health:

- Giving people with long term conditions the skills, confidence and support to self manage.
- Helping clinicians develop the skills, knowledge and attitude to support and motivate people with long term conditions.
- Changing health systems so that they encourage and facilitate self management.

This section outlines a step wise process, based on work undertaken in Abertawe Bro Morgannwg University Health Board, and a range of tools that can be used at the frontline by health and social care professionals and teams to deliver person-centred care in the context of co-creating health.



Step 1: Share knowledge - Evaluate known information

At the start of the process there is a need for patients and clinicians to consider and evaluate what is known prior to their interaction. This step requires both patients and clinicians to know about the patient's medical history and have access to a shared source of information about clinical conditions.

An individual's level of understanding of their condition and health care provision should not be assumed - assumptions can be a significant barrier to fully involving patients. Healthcare professionals should aim to help empower people to take active responsibility for their own care, health and wellbeing.

One way in which people with long term conditions can be supported in understanding and self managing their condition is through self education programmes. The Education Programme for Patients (EPP) Cymru⁴² has been a leading provider of self-management education and support in Wales for nine years. Courses are run in each health board in Wales. 1,517 individuals in Wales completed an EPP course in 2012/13. The courses are led by volunteer tutors who themselves have long term conditions - true co-production.

Courses aim to support individuals with a chronic condition to develop skills to help them to manage their health and well being. Additionally, courses aim to give participants the confidence to take responsibility for their own care and make better use of health services, whilst also encouraging them to work in partnership with health and social care professionals. This in turn should improve the quality of life of individuals with a chronic condition and reduce pressure on NHS services.

There are a number of courses that are provided throughout Wales (with the exception of Powys);

- Chronic Disease Self Management Programme (CDSMP),
- Looking After Me (LAM) for carers.
- An on-line version of CDSMP
- Introduction to Self Management (ISM)
- A course for individuals with Chronic Obstructive Pulmonary Disease is being delivered in Hywel Dda Health Board and is available throughout Wales.

In some cases the individual may have communication difficulties brought about by their condition. In this case clinicians should ensure that they are as aware of the patient's background and preferences as possible. The 'This is Me Leaflet' was designed by the Alzheimer's Society for those affected by dementia, to help professionals build a better understanding of the person in their care.

This simple tool aims to record personal information and preferences. It should be completed by the patient or someone close to them and should accompany the patients throughout their care journey to help smooth transitions and changes that could otherwise be very confusing and frightening for someone with dementia.

Health care professionals should actively encourage patients and carers to consider completing such a form which can be accessed from the Alzheimer's society website⁴³ in English and Welsh.

Such tools could also be applicable after some modification and testing to other settings such as children services, learning disabilities, and complex care cases.

Step 2 Have conversations, build partnerships - Health interactions

The second step is for the individual and the clinician to begin their interaction within an agenda set by the patient. This can be face to face, but may also be conducted over the telephone or through a telemedicine discussion.

Within this phase, there must be mutual recognition of three sources of expertise:

- The individual brings expertise and knowledge about their own health, social circumstances, personal preferences, attitude to risk and values.
- The health care professional brings expert knowledge of human function, interventions, their own ability to resolve issues and understanding of navigating through complex health services.
- Information and knowledge such as relevant clinical outcomes, patient-reported outcome measures, patient-reported experience measures, evidence-based research and appropriate literature describing the patient's conditions.

This step starts to build a meaningful, possibly long term, partnership between clinicians and individuals. The aim of this should be a mutual wish to impact positively on the person's health and wellbeing within the context of continuous and consistent relationship. At the end of this phase there should be a jointly agreed, and understood, plan for the next steps which may include the need for additional information, tests or reflection to enable a management plan to be developed and agreed.

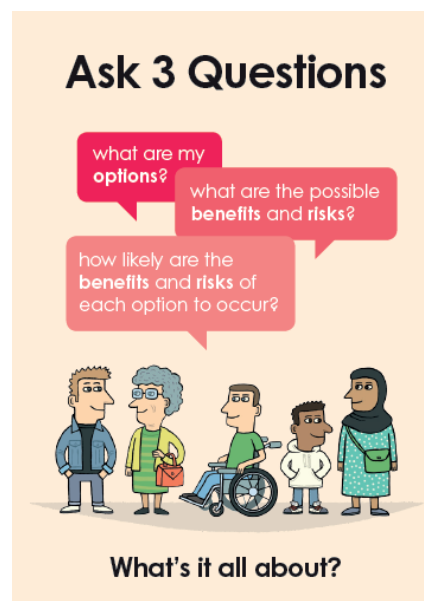
In order for this to happen the patient needs to be ready to engage in a collaborative way. Many patients may not be prepared for this type of interaction. There are several ways in which patients can be encouraged and supported to discuss treatment risk, benefits and options and their own preferences.

The 'Ask 3'⁴⁴ Campaign was developed as part of the MAGIC shared decision making programme⁴⁵ to support patients who face more than one treatment option to gather relevant information during a consultation.

Patients are encouraged to ask:

- What are my options?
- What are the possible benefits and risks of those options?
- How likely are the possible benefits and risks of each option to occur?

By encouraging a discussion based on these three questions the patient can begin to consider the answer to a fourth question, 'What is the best option for me?'



Case study

Ask 3 Questions in primary care

As part of the introduction of shared decision making, the Practice of Health in Barry tried to raise patients' awareness through a marketing campaign with posters and flyers based on Ask 3 questions. The campaign was designed to support patients to become more involved in their healthcare decisions by encouraging them to get the answers to the 3 simple questions when faced with a choice between options.

While some patients were aware of the poster campaign, the staff felt that many patients still did not understand what shared decision making meant for them. The practice manager said: 'We asked quite a few patients about the poster campaign, and most of them did not understand what the three questions were. They were keen to say that they want the doctor to ask these questions.'

However, when the Ask 3 Questions principles were explained to patients, they reported having a much better understanding of what shared decision making was and felt that it was a good idea.

The team recognised that simply providing information was not enough. Patients needed to have shared decision making explained to them and be actively encouraged to ask questions about their care options - to be 'given permission' to ask about treatment options.

Often, even when a meaningful discussion has taken place patients find that they can not recall key aspects of the consultation. 'Teach-back'⁴⁶ is a way to confirm professional staff have explained to the patient what they need to know in a manner that the patient understands.

The technique is a simple way to ask the patient to repeat or show the information or skill that has just been imparted. This is particularly important considering that research,^{47 48} shows that patients remember and understand less than half of what healthcare professionals explain.

The Teach Back technique requires asking patients to use their own words (not yes/no) to repeat the health information that have just been given during the consultation. It is very important that this is done in a way that is not patronising or shaming.

To make the most of the Teach Back technique it should be combined with effective communication techniques such as using plain language, breaking the message into 'chunks' and use of Teach Back after each 'chunk' before moving on to the next section.

Some examples of how to ask the patients to repeat the message are:

- 'We've talked a lot about your condition today, and I want to make sure I have explained things clearly. Could you help me review our discussion by explaining how you will be able to manage your condition when you go home?'
- 'I want to make sure I have explained how to take the new medication correctly. Can you tell me/show me how you're going to take it?'

Step 3: Additional information

This step may include the results of diagnostic tests and reviewing of knowledge by either patient or clinician. It could also be giving patients the opportunity to discuss issues with friends, family or the wider community. Patient may also value spending time considering their own attitudes to risk or possible interventions.

The purpose of this stage is to ensure that enough knowledge is available to fully explore the patient's physical, emotional and social condition together with their personal goals.

Step 4: Shared understanding of options

This step requires the patient and the clinician to discuss their shared knowledge and come to a mutual agreement about the nature and extent of the physical, emotional and social issues impacting on the individual.

Effective communication and active listening skills will be an essential part of this interaction. One challenge is often how to present often complex information about choices, risks and benefits in a way that enables individuals to be fully involved in making decisions. Many Decision aids have been developed, however these are often detailed and only available online or through a medium such as a DVD. These are of value, however in many clinical settings a simpler approach is desirable.

Option Grids⁴⁹ are brief easy-to-read tools made to help patients and clinicians talk about difficult decisions and are designed to help compare reasonable treatment or screening options. This is achieved by using a grid, where the questions that patients frequently ask are in the rows and the answers relevant to each option are in the columns.

Option grids have been developed for a range of conditions and can be accessed through the Option Grid web site. Grids are ideally developed in a co-productive manner with patients identifying those "frequently asked questions" that would help them decide the best option for them. An option grid for breast cancer is shown below.

Breast Cancer Surgery

Use this grid to help you and your clinician decide whether to have mastectomy or lumpectomy with radiotherapy

Frequently asked questions	Lumpectomy with Radiotherapy	Mastectomy
Which surgery is best for long term survival?	There is no difference between surgery options .	There is no difference between surgery options.
What are the chances of cancer coming back in the breast?	Breast cancer will come back in the breast in about 10 in 100 women in the 10 years after a lumpectomy.	Breast cancer will come back in the area of the scar in about 5 in 100 women in the 10 years after a mastectomy.
What is removed?	The cancer lump is removed with a margin of tissue.	The whole breast is removed.
Will I need more than one operation on the breast?	Possibly, if cancer cells remain in the breast after the lumpectomy. This can occur in up to 5 in 100 women.	No, unless you choose breast reconstruction.
How long will it take to recover?	Most women are home 24 hours after surgery.	Most women are home 2-3 days after surgery.
Will I need radiotherapy?	Yes, for up to 6 weeks after surgery.	Unlikely, radiotherapy is not routine after mastectomy.
Will I need to have my lymph glands removed?	Some or all of the lymph glands in the armpit are usually removed.	Some or all of the lymph glands in the armpit are usually removed.
Will I need Chemotherapy?	Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.	Yes, you may be offered chemotherapy as well, usually given after surgery and before radiotherapy.
Will I lose my hair?	Hair loss is common after chemotherapy.	Hair loss is common after chemotherapy.

Case study

Option Grids

The development process for Option Grids involves the clinical team and patients:

- Identifying the need for a short decision support tool.
- Establishing an editorial team.
- Developing frequently asked questions.
- Reviewing the evidence.
- Populating the grid.
- Testing it out in practice using the Model for Improvement.

In Cardiff and Vale University Health Board, option grids have been shown to:

- Standardise the provision of information across team members:
“We have always done this - give information to patients - but now it’s in a more organised fashion... Everybody will use the same Grid, so all the patients will have the same information.”
(Surgeon, multi-disciplinary head and neck cancer team)
- Help patients to visualise the difference between treatment options:
“... patients can now actually see for themselves the actual differences in the choices they have, on a piece of paper. Previously they had to imagine it. Now they can actually see it on a piece of paper ... This visualisation ... makes things easier for them to understand.” (breast surgeon, multidisciplinary breast cancer team)
- Help to operationalise the shared decision making process:
“I thought this [using the Option Grid] is going to take a lot longer in the clinic. It doesn’t. You are actually doing it at the same time as you are talking, and I don’t think it takes any longer at all. The parents ask you a few more questions, but that’s what they should be doing anyhow. It’s not ‘them and us’ anymore, we’re making a decision between us. It feels like that now” (Nurse, ENT clinic)

Step 5: Agreement of the way forward

In this phase patients and clinicians discuss the preference-sensitive choices available to the patient to make an informed decision based on evidence, and take into account their preferences.

The clinician can also look for triggers from the patient to potentially engage in ‘brief interventions’ around health behaviours such as referral to smoking

cessation, national exercise referral scheme, weight reduction programmes or alcohol reduction programmes. The patient and clinician should jointly agree a management plan with appropriate goals and timescales. This plan should ideally be based on a shared decision.

Shared decision making⁵⁰ is an approach where clinicians and patients make decisions together using the best available evidence. Patients are encouraged to think about the available screening, treatment, or management options and the likely benefits and harms of each so that they can communicate their preferences and help select the best course of action for them. Shared decision making respects patient autonomy and promotes patient engagement. It involves the provision of evidence-based information about options, outcomes and uncertainties, together with decision support counselling and systems for recording and implementing patients' treatment preferences.

Shared decision making clearly means involving patients as equal partners in their healthcare. It shares the same philosophy as self-management support, which takes as its starting point the understanding that all patients with chronic illness make decisions and engage in behaviours that affect their health. Self-management support acknowledges that people are expert in their experience of their own condition and recognises that health outcomes depend to a significant degree on the day to day decisions and activities that people with chronic conditions and their families make and undertake to manage their condition.

Through the use of all tools described in this and the previous steps (e.g. Ask 3 Questions, Options grids) the patient and clinicians can work as partners to identify the best option available taking into consideration all available information. However just using the tools described will not provide true shared decision making. What is fundamental is a shift in relationship between all parties involved to work jointly as equal partners to achieve optimum health and well being for the patient.

Step 6: Facilitation of agreed action(s) and choice(s)

When decisions have been made, the clinician facilitates the agreed management plan, either by personally carrying out an intervention, agreeing another time for this to be carried out, making the appropriate referral, or informing the patient of the mechanism that would allow the patient to interact with them as required. If there is a delay between the shared decision being made and the intervention/action taking place effective communication should be maintained throughout and the processes clearly explained.

In mental health services there are statutory requirements for mental health service users to have care and treatment plans. Wherever possible these plans should be made in partnerships with those accessing mental health services and, where appropriate, their families and carers.

To achieve this goal, peer support, advocacy, care co-ordinators and sometimes training is offered to ensure all parties can work in partnership to ensure care and treatment plans are produced with the full and active engagement of service users and their families.

Similar plans can be used outside mental health to identify daily achievable goals in partnership with patients. These goals could be simple tasks such as going for a short walk unaided, or sitting on a chair instead of the bed for a defined period of time. They should be decided in partnership with health and social care staff, who will then be responsible to support the individual in achieving their goal.

Patients often need information, written and online, to support them self manage. It is important that this information is written in a way that facilitates understanding and that it answers the type of questions that people want the answers to.

Case study

Patient manual for opioid use

A new patient information manual is available for palliative care patients who are being offered strong opioids for pain. It was written and co-ordinated under the supervision of hospital consultant Dr. Mark Taubert, clinical lead for palliative care at Velindre Cancer Centre in Cardiff, but has been developed with extensive feedback from patients and relatives over a period of nearly two years.

Opioids are offered frequently in palliative care to help reduce pain and breathlessness. Information on opioids in palliative care tends to be verbal and is not always backed up by written guidance. However, these medicines have varying, sometimes complex dosing regimens. They can carry a lot of stigma and are also feared by some people.

The manual started off as a two page document, but grew in response to questions patients and carers had when they were being offered strong opioids for the first time. Often doctors and nurses focused more on the side-effect issues and how to take these medicines, but patients said they were also keen on information regarding driving or, for instance, whether it was possible to have a drink of alcohol when taking this medication.

Patients and carers who helped produce Welsh and Polish language versions, contributed even more to the overall goal of making the information easy to understand.

It uses a question-and-answer model, which patients and carers can dip in and out of at a time that suits them. There is a diary at the end that they can fill in and bring to the prescribers attention, for instance to show how many doses of fast-acting breakthrough opioid they have taken in the last few days.

The Opioid Patient Manual has been shown to support a significant improvement in patients' understanding of these medicines.

Step 7: Evaluation of outcomes

This step sees the patient and clinician working together to evaluate the impact of the intervention/action against the outcomes and goals agreed during previous steps.

The evaluation should look further than the clinical outcome, it should also take into account the impact on what was identified as being of primary concern or importance to the patient and their family or carer.

The patient and clinician can review the outcomes of the intervention using post-intervention clinical outcomes PROMs (Patient Reported Outcome Measures) or PREMs (Patient Reported Experience Measures) to decide whether the goals of the intervention or the change towards health behaviours has been successful for the individual patient. If this is not the case, and further improvement is possible, then the patient and clinician would discuss further iterations of similar or different interventions or health behaviour changes.

PROMs ask patients about their health and quality of life before they have an operation or intervention and about their health and the effectiveness afterwards. PREMs are the self-reported experiences of patients as they use health services. Ideally, a triangulated view would be based on a combination of Quality of Life (reported through EQ5D or similar), a PROM and a PREM.

This step is repeated until there is agreement between patient and clinician not to pursue further intervention or changes in health behaviour, although further interaction is possible to address different physical, emotional or social concerns.

Step 8: Clinical audit

The eighth step is clinical audit where the clinician routinely audits both clinical outcomes, PROMs and PREMs to determine whether interventions are resulting in appropriate improvement for the population of patients served.

Results of clinical audit should be routinely discussed with colleagues, compared with benchmarks and used to improve the service delivered and inform prospective preference-sensitive choices of patients. The use of information from complaints, incidents, claims and sentinel events such as harm or mortality reviews should also inform a clinician's practice.

Step 9: Continuous improvement

The ninth and final step in the model is service improvement activity or action research using the Model for Improvement and small size PDSA cycles that introduce novel aspects of service provision, with the intention of delivering improved service provision. This can be linked back to the co-production of services.

5. Getting Started

“The need to rethink public services in fundamental and radical ways is unarguable.⁵¹”

Our existing assets and resources in terms of community and partner support are considerable; we also have high levels of buy-in from staff who share the values and aspirations of co-production. However, often healthcare tends to work in isolation, focusing only on the medical model of health and disability, and frequently driven by systems and targets rather than by the broader outcomes that matter more to our service users.

Co-production requires a more open and holistic approach. We need to build genuine partnerships with citizens, their communities, and the third-sector and local organisations who support them. We need to incentivise and empower all participants (professionals and service users) to work with us on this transformation. That is likely to require new skills, particularly in relation to engagement, creative problem-solving, co-design and creative evaluation.

Training and support

A wealth of experience exists in third-sector and community organisations, especially in relation to engaging with communities and individuals. Training programmes may not always be given a ‘co-production’ label, but engagement and partnership working are at the heart of a successful co-production initiative. The expertise of these frontline organisations is invaluable and collaboration is strongly recommended.

The NHS Wales Partnership and Integration Team and the Welsh Council for Voluntary Action (www.wcva.org.uk) can provide valuable support, guidance and information.

In addition, organisations offering specific co-production training include:

Co-production Training UK

www.coproductiontraining.com

The training and consultancy arm of the co-production campaign organisation Co-production Wales / All in This Together. They offer a comprehensive training programme for leaders, managers and frontline staff, alongside consultancy and introductory presentations. Wales-based.

Empower

www.empowersvs.co.uk/index.php/training/all-course-details/co-production-training-course

Focus is on supporting the Voluntary Sector. They offer a wide range of training programmes (many available in Welsh) including: Co-production; a framework for delivery through effective partnerships. Wales-based.

Working With Not To

www.scarletdt.com/wp_WWNT/services/training

Co-production training, events and facilitation. Wales-based.

Governance International

www.govint.org/our-services/co-production

Governance International delivers tools, training, research and peer learning to transform public services based on international good practice.

Helen Sanderson Associates

www.helensandersonassociates.co.uk

Focus is on working with people to achieve person-centred change and social justice. Range of co-production related training courses available.

Organisations using co-design in health and social care

The Design Council: Towards a (short) definition of co-design

www.designcouncil.org.uk

MaRS (www.marsdd.com) in Canada has produced a summary of worldwide activity.

www.marsdd.com/wp-content/uploads/2012/02/MaRSReport-Labs-designing-the-future_2012.pdf

Other organizations include

The Innovation Unit, UK, www.innovationunit.org

Ideo, USA Ideo.org,

Mindlab, Denmark, www.mind-lab.dk/en

TACSI, Australia www.tacsi.org.au

Reading List

There is a wealth of information online on co-production theory, practice and application in health and social care.

The Health Foundation (www.health.org.uk) is an independent charity working to improve the quality of healthcare in the UK. It funds a number of programmes supporting people to make informed decisions about and successfully manage their own health and care. Relevant publications include:

- Realpe, A., & Wallace, L. (2010) What is co-production? London: Health Foundation
- Wallace, L. et al (2012) Co-creating Health: An independent evaluation of the Health Foundation's Co-creating Health improvement programme. London: Health Foundation 2012
- Newbronner, L. et al (2013) Sustaining and spreading self-management support: Lessons from Co-creating Health phase 2. London: Health Foundation

Nesta is an independent charity with a mission to help people and organisations bring great ideas to life. Their People Powered Health programme was designed to support the design and delivery of innovative services for people living with long term health conditions. They have published a number of guides based on this work:

[By Us, For Us: The power of co-design and co-delivery](#)

[Networks That Work: Partnerships for integrated care and services](#)

[People Helping People: peer support that changes lives](#)

[Redefining Consultations: changing the relationships at the heart of health](#)

[People Powered Commissioning: Embedding innovation in practice](#)

[Health For People, By People and With People](#)

[The Business Case for People Powered Health](#)

The Social Care Institute for Excellence (SCIE) is an independent charity working with adults, families and children's social care and social work services across the UK. It works closely with related services such as health care and housing. It gathers and analyses knowledge about what works and translates that knowledge into practical resources, learning materials and services including training and consultancy

The Co-production Network is a key part of SCIE's co-production strategy and their web site (www.scie.org.uk/index.aspx) contains a range of information on co-production including Co-production in social care: What it is and how to do it, SCIE Guide 51.

The Joint Improvement Team in Scotland (JITS) is a strategic improvement partnership between the Scottish Government, NHS Scotland, Convention of Scottish Local Authorities (CoSLA), Third Sector, independent, and housing organisations. JITS is a strong advocate of co-production and has published:

Loeffler, E. et al (eds) (2012) Co-production in health and social care: What it is and how to do it. Birmingham: Governance UK

The University of Birmingham has also published:

Durose, C. et al (2013) *Transforming local public services through co-production*

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