Co-producing with carers in health settings: A co-production toolkit for professionals working in and with the health sector

This toolkit is available in Welsh and English. The follow-up / further reading suggestions link to content that is external to the toolkit. Where this is available bilingually, the link will take you to the appropriate language. Where the external content is only available in one language, this is noted.

In co-production, professionals come together with service users and carers to combine their professional and lived experience, and design solutions that improve services and communities. People’s involvement in co-production offers very tangible benefits, both for the service users and carers, and for the professional teams who support them.

In Wales, the Social Services and Well-being Act, the Well-being of Future Generations Act, and the Health and Social Care (Quality and Engagement) Act, along with the programme for government and the government plan for health and social care, all set a duty on public bodies and boards to involve citizens’ voices in the design and delivery of services.

While there is an increasing focus on co-production through legislation and statutory duties, we know that it still feels like a vague and risky undertaking for many, and at the time of writing it is widely underutilised - especially in the health sector which is the focus of the Carer Aware programme.

As a result, services are still trying to meet increasing demand with shrinking budgets, which leads to staffing challenges, delays in support provision, and the narrowing of eligibility criteria to focus on the most severe and urgent needs. Taking a co-production approach would help them to make better use of shared resources, reduce duplication and waste, and leverage the assets and resources of patients, service users and carers - leading to person-centred services, improved outcomes and reduced demand on services through prevention.
We have compiled this toolkit to support healthcare professionals on their co-production journey, along with their colleagues in other statutory organisations, partners in the third sector, and service users and carers who are travelling the co-production path with them.

Our intention is to demystify the concept, offer examples of practice that will inspire and show what’s possible, and offer a set of tools and thinking steps to draw on along the way.

Part 1. Understanding co-production.........................................................3
   1.1. If you have 10 minutes........................................................................3
   1.2. If you have 30 minutes.......................................................................5
   1.3. If you have an hour.........................................................................13
   1.4. As a follow-up................................................................................13
Part 2. Examples of co-production in action.............................................15
   2.1. Pembrokeshire Dementia Support Carers’ Card...........................15
   2.2. Maggie’s Cancer Centre, Swansea...................................................15
   2.3. Gwynedd Council Direct Payments.................................................16
   2.4. North Wales Cancer Network Patient Forum (CPF) Website..........16
   2.5. Drive New Staff Induction Process..................................................17
   2.6. Further reading...............................................................................18
   2.7. As a follow-up...............................................................................18
Part 3. Doing co-production......................................................................19
   3.1. Individual co-production..................................................................19
   3.2. Group co-production......................................................................21
   3.3. Strategic co-production.................................................................30
   3.4. Building your co-production plan.....................................................32
   3.5. As a follow-up...............................................................................32
Part 4. Co-producing with carers.............................................................34
   4.1. What we mean by “carers”..............................................................34
   4.2. How to co-produce with carers.......................................................34
   4.3. What carers say.............................................................................35
   4.4. How to better meet carers’ needs in services...............................35
Part 5. Next steps and further support....................................................37
   5.1. A few thoughts to conclude............................................................37
   5.2. Further support.............................................................................37
Part 1. Understanding co-production

There are a few key concepts that contribute to a rounded understanding of co-production:

- the definition and the 5 values that underpin the approach;
- where co-production sits along the spectrum of engagement approaches;
- when co-production is the most relevant approach (to address complex challenges).

In this section we share the general framework of co-production, and you will find case studies in Part 2.

1.1. If you have 10 minutes

Check out these summary factsheets.

Understanding co-production: What is co-production?

**Definition of co-production**

Co-production (of public services) means that people who provide and deliver services, and people who access and receive services, share power and responsibility, and work together for mutual benefit in equal, reciprocal and caring relationships.

It enables:
- people to access relevant and meaningful support when they need it;
- services to be effective and make a positive difference in people’s lives; and
- people, services and communities to become more effective agents of change.

**5 values of co-production**

1. Value all participants, and build on their strengths.
2. Develop networks across silos.
3. Do what matters for the people involved.
4. Build relationships of trust and share power.
5. People can be change makers, and organisations become enablers.
**Understanding co-production:**

A spectrum of engagement

<table>
<thead>
<tr>
<th>doing to</th>
<th>doing for</th>
<th>doing with</th>
</tr>
</thead>
<tbody>
<tr>
<td>coercion protection</td>
<td><em>e.g.</em> smoking cessation programmes</td>
<td><em>e.g.</em> drop-in events, focus groups</td>
</tr>
<tr>
<td>education persuasion</td>
<td><em>e.g.</em> Council website info on bin collections</td>
<td><em>e.g.</em> person-centred care, shared decision making</td>
</tr>
<tr>
<td><em>We have a duty to act to ensure people’s safety.</em></td>
<td><em>We provide information where /when /how people need it.</em></td>
<td><em>We listen to people’s lived experience, to inform our thinking and decisions.</em></td>
</tr>
<tr>
<td><em>The organisation has the knowledge.</em> The organisation makes the decisions. The organisation enforces the decisions.*</td>
<td><em>The organisation listens to people’s knowledge.</em> The organisation makes the decisions. The organisation enacts the decisions.*</td>
<td><em>The organisation and the people listen to each other’s knowledge.</em> The organisation and the people make decisions together. The organisation and the people both take actions on the decisions.*</td>
</tr>
</tbody>
</table>

To identify which approach is occurring, ask yourself:
- **Who holds the knowledge:** the organisation, the people, or both?
- **Who makes the decisions:** the organisation, the people, or both?
- **Who enacts the decisions:** the organisation, the people, or both?

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**Understanding co-production:**

Complexity theory

<table>
<thead>
<tr>
<th>simple</th>
<th>complicated</th>
<th>complex</th>
<th>chaotic</th>
</tr>
</thead>
<tbody>
<tr>
<td>documented process</td>
<td>documented planning training / specific skills</td>
<td>no documented process no definitive answer networked adaptive systems</td>
<td>no clear path to the end rapid adaptation distributed &amp; local action</td>
</tr>
<tr>
<td>little / no training linear &amp; predictable</td>
<td>linear &amp; predictable</td>
<td>good / emergent / honest practice</td>
<td>new patterns appear</td>
</tr>
<tr>
<td><strong>best practice</strong></td>
<td><strong>best practice</strong></td>
<td><strong>call in the specialists</strong></td>
<td>gather the people to co-produce!</td>
</tr>
</tbody>
</table>

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4
**Understanding co-production: The co-production imperative**


**1.2. If you have 30 minutes**

Read through this essay which is based on a conversation with Noreen Blanluet from the Co-production Network for Wales, and covers the four topics above.

**Understanding co-production**

*Reading time: 30 minutes*

**a) What is co-production?**

*Can we start with what we mean by co-production?*

This is our official definition: co-production is an asset-based approach to public services, that enables people providing and people receiving services to share power and responsibility, and to work together in equal, reciprocal and caring relationships. It creates opportunities for people to access support when they need it, and to contribute to social change.

In a nutshell, co-production is when we’ve got citizens and professionals together at the table having conversations - usually about what a service could look like - but it fits into
a broader philosophical picture: of being active citizens and participating in democracy and shaping our society, not just the services that support us.

If you have just citizens designing things together without the involvement of professionals, it's called community organising or community-led action. And that's great, it's really important. It happened loads with all the mutual aid groups and local volunteering during the Covid pandemic. It's awesome... It's just not co-production. (I'm going to be pernickety about the terms of this stage and then we'll expand from there.)

If you have organisations involving other organisations, it’s collaboration or partnership working. It's brilliant. And it's important... but if you don't have the citizens, the people whose lives you're going to touch through the service, being part of the conversation, then it's not co-production. Collaboration is really important because good collaboration leads to great co-production. It's very necessary. But I just want to be clear, if you don't have citizens at the table, it's not co-production.

There's an expression in community organising which says “if you're not at the table, then you're probably on the menu”. And that's what we're trying to avoid with co-production: we are making sure that people who have an investment in this, who are stakeholders in this (whether the professionals or the citizens) should be part of the conversation.

Now, this is the “pure” definition of co-production. In practice, you will probably be dancing between all of them: doing some co-production as well as some collaboration, and letting the community get on with community organising for other things.

Okay, so how do we go about doing co-production then?

I wish I could give you a recipe, a 12 step checklist to do co-production with. Unfortunately I cannot, because it's based on a set of values. But what I can do is tell you about these five values and show you how, if you keep coming back to those and bear them in mind at all times, then you can't go far wrong on your co-production journey.

(And I should add: co-production is a journey. It's never going to be black or white, you've “done co-production” or you “haven't done co-production”. When you've done some co-production - and even if it's maybe not as much as you had hoped - it all counts, because it sets a precedent which you can build on. So don't be discouraged if it's not as perfect as you'd like it to be straight away. Some co-production is better than none.)

The 5 values are:
- building on everyone's strengths,
- developing networks across silos,
- focusing on outcomes in people's lives,
- working on the basis of great relationships, and
- enabling people to be change makers.

First, building on everyone’s strengths
The place to start is with focusing on people. We always say that co-production is an “asset based” approach, and the assets are everything in people's lives that add value: knowledge, experience, things they can do or they know, etc. As well, we have the resources within communities: activities that already happen, tangible resources, buildings, parks, places to meet, sports equipment, allotments, things like that - all these are assets and resources that are a part of people's lives.

We start with the premise that the people we're working with, even though we might think of them as the people who need our support, also have richness and wisdom to offer us. It's a two way relationship. And so we have to begin with what's there for people and what they've already got, build on that.

There's a tendency to think that when people are in difficult situations and have complex issues going on in their lives, that actually, we can't ask them for anything. It's too much, it's rude or disrespectful to ask, or there is nothing that they can do. That's a huge wasted opportunity! Because if nothing else, people have the experience of using the service that we deliver. That wisdom in itself, that experience is valuable because they will see things from the other end of the telescope in a way that we never can see, even if it's just a knowledge of the service from the receiving end. That's valuable in itself. On top of that, they have knowledge of the condition they're living with (if it's a health condition), or the circumstances they're living in, and so on: they bring a wisdom that we can't have as professionals, unless we're in the exact same situation.

Something else to mention here is that it's not just about the people we support. If we want our teams and our frontline people to model these kinds of behaviours, and make the right decision at the right time with the people they support, we need to be able to demonstrate these behaviours within our organisations as well. It's impossible to be in a really controlling hierarchical organisation, with a narrow focus on key performance indicators, and then expect the people on the front line to be not focused on indicators, and willing to kind, and be flexible, and find the things that work in a very human way! We have to have that quality running all the way through our teams and organisations.

So that's the first thing: start with the people and start with what we all bring as our assets, ourselves, our teams and the people we support.

**Second, developing networks across silos**

The second value of co-production is about working across silos. As organisations, we are really good at working in silos, each department doing its own thing; and between organisations as well, we work in our own separate silos. Our organisation might be supporting the same people as another organisation, but we don't really talk because we keep ourselves to our separate areas completely. It's a huge wasted opportunity, because if we're not working well with the other professionals who support the same people that we support, then we're probably duplicating and wasting resources. We could do much more with what we have, if only we linked up and understood what the other is doing, and where our different strengths lie.

That is why good collaboration enables good co-production: if you're well linked up with
the other departments in your organisation, or with the other organisations that also support the same service users, then you'll get stronger results, and you'll also be able to do better co-production in terms of bringing in citizen voice.

The biggest silo of all, to break down or at least to start blurring the boundaries of, is the silo between professionals and citizens. If we're all working together to solve a challenge, for example to improve a service, then the service users and carers should be part of the team: they also care about having a service that works well, and they have unique knowledge to add to the picture. Making sure that they're as valued as the people who are part of it in their professional role is really important, so that everybody can bring their best to the conversation. So let's build networks, let's build teams that are pluri-disciplinary, and that bring in all the people who have a stake in the solution.

**Third, focusing on outcomes in people's lives**

The third principle is being outcomes focused, and focusing on what matters to all the people involved. And obviously, that means the people we support, so that means starting with conversations in which, rather than saying “What are you eligible for, which bits of the service do you fit into?” we consider the question “What does a good life look like for you? And how can we help you get there?”.

So far in public services, it's become the responsibility of the public service professionals to be all things to all people. But rather than relying on the professionals to do everything, there's a huge bunch of skills and resources within communities. If we leverage those in parallel with the skills of the professionals, we get a whole that is much bigger than the sum of its parts. So it's about that - it's not about saying "it's all up to the community now because we can't afford it", it's saying, there's bits that the community is amazing at doing, that the professional shouldn't be doing. You can't be paid to be somebody's friend, it would never be the same result as a genuine friendship. You can be paid to support and bring in the extra capacity or the extra skills that the friend circle can't bring in. So the combination of the two is much better than putting the weight of responsibility on each one separately.

But to do that, we've got to start with what matters to people: where they would like their life to be and what they would like it to look like.

And as an additional thought, this also applies to the people in our teams: what matters to us as professionals, as public servants or as civil servants? Why do we do the work that we do? What is the outcome for us in terms of doing good work, because nobody goes into the public service for the fame and the fortune - but we do this because we want to make a difference. And so what are going to be good outcomes for us, not just for the people we support? If we have good outcomes as professionals, we'll be in a better place to support the people that our service supports.

**Fourth, working on the basis of great relationships**

The fourth principle is about building trusted relationships. I keep talking about relationships all the time in the context of co-production, because they completely underpin what co-production is about. It's about being able to have the conversations
between people who care about the outcomes, and finding solutions together, and we need the trust in order to be able to do this work - to bring understanding, and the ability to work together and to design better solutions together, and creativity.

**Fifth, enabling people to be change makers**

And finally, the fifth principle is specifically for organisations: shifting from just delivering a service to actually enabling people to be the drivers of change. And it could be people in our teams, or it could be the patients and service users and carers that we support: how much can they actually bring their ideas to the table, and make those ideas happen with our support (as opposed to feeding in the ideas to us, and then we take it away and do it. I'll talk about that a bit more shortly.)

So those are the five co-production values: keep coming back and checking your practice against them.

**b) Co-production is part of a spectrum of engagement approaches**

**So we should be aiming to do co-production for everything then?**

Well, no. To unpack that, let’s talk about all the different kinds of interactions that occur between a public service and its citizens and service users.

You may have come across the “ladder of participation” which was designed by Sherry Arnstein in 1969. Sherry was doing research about citizens and how much they participate in civic life, and the ladder of participation goes from not participating at all, at the bottom, through tokenistic involvement of citizens, all the way to to citizens having complete power without the state having to be involved at the top.

In co-production, we don't quite go into the area where citizens are just completely in control and self determining. That's more of an area for asset based community development. There is space in our public services and in our communities for all of these different types of engagement, but we are interested in the bit where there’s a relationship and shared decision making between citizens and state. I really like that model, but there is one thing I don't like about it: because it's stacked like a ladder, it suggests that the top of the ladder is the place where you want to get to, at all costs and in all situations. And I disagree with that, so I have flipped it on its side to turn it onto a spectrum. You still have “doing to”, “doing for”, and “doing with”, but the spectrum indicates that in some cases you will need one approach and in other cases, a different approach.

Under the “doing to” label, and depending on your context, you could be looking at protection (for example safeguarding) or coercion - for situations where there is risk to life for example; and education is also a “doing to” (for example smoking cessation campaigns). In this context the citizen is more passive, and the central agency has the knowledge, the decision-making power, and the power to act. “We know what people need, and we know what needs to happen. We just need to find a way to make it happen.”
In the “doing for” category, you find approaches like:

- providing the information that people are looking for (e.g. how do we make it readily available when people come in and ask for it?)
- consultation: let's ask people what they think about this. By the way, consultation gets a really bad rap because quite often It's done badly or inappropriately, in place of another approach that would be more meaningful. But a good consultation done in the right context for the right reasons is a powerful tool to inform decision making.
- participation: there's more interaction between the professionals and the citizens, enabling citizens to shape maybe a new building, or a new service, or something that's going to happen in their community. So we make sure we listen to the voice of citizens. But the question I always ask is: who's holding the decision-making power and the power to act? If we have a really good event, and lots of people share their views and ideas, at the end of the day it's the role and responsibility of the professionals to take away all the data and shape the design based on what people have said (decision making power), and then apply it and make it a reality for the community (power to act).

The key difference between “doing for” approaches and “doing with” (i.e. co-production), is professionals and citizens, patients, service users, carers… working together all the way through. It's not just people feeding into what professionals will do, it's also everyone bringing knowledge and ideas, coming up with solutions together, having a part also in delivering it, and evaluating together. Citizens are able to do things that professionals can't do, and vice versa. When citizens have equal power with professionals, I don't mean it's exactly 50/50 split down the middle, but it's a bit of a dance between the two, sometimes professionals do a bit more, sometimes citizens do, but it averages out to people all having a chance to be part of creating the solution.

I have to add that for professionals, “doing with” is often quite a mindset change, especially at the level of involving people in designing services or in strategic decisions. But it's also a culture change for citizens, who have been taught from previous interactions to look upwards for solutions: “the council should sort this, or the government should fix this”. Actually, we need to do all of this together. We need to all have a voice in this, which is also a shift for citizens! It's a shift for all of us in the way of working. Something to bear in mind is, it won't happen overnight; but it's by taking the steps together that we learn how to do co-production together.

The point of the spectrum is that “doing to”, doing for” and "doing with” are different approaches appropriate for different situations, so it's about choosing the right one for our situation and purpose.

**c) Complexity theory helps us identify where to take a co-production approach**

**When do we do co-production and when do we choose something else?**

To understand how we choose our approach I want to tell you about complexity theory. Bear with me, because this may feel like a tangent, but it is really very relevant to co-production.
Complexity theory is an academic discipline, which is still fairly young and still evolving, but which concerns itself with: how do you classify the types of challenges you're working with? And most importantly, how do you respond to them? What are the different kinds of responses that are appropriate to different kinds of problems?

In most complexity models, there are four categories of challenges.

The first one is called simple (sometimes obvious). It's like making a basic cake: you have a documented process (a recipe), you don't need much training, maybe just a little bit of practice; but if you do all the things in the right order, you will get what you expect (it's predictable). And it's linear: you have to make sure everything happens in the right way and the correct order for it to work.

The next category of problem is called complicated. It's like building a rocket: you also have a documented process (your planning and blueprints). You must plan upfront, allocate all your materials and staff hours, ensure that things happen in the right order. You also need specific training and skills: you either recruit people who have the technical skills so you have them in-house, or you bring in specialist consultants to join your team. Either way, that expertise is available to you. But like baking a cake (just at a very big scale), it's linear and predictable. So if you do all the right actions in the right order, you will complete your rocket, launch it, and put a Rover on Mars.

Simple and complicated processes are both linear and predictable. There is a right way to do things, and if you follow it step by step, you will end up with what you're aiming for.

The next kind of challenge is where the relevance to co-production becomes apparent. This dimension is that of complex challenges (hence the name, complexity theory). A great analogy for a complex challenge is raising a child: there's no documented process, or rather no definite documented process. (Hundreds of people have written thousands of books about raising children, but not one single person has got the definitive answer, the magic formula that you can apply consistently to return perfect results every time.) And just because you've done it once with your firstborn doesn't mean that the same rules will apply with your second child.

This is because every single human being is what we call a “networked adaptive system”. Every one of us is networked, in connection, with our family, friends, neighbours, colleagues, ... also our natural environment, our urban environment, and society in general - and all the different factors that make up our lives. And we are adaptive in that every time something changes in our personal ecosystem, we change and adapt in response. So every one of us is in a constant state of dynamic balance, and when you put a bunch of us together in a community or a society, the complexity goes up exponentially.

Complex challenges tend to be about relationships and about people's lives. In public services they are the ones labelled as “wicked problems”, like loneliness, substance use, poor health outcomes; whereas broadly speaking, simple and complicated challenges tend to be about building things and fixing things (like surgery, or building an
app for patients, or a new hospital).

For the sake of completeness, let me tell you about the last dimension of complexity theory: the chaotic domain. This is what we went through with the COVID emergency response: there wasn’t a clear path all the way through, so the government had to take rapid actions, and adapt as things evolved and new data became available. In a chaotic system, the central agency produces guidelines, which enable local distributed systems to make sense of them and apply them locally. (There isn't enough brain power in the world to work out centrally all the different context-specific situations for all the local areas.) Chaotic systems tend to be short-term (even if it might be a few years), and resolve themselves eventually into either a complex or a complicated system.

**Okay, so co-production is... for complexity?**

Absolutely! When we’re trying to design support, or services, or even whole organisations, that are geared towards meeting people’s needs and improving their outcomes, there are so many interdependent factors that there can’t be a single expert of everything. What we need is a range of perspectives and knowledge around the table, to build one another’s understanding, and pool ideas to design and test solutions together.

So whenever we’re dealing with a complex challenge, we want to co-produce, and to co-produce, we gather people and work on solutions together. Conversely, when we’re in a linear process, dealing with a complicated challenge, we can (and should!) call in the people with specialist training and expertise, to do what they know how to do. They might do some user research (or some consultation or participation) to understand what people need and how they’re going to use it, but the technical specialists make the decisions and do the build.

When we’re working in complexity and co-producing, we don't know at the start what the final output is going to be; it's pretty impossible to plan that level of detail up front. Lack of clarity doesn’t mean lack of a plan however! We know what direction we’re pointing ourselves in and how we’re going to work, and we'll find out what the solution is as we shape it together. In co-production, we need to learn to work with that uncertainty, because that’s where the value lies.

**d) The co-production imperative: why we can’t afford to not do co-production**

**It sounds difficult!**

The truth is, it kind of is: it’s difficult because it’s a different way of thinking about things, with a focus on the people and service users, instead of on the mechanics of the system. It’s a mindset and culture change for many, although there are also plenty of professionals who are already taking a person-centred approach, and for whom co-production makes complete sense because it’s the extension of that thinking from individual to service and organisation level.

There are a few broader factors that are putting co-production on everybody’s agenda
at the moment. After more than a decade of austerity, and the COVID-19 pandemic, we're in an economic context with drastically less resources available to support people with public services, at the same time as we have a changing and ageing population generating increased demand.

We also have a pattern of public services that can be very disempowering: the message tends to be that service users have nothing to offer while the professionals have the resources, knowledge and power. The way to keep receiving help is to keep coming back with more problems, and this kind of “old school” public service model is actually creating a cycle of disempowerment.

Combining the lack of resources with the dependencies created by the system, we have a organisations under pressure which have no choice but to raise the eligibility thresholds - because we need to be selective about who we can help with the limited resources we have - which means more people falling through the net; and by the time they are able to access services, presenting with more complex problems, with fewer options and more urgency, which in itself adds more strain on the system. The pressures are such that to deliver good services that provide the right support to people when they need it, it’s no longer enough to work in the way we have always done.

With a legislative and policy context that is making co-production a statutory duty, and consumers used to interacting digitally with private sector organisations expecting a new kind of responsiveness from our public services, this all adds up to a need for public services to understand and master the co-production approach, and leverage service users and carers’ voices.

1.3. If you have an hour

Watch the recording of this co-production introduction training.
https://www.youtube.com/watch?v=rqsmRZVd1Jg

The slides are included below. (You can open the slides in your browser, or right click and download them.)
https://drive.google.com/file/d/1Iwl0VyBKIZB4BeaE8UJBiUDN4xNzZoyr/view

1.4. As a follow-up

You might like to:

- Discuss what you’ve been reading / hearing with your team
- Listen to these Co-production Network for Wales podcast episodes on
  - the co-production definition and values (39’28")
    https://podcasters.spotify.com/pod/show/copronetwales/episodes/S02E01-What-is-co-production--Part-1-e20m4kk
  - the ladder of participation (27’12")
    https://podcasters.spotify.com/pod/show/copronetwales/episodes/S02E03-The-Ladder-of-Participation-e20msf1
simple, complicated and complex (16’46”)

● Watch (or listen to) this online session about “co-producing with carers in healthcare settings” (59’42”), run as part of the Carer Aware project. https://youtu.be/9JiiDahD218

● Carry out a stocktake of your current co-production practice (individually or as a team) using the Co-production Network for Wales co-production audit tool. https://info.copronet.wales/the-self-evaluation-audit-tool/
Part 2. Examples of co-production in action

We have gathered some case studies and examples of co-production practice in health and in social care, to translate the theoretical frameworks in Part 1 into what it looks like on the ground. These are intended to offer some inspiration and a sense of the wide range of contexts where co-production can make a difference and add value. Some involve carers directly, and others contribute to creating the conditions where everyone, patients and carers, can be involved. Remember that every situation (service, team, service users and carers) is different, and your co-production will be similar but unique!

2.1. Pembrokeshire Dementia Support Carers’ Card

Carers co-design a resource for new carers based on their lived experience

Conversations and co-design sessions with carers in Pembrokeshire identified the need for support for (unpaid / family) carers at the early stages of the dementia journey, when they are at the GP’s for the first conversation about their loved one’s memory or behaviour, prior to any diagnosis.

The solution proposed by carers: an A6 card to be handed to the carer in person at the GP practice, with some verbal information about this service being specifically for them (not the patient). The card includes the phone number of PCISS (Pembrokeshire Carers Information & Support Service), where carers can access support as well as information.

*The difference co-production made:*

The problem was identified by staff based on what carers were saying, and the result was co-designed with carers, ensuring it was the right solution for other carers in a similar situation.

The process and the end product were very simple, but the impact was powerful. The uptake of the cards with GP surgeries and other health professionals across the county has been very successful because it feels so relevant to carers’ needs.

2.2. Maggie’s Cancer Centre, Swansea

A patient and their family work with healthcare professionals to develop support for patients and their families

Maggie’s was created through a co-design approach, using the expertise of someone with a cancer diagnosis and their family members, alongside cancer care professionals, architects, landscape and interior designers.

People supported by Maggie’s make a significant contribution to service design and
delivery, particularly through the peer networks. The focus is firmly on the whole individual, their strengths, interests, and the outcomes that matter to them. There is also support available for their carers.

Staff expertise is complemented by the lived experience of those they support, and by the assets of the wider community.

**The difference co-production made:**

The work of Maggie’s is an example of how the third sector and NHS can work together to meet the holistic needs of patients. It demonstrates the power of community and the impact of people sharing their stories and experiences.

People felt less alone and better able to manage stress.

*Read more: Maggie’s website*
https://www.maggies.org/about-us/how-maggies-works/our-story/

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**2.3. Gwynedd Council Direct Payments**

The Council works with service users and carers to make their service flexible and person-centred

Take up of Direct Payments in Gwynedd was low, due to an inflexible and inaccessible system, with minimal autonomy for either recipients or the social workers who supported them; the focus was on financial compliance rather than effective outcomes.

To improve the service, the Council set up a task group of service users, carers and staff, to consider what they wanted from a Direct Payments service. The task force engaged all existing users in surveys, ran focus groups and training events, and developed a set of principles to underpin the new policy.

**The difference co-production made:**

The Council now have a Direct Payments scheme that supports people to design a care package that's right for them; flexible, personal and easily adapted as circumstances change.

In addition, through involving service users the Direct Payments policy was reduced from over a 100 pages to a simple to use 4 page booklet.

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**2.4. North Wales Cancer Network Patient Forum (CPF) Website**

Patients and families develop a resource with professionals
The North Wales Cancer Network Patient Forum (CPF) is a voluntary group of people affected by cancer. ‘Listening events’ organised by the Forum highlighted a need for better information around managing the wider impact of a cancer diagnosis – financial, emotional and practical. This evidence was supported by feedback from local surveys.

Members of the Forum led the development of a bilingual website for this purpose, working as equal partners with a range of health care providers to provide a solution for the benefit of other service users and carers.

**The difference co-production made:**

The project has had positive outcomes for patients, their families and the health professionals. They established the format, content and design of the website based on lived experience and user needs and preferences.

As a result, people are accessing the information they need when they need it. In the process, members’ networks have grown and the Forum itself has been re-energised.

### 2.5. Drive New Staff Induction Process

Staff co-design the induction for new colleagues, to embed co-production practice with the people they support and their carers.

Drive in south Wales provides support to people with learning disabilities to live the lives they choose in their local communities. The Co-production Lead and Training Lead identified an opportunity in the staff induction process to provide a focus on co-production, in order to ensure Drive colleagues have a shared understanding of co-production and feel confident to implement its values in their work.

The existing induction process already focused on person-centred practice. Drive is committed to ensuring staff listen to the voices of those they support and their families; to further strengthen this, they decided to bring an explicit focus on co-production throughout their everyday work. The co-production induction content was co-designed by Drive members of staff with Co-pro Lab Wales specialist support and advice.

The resource created is an animated visual that explains what co-production is and what it looks like in practice, accompanied by a written guide. To embed these meaningfully with new and existing staff, the resource will be followed by a facilitated group discussion to further explore co-production with colleagues. Drive is aiming for these discussions to be co-facilitated by a Trainer with Lived Experience from the Carer Aware project.

**The difference this will make:**

Early discussions highlighted that staff held different levels of knowledge about co-production. Drive want to ensure all their staff have a shared understanding on which to develop an effective culture and daily practice of co-production. Existing staff
will have access to the resource via the staff intranet, and all new staff coming into Drive will engage with it as part of their required induction process.

With wide adoption across the organisation, this will lay the foundation for the meaningful implementation of co-productive practice and values throughout Drive, creating an asset-based, person-centred, and relational experience for the people they support and their families.

2.6. Further reading

A collection of co-production case studies from health and social care across the UK (Nesta)

2.7. As a follow-up

You might like to:

- Discuss what you've been reading with your team: which case study stood out for you?
- Listen to these Co-production Network for Wales podcast episodes:
  - Co-production stories with Daniel Madge, Senior Organisational Development Manager for Aneurin Bevan University Health Board (37’27’’)
  - Co-production in health and social care, with Jenny O’Hara Jakeway, Chief Executive of Credu Connecting Carers, and Daniel Madge, Senior Organisational Development Manager for Aneurin Bevan University Health Board (37’26’’)
- Watch (or listen to) this Co-production Network for Wales online session about “co-producing with unpaid carers” (1:32’32”) that includes colleagues from Kirklees Council, Neath Port Talbot Council for Voluntary Service (NPT CVS), Swansea Parents Carers Forum, Hafal Crossroads and Pembrokeshire Association of Voluntary Services (PAVS).
  https://youtu.be/KlupyFSluHY
- Reflect on your service or work area (individually or as a team), and identify any opportunities where co-producing with service users and carers would be helpful.
Part 3. Doing co-production

Co-production will look different depending on the kind of organisation you’re in, what your role is, and how much scope you have to influence the shape of services or strategy. There may be systemic barriers to implementing co-production as widely as you wish to, but there is usually something you can do co-productively wherever you are. Some co-production is always better than none, and it all counts – anything that makes a positive difference to the lives of service users and carers is worth doing.

Like we’ve said before, co-production is an approach and a way of thinking, so it’s not a process as such with a set number of steps to do in the “right” order. However, we can offer some pointers and things to consider to help you get started - with the caveat that they are presented in an indicative order, but you will keep revisiting them all as you develop your co-production practice. If you are already doing co-production with service users and/or carers, this might offer some additional ideas! The key is to keep checking in with the 5 values of co-production (see Part 1) in whichever context you operate in. Below we consider what this might look like at the three levels of co-production.

3.1. Individual co-production

If you can influence how you (and maybe your colleagues or your whole team) do your job, then you can embody the values of co-production in the way you deliver your service, through your day-to-day interactions with carers and the people they care for. Depending on the situation, you may be interacting with a carer who is accompanying the person they care for in a healthcare setting, or a carer about their own life and health, or specifically about their caring role and responsibilities. Remember that carers are people with complex lives like everyone else, and that they are more than just their carer role. Address a carer by their name, not their perceived role (e.g. mum, dad, taxi driver, etc).

- Valuing all participants, and building on their strengths:

You look for and recognise the strengths, knowledge, ideas and experience (lived or professional) that people have to contribute, whether they are on your staff team or they are carers and the people they care for. For example, in your job you say when you appreciate a quality, a strength or a skill that your colleagues bring; and likewise with carers when discussing their situation, you look out for expressions of their qualities, strengths and skills, and you notice them out loud. Be a treasure hunter (not a deficit detective!)

- Developing networks across silos:

You help people become part of supportive peer networks and broaden their horizons by connecting with groups, activities, or other organisations that can contribute to supporting them. For example, you point a carer towards groups and networks that you know about, that they may not be aware of. You could check whether they feel these are for them, whether
they could go, whether they might need some support - and think through together what support options there are. You don’t have to bring all the solutions and provide all the support, but a conversational space to figure things out is always useful.

- **Doing what matters for the people involved:**

Your work is shaped around what matters to the individual. You ask how people are doing, what solutions they have already thought of, and what a good outcome looks like for them, before you decide what's best for them. For example, you talk with a carer about what communications work best for them to be kept up to date about the person they care for; or you discuss what respite would be useful for them and what it could look like, before you reach for a menu of existing respite options. It may well be that the existing options aren’t an exact match to their wishes, but by discussing what good looks like you can identify what aspects are important and find the best available match. It could also open unexpected possibilities that aren’t on the menu but would be easy to implement.

- **Building relationships of trust and sharing power:**

You take the time to build connection, trust and understanding. Even when time is tight or you might only meet a carer or a patient once, you can take a relational approach by listening deeply and engaging in dialogue, demonstrating that they matter and that you value this moment of connection. For example, instead of typing up the notes while someone is speaking, take a moment to give them your undivided attention. Listen for what they are anxious about and ask what they are hoping will happen (what a good outcome looks like for them). Recap what they have just said to show you’ve listened and understood, and then capture this information in your notes. (Remember how emotive the situation is for anyone attending a healthcare setting for a healthcare issue, whether it’s for themselves or the person they care for. Patience and understanding are essential.)

- **Enabling people to make change happen:**

You see your role as enabling people to change, not simply delivering a service. For example, by listening for their strengths and what they need, helping them make new connections, and shaping solutions together, you help people to grow their confidence and build up their own resources.

Individual co-production happens mainly in the moments of interaction with the people you support and their carers. It might feel simple and small, but the effects are powerful and important.

It might be helpful to think of individual co-production as a set of life or work practices, a bit like exercise; we don’t ask, “When will I be in shape and can I stop exercising? The human body never seems to get healthy.” Likewise, co-production isn’t a to-do list item or a project that finishes, but it doesn’t mean we can’t get in better shape (personally, professionally, as a service, as an organisation and as a society).
3.2. **Group co-production**

If you can influence how your service functions and delivers to its objectives, then you can shape a service built on the experience of carers and the people they care for, by bringing a group together to co-produce your service design (or improvement or transformation).

- **Valuing all participants, and building on their strengths:**

You find ways to use and develop the assets and resources that are present in your teams; in your service users and carers; and in your networks and their communities. This will contribute to building everyone’s confidence and capacity further. For example, in co-production with carers you would look to put carers at the heart of the conversation, and figure out who else needs to be included who will have useful input to offer, which can include the person they care for as well as professionals.

Make sure that when considering “carers” you include a range of different perspectives, from young carers and young adult carers, to parent carers, sandwich carers (looking after children and elderly relatives at the same time), older carers, carers from minority ethnic communities and from the LGBTQ+ community, etc. - as well as the range of situations and conditions they could be caring for, for example dementia, mental health issues, learning disabilities, substance use, etc.

In practice, you might want to start by mapping who and what you know.

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### Map who and what you know

You’ve identified a challenge that you’d like to address through a group co-production approach. A stocktake is a good place to begin - make a list of:

- what you know about the question;
- who you know who are relevant to your question.

#### 1. What you know

Compile the research or information you already have on the challenge, including published data, results from surveys and consultations, and any previous engagement or co-production phases and their outcomes. We rarely begin with a blank canvas; indeed there’s usually a rationale for taking a co-production approach to addressing a challenge, and this in itself is useful information.

Remember to take into account both kinds of knowledge:

- “professional” information which comes from sources that usually only professionals, not citizens, have access to (e.g. health outcomes in a population): this is an opportunity to share this data with the service users and carers in your co-production group;
● “citizen” information which comes from lived experience of situations (e.g. health conditions) or of accessing and using services: this is knowledge that professionals need carers and the people they care for to contribute.

If your co-production challenge is place-based and focused on carers in a specific community or neighbourhood, you also want to map what you know about the assets in that location: places and venues, people and skills, activities and events, resources and equipment, anchor organisations and community groups. You can make a list by category, or identify them on a map of the area. Do this as a team exercise with the members of your co-production group (see below!), and especially with the local partners and residents who know the area inside out. This will help you to collectively draw on the place’s strengths and existing assets to develop solutions.

2. Who you know

You want to pull together a multidisciplinary co-production group that consists of people who have an interest in solving the challenge, including carers and the people they care for. Other people will also have a stake in the outcomes, but may not need to be directly involved in the co-production group.

● Start by listing all the people who you think are relevant to your question: carers, the people they care for, other stakeholders from third sector or statutory organisations, colleagues in your team and your wider organisation, other organisations like funders and policy makers.

● Place them on a matrix according to interest and impact (to the best of your knowledge, as this is a starting point and you can amend it when you find out more):

  o How interested are they in your question (low / high)? The question might be very relevant to them but it might also be a low priority for them, or they might not be aware that there is an opportunity to get involved.

  o How much will they directly benefit from the question being solved (low / high)? The impact might be high for carers, and low for large organisations where this question is one of many within a wide range of services. (This doesn’t mean it’s not impactful in itself, but it’s relative to everything else.)

  o Bonus action: underline, star, or somehow highlight those people across your matrix, who are people from underrepresented groups who don’t usually have a voice (to prompt your thinking, you can start with the list of protected characteristics).
This is the first building block of an engagement and communications plan that will support your co-production project:

- Group 1 (high impact / high interest) are the people who you invite into your co-production group.
- Group 2 (high impact / low interest) are key but they are not currently interested (or aware of the opportunity): you reach them through partner organisations and in raising their awareness or interest, they can move into Group 1.
- Group 3 (low impact / high interest) care about the outcomes but are not directly affected by any changes; they are often the partners who can act as advocates and champions of your co-production challenge, and help involve Group 2.
- Group 4 (low impact / low interest) are relatively interested and any changes will contribute to their bigger picture, but this is not their main focus (funders or commissioners, for example): you keep them informed of developments. They might have the power to be enablers or blockers to your co-production approach,
so it’s important to take them into account and share an appropriate level of information, without them taking centre stage and calling the shots in the co-production process.

We build on this and look at inviting people into your co-production challenge in the next section, where we reflect on the second value (“developing networks across silos”) in a group co-production context.

- Developing networks across silos:

You help people to make connections with other actors, stakeholders, communities, groups or networks, by bringing together a multidisciplinary team of stakeholders from a range of backgrounds and experiences. For example, through your co-production with carers, they will encounter other carers along with groups and organisations that they might not have been aware of, and who can offer input and support, and extend their networks beyond who and what they already know - and this also applies to everyone else involved including professionals, who benefit from connections across organisational silos.

In practice, here are some pointers about inviting people to join your co-production group.

**Invite people to join you**

You have mapped what you know and who you know, the foundation of your engagement and communications plan; it is time to invite people to get involved.

1. **Start building your multidisciplinary co-production team**

For Groups 1, 2 and 3 who will be contributing to your co-production team, consider:

- **existing contacts**, who you have an existing relationship with and who you are able to reach out to directly (whether they be professionals in your organisation or other organisations, or carers and the people they care for);

- **new contacts**, who you also need to reach and invite in, but don’t already have contact with directly.

Build up your engagement and communications plan by thinking about each person you want to reach. While you might have a good idea of your organisational partners’ priorities, make sure you consider very carefully the needs and priorities of the carers you want to involve:

- What are their preferred communication channels?
- What do their days and priorities look like?
- What invitation will “land” and interest them?
- How can you demonstrate that you value them and their input?
- Can you remove any barriers to their taking part?

If you’re not sure about the answers to these questions, find someone who knows and
ask! Ask carers what would work for them, or if you’re not connected yet ask colleagues who work with carers directly, they will have some good ideas and will be able to put you in touch with carers who can help.

Work with and through other organisations, whether statutory or third sector, and local community groups. By building your relationship with them, and valuing their knowledge and experience, you form trusted allies and partners who can help you access insights and cultural context, and reach the people who you are looking for in the right way.

2. Craft your invitations

There won’t be a one-size-fits-all, so give people a choice about how (and how much) to get involved: offer a few options, like meeting in person, or a backup online meeting for those who can’t attend in person, or a one-to-one phone call if they want to share their ideas but can’t attend a group setting, or an online survey if they want to share some thoughts but don’t have much time, etc.

An appealing invitation also gives people a reason to get involved: what’s in it for them? What difference will this make, to them and their families, to the service that supports them? Will there be lunch provided, vouchers, or payment in recognition for their time and contribution?

It’s helpful if the invitation also demonstrates that you have thought carefully about people’s access and comfort: this shows in the time and duration you select, the location (including online), the format of the event, and any access provisions you have organised.

3. Keep an eye on inclusion and diversity

Disseminate your invitations and monitor the responses.

Make sure that you include all the seldom heard voices: partly because it’s the right thing to do, and partly because when you design from the margins, everyone benefits. (“Design From the Margins” (DFM) is a design approach that calls for centering the most impacted and vulnerable individuals in our society into the design process, from idea to execution. This is beneficial for all, because understanding the needs and wants of the more specific, complex and vulnerable communities, not only supports and protects them, but cases can always be generalised and bring transferable benefits for the broader audience.) Lean towards overrepresenting the underrepresented voices, as that is how you will gain the most insights.

As part of ensuring that your group is representative and diverse, check that the widest variety of situations and experiences is represented - for example, carers can be parent carers, young carers, dementia carers, etc., so one carer can’t (and shouldn’t have to) speak for all. Likewise, try to have more than one rep for a whole category, region, etc. so that the responsibility is spread across several shoulders and it’s sustainable for people to participate.

Remember that carers and the people they care for are taking part on top of their other
work and life commitments and responsibilities, and they are dealing with life situations that are precisely the reason why their lived experience and input are so important. People are generally not paid to co-produce (well, they should be, but that’s another wider topic!) - so it’s not their job to get involved, and they don’t owe us their time or their interest. How can we demonstrate that we value them, and support them to take part?

4. Keep building your co-production group

You won’t get everyone on your wishlist to get involved from the word go. First of all, it’s ok to work with small numbers. This is co-production, not research: a good idea is just as good if just one person has it! But also, it’s an ongoing dialogue, not a one-off conversation, so you can continue bringing more stakeholders and people into the conversation: keep asking “Who’s not here?”

If people don’t show up, don’t assume lack of interest, lack of engagement, or worse, apathy! Have you found the channels and messages that work for them yet?

Top tip! Do a mini co-production loop: co-design the events and invitation materials with some of the carers they are intended for. When we are embedded in organisations and processes, we are so used to them that we forget what it's like to encounter them as an outsider, and we need fresh eyes! Don’t get defensive, the aim is to do better together: listen, understand and improve.

5. Keep other people in the know

Your Group 4 (low impact / low interest) are people who are relatively interested in the outcomes as part of their bigger picture; they might be funders or commissioners, for example. Make sure you keep them informed of developments. They might have the power to be enablers or blockers to your co-production approach, so it’s important to take them into account and share an appropriate level of information, without them taking centre stage and calling the shots in the co-production process.

Now you’ve started building your group, it’s time to listen! In the next section, where we reflect on the third value (“doing what matters for the people involved”), we look at building a shared understanding by listening to people’s values, experiences, and ideas.

● Doing what matters for the people involved:

You focus on creating good outcomes (the difference your work makes in someone’s life) as much as on the outputs you need to report on (what you did and how much or often). To find out what these outcomes are, you start with a conversation, and you listen to those who are not usually heard in these contexts. For example, carers and the people they support usually have good ideas based on practical experience about what could work.

It’s important to listen to those partly because it’s good person-centred practice, and also because they could be simple, effective solutions that organisations wouldn’t have
considered. (Take the example of a visually impaired person who was struggling to find the white light switches on the white walls in the flat they’d just moved into. The local council proposed £13,000 worth of assistive technology, but the solution that worked was adding black borders around the light switches, which cost less than £10 across the whole flat.)

In practice, there are a few key questions you want to weave into the dialogue.

**Listen out for ideas and strengths**

You have gathered together your co-production group. You now need to build a shared understanding and good working practices, by listening to everyone’s values, experiences, and ideas.

Create a space where everyone can share what they know and think about the challenge you have gathered to address. As well as the data from professionals, it is essential to hear people’s lived experience and listen out for their strengths, ideas and potential solutions. (When you identify strengths, see if you can leverage them in your project. This is part of building on all the resources available to us collectively.)

It is useful for professionals to hear carers’ lived experience first hand; and it is also useful for carers and families to hear the professional’s perspectives, and gain insights about the organisations and systems (and constraints) that they operate within. A greater reciprocal understanding leads to more robust co-designed solutions.

**Start the dialogue with a “tell me about...” question.** (For example: “tell me about what a typical day looks like for you as a carer”.) Keep the question topical but open, and framed in a way that elicits people’s stories. Keep the questions about your service at the back of your mind for now, and start by listening to people’s experiences and ideas. (You can ask follow-up questions after.) You’ll get all the information you need through dialogue but the energy is different: “we’re here to listen to you”, vs “we’re here to talk about us”.

Allow people to talk about what they want to talk about. If it seems like the topic is drifting, ask questions about how their story relates to the challenge you are solving together, or tease out the links yourself. (For example in one workshop, a comment about dog fouling led to a wider conversation about green spaces, exercise, community connections and isolation - a number of key determinants of health.)

**Another useful question is “what does a good outcome look like” or “what does a good life look like for you”.** Don’t be worried about people asking for things that are outside of your power to influence (for example, winning the lottery!) - use this as a springboard to find out more about what this would enable them to do, which reveals what they need (rather than what they want).

Of course, we want to manage expectations and be honest about what we can and can’t act on directly; but sometimes we might be able to influence or partner with other organisations who can!
Finally, make sure you build into your dialogue some questions around ideas and solutions. What’s worked in the past? What ideas do people have? What’s worked elsewhere? Think more broadly about what might be possible, rather than starting with a menu of what’s available. People often come up with simpler (and therefore cheaper!) solutions.

As the conversation flows and evolves, you will cover an analysis of the current situation and data, and tease out potential solutions which you will shape into an action plan to test out, evaluate and adjust. Decide who does what and when you’ll come back together to feed back and reflect. Remember everyone has a role to play, but not everyone will play the same role.

**Top tip!** To prepare the ground before the “main co-production meeting”, you may want to work with different groups separately before bringing them together, for example professionals together to discuss co-production mindsets and behaviours; and carers together to discuss their rights, confidence and expectations. There is strength in peer learning! Then together they will be ready to have a constructive dialogue. (Just because it’s co-production doesn’t mean everyone has to be in the same room all the time. But make sure that they do meet and co-design together after laying the groundwork, otherwise it’s not co-production!)

- **Building relationships of trust and sharing power:**

You respect everyone’s perspective and the value they bring to the table. For example, if you have a co-production group which carers are part of, make sure they are heard front and centre, and not as an afterthought once the professionals have had their say. Put governance processes and support in place so that they have equal voice and are considered as highly as everyone else - like having a carer and a professional co-chair the group.

For people to trust you, you need to demonstrate trustworthiness. It’s up to you to show up, think with empathy about people’s experience in this group and challenge any practices that fall short, close communication loops and tell people what’s happening as a result of their involvement. (Don’t be a bad friend who only gets in touch when they want something!) For example, in co-production projects the action that always gets lots of positive feedback is going back to the carers and service users who have been involved along the way, and showing them the end product that they have contributed to shaping. The comments are partly about the product itself, but mostly in appreciation for the update. As a result people always agree to be involved again in the future; this contributes to building long-term relationships, and a pool of allies and friends of the organisation who you can turn to again.

- **Enabling people to make change happen:**

You help people to build the life they want by enabling them to take action. For example, by being involved in a co-design project, people can go on to input further into other topics, find
their voice and build their confidence, share their good ideas, and make positive change happen in their communities and networks.

You enable your team and colleagues to work in a person-centred way. For example, through creating the conditions for a co-productive approach like supportive structures and ways of working, everyone involved can experience first hand the value of hearing from a diversity of voices and lived experience, and strengthen their day-to-day practice.

You keep working on your mindset and values, and on how you understand (and relate to) power. For example, you notice the different forms of power that are present within a co-production group. Is lived experience being valued less, more, or equally with professional expertise? Who holds more or less social power due to their gender, age and ethnicity? Who has positional power (from their position or status in an organisation) and how do they wield it? Do the people with power use this to raise and make space for other voices?

You learn that YOU don’t have to fix everything. (We’re trained to take responsibility, but this also disempowers others if we don’t let them do their share.) For example, in a project setting up a dementia cafe, carers led on the design, finding a venue, and connecting with local people in the village; the professionals in the group maintained a balance between allowing carers to get on with it, while being on hand to advise and guide where needed; and they took the lead on navigating the administrative and bureaucratic processes.

You learn to say, “I don’t know. Let’s figure it out together.”; to show up with questions instead of answers; to bring the things only you can do, and to look or listen for the things only others can do, adding to your collective strength. For example, council officers noticed that the education data consistently showed lower results for boys in a specific minority group in the region, despite different attempts to improve this. Through the schools they approached mothers, brought a co-production group together, showed them the data and findings, and opened a conversation about the results, how what they’d tried so far hadn’t worked, asked about what they didn’t know, and about how to solve the issue together. This resulted in the creation of a group run by the community, with input and support from the council, successfully addressing the disparity in results.

You learn to show up with curiosity, compassion, empathy, kindness - towards others and towards yourself. For example, in getting to know the other stakeholders in your co-production group you are reminded that carers, the people they care for, and all the professionals that support them are whole human beings with rich lives and more dimensions and experience than you can tell at first glance. Allow the space and time for stories to be told and shared, they contribute to building the working relationships.

Through co-production you can be part of the change you want to see in the world. For example, you aim to embody co-productive and person-centred values, but you notice your co-production group coming up against structural or mindset barriers. You use your group agreements and values to work as inclusively and flexibly as you can within these boundaries by finding solutions together. You recognise that people are generally doing the
best they can, but they are sometimes constrained by the situation they are in (including carers as well as professionals). But through pursuing your co-production aims to the fullest extent possible within these limits, collectively you influence the broader system by demonstrating innovation, prevention and long-termism through your practice.

Group co-production holds the potential to transform services, outcomes and lives. If you’re being tokenistic you will not only waste everyone’s time (professionals, as well as carers and the people they care for), but also damage relationships, trust and goodwill towards any future participation or involvement endeavours. Make sure that if you’re embarking on a co-production process, you’re doing it for real, not for show; and that you are committed to act on the group’s findings.

### 3.3. Strategic co-production

If you can influence how your organisation operates and meets its statutory duties, then you can create a culture that puts the voice of carers and the people they care for at its heart, by establishing policies and governance processes that foster co-productive and carer-supportive behaviours across your organisation.

- Valuing all participants, and building on their strengths:
You demonstrate that you value everyone’s contribution, and you ensure everyone’s voice is heard. For example, you have space for carers on your boards and steering groups, and you make sure you provide them with the support they need to take part fully (by having conversations about what would help, and finding joint solutions that meet their needs); you have ground rules and you call out behaviours that fall short of respecting and valuing their presence and contribution. You can have a carer and a professional co-chair a group; you can have a designated point of contact and support for the carer reps to have additional briefings and prepare for meetings - and all the better if this point of contact is a senior person, as this demonstrates the value you place on the carers and your commitment to hearing them.

- Developing networks across silos:

You use networks to make positive change happen. Connecting professionals with service users and carers creates shared understanding, increased insights, and innovation. For example, you could join or create a working group with partners from across organisations working in your sector or on a particular issue. You can advocate for carers and service users to have a place at the table and create the structure within your organisation for this to happen. You could set up service user and carer groups to maintain these connections on an ongoing basis, and have a consistent voice in the broader conversation without putting all the responsibility and commitment on one or two people.

- Doing what matters for the people involved:

Your monitoring and evaluation systems include measuring the good outcomes as defined by your service users, patients and carers; and they are a part of the process. For example, if you are running a project or programme that will benefit carers, it is the carers who are best placed to determine what success looks like and what indicators would be useful; as well as evaluate from first hand experience what has changed during and after the intervention. Consider adding participative and co-production monitoring and evaluation processes that can run alongside your organisational metrics.

- Building relationships of trust and sharing power:

You ensure your approaches, systems and structures enable and encourage people to build connection and trust, and lead to shared decision-making. For example, you co-produce a co-production policy with your service users and carers; this results in a shared understanding of the aims and ways of working, and gets translated into your strategic plans, business plans and workplans. The organisational commitment is understood at every level and supports the change in day-to-day practices.

- Enabling people to make change happen:

You work in partnership with the service users and carers you support to co-commission, co-design, co-deliver and co-evaluate your services. For example, they are part of boards
and steering groups. Through these structures they participate in shaping the services that support them and others, contributing to positive change for themselves, their communities and the organisations. You keep asking, ‘how can we make this better?’

Change at strategic level doesn’t happen overnight, but remain alert to the signs of co-production that you can nurture and develop. Strategic co-production creates frameworks that enable more group and individual co-production to take place, instead of practitioners having to find ways to co-produce in spite of the system they operate in.

3.4. Building your co-production plan

Now you’ve read through what co-production looks like at individual, group and strategic level, you will have a clearer idea of where your work and potential co-production projects with carers can sit. You may want to think through translating the values into actions in your specific context, which you can do on your own as a thought experiment, or as a team with your colleagues.

3.5. As a follow-up

You might like to:

- Discuss what you’ve been learning with your team.
• Watch these short videos from the Scottish Co-production Network: https://www.coproductionscotland.org.uk/resources/100-stories-of-co-production
  o ‘Better chance than that’ (1’30”) about change led by people recovering from addiction;
  o ‘My Opinion’ (2’15”) in which Jamie, a parent with learning difficulties, tells what it feels like when citizens aren’t taken into account in service design and delivery;
  o ‘The F Word’ (1’20”) about not getting it right the first time and learning from “failure”.

• Check out the National Principles for Public Engagement in Wales on the Third Sector Support Wales website. (A login is required to access the resources but registration is free.) These are useful guidelines for behaviours and practical approaches to deliver great person-centred engagement and co-production. https://thirdsectorsupport.wales/resources/national-principles-for-public-engagement-in-wales/

• Meet as a team and fill in your co-production action plan canvas together: what and how are you going to co-produce with your carers?
Part 4. Co-producing with carers

In the previous sections we have covered general considerations about co-production and how it can be applied in a wide range of situations and with a variety of carers and service users, colleagues and partner organisations. In this section we’re looking at more carer-specific issues: what their circumstances or concerns might be, and what to bear in mind when working specifically with carers.

4.1. What we mean by “carers”

Carers are people who offer support to a friend, neighbour, or family member who wouldn’t otherwise cope without their help; and who provide this support on a voluntary, unpaid basis. (This is not to be confused with some jobs which may include the word ‘carer’ in the title! The carers we are referring to can sometimes be referred to as “unpaid carers” or “family carers” to avoid this confusion, although both terms have their limitations.) Carers may support someone with learning disabilities, mental health issues, substance use issues, or physical health conditions.

The 2021 census recorded more than 310,000 carers in Wales – that’s 1 in 10 people looking after a loved one (and sometimes more than one). Carers can be any age, and include many young carers: children and young adults looking after siblings, parents or grandparents. Parent carers support a disabled child or children, often continuing into adulthood. Working carers fulfil their caring responsibilities alongside their day job. Two people may be co-carers – this is common among older couples, where each one looks after the other in different ways. Carers can be a combination of the situations above, for example working, looking after a disabled child, and supporting an elderly parent all at the same time.

For more on who carers are, what they do, and what their rights are, watch the Carer Aware animation with accompanying handout: https://carers.org/carer-aware-project/learn-about-carers-rights

4.2. How to co-produce with carers

All the co-production values and approaches we have already covered apply equally to carers as to service users and other citizens; but there are some specific issues it will be helpful for you to bear in mind.

Carers typically have very high demands on their time. Many are combining their caring role with work, education, and/or the other responsibilities that we all have in day-to-day life. You really must value carers’ time, and make sure that any time you’re asking them to contribute to a co-production process is meaningful and well spent.

Carers typically have very little spare time, let alone time for themselves. Consider how any time they spend co-producing with you could either combine with something they’re
already doing, and/or, offer something that allows them some 'me' time such as a social activity or food.

**Carers may have to arrange alternative care in order to join a co-production activity:** either booking in paid care, or asking a favour from other friends or family. Can you cover any replacement care costs, or otherwise offer help? This also means that carers may not be able to be as flexible as others, due to the planning and other people involved; give people plenty of notice, be well organised, and avoid last minute invitations or cancellations.

**Carers are frequently excluded from healthcare planning discussions**, and/or expected to start (or re-start) their caring role with little notice, despite usually providing more day-to-day care than the professionals do. You must consider how you include the carers’ perspectives and expertise in decisions, as well as those of your service users and patients. Remember: you may be the expert in your professional area, but the carer is the expert in knowing the person they care for and their own life as a carer.

### 4.3. What carers say

Check out “In Carers’ Own Words”, our series of self-filmed videos in which carers describe their day-to-day lives, as well as their experiences of working with health and social care professionals: [https://carers.org/carer-aware-project/resources](https://carers.org/carer-aware-project/resources)

- Meredydd Owen (2’48") [https://www.youtube.com/watch?v=npene0qKEOU](https://www.youtube.com/watch?v=npene0qKEOU)
- Isabella Jones part 1 (3’11”) [https://www.youtube.com/watch?v=sUT2b98KPIY](https://www.youtube.com/watch?v=sUT2b98KPIY)
- Isabella Jones part 2 (3’10”) [https://www.youtube.com/watch?v=Bf-5d4sEmsQ](https://www.youtube.com/watch?v=Bf-5d4sEmsQ)

Carers from Black, Asian and minority ethnic communities reported an especially pronounced ‘lack of fit’ between services and their needs, in recent research carried out by Carers Trust Wales. Please see our findings about carers’ experiences, and recommendations for services.

Experiences of unpaid carers from Black and minority ethnic communities report:


### 4.4. How to better meet carers’ needs in services

One area which carers frequently say doesn’t work as well as it should for them, is when the person they care for is admitted to hospital and, especially, when they are being discharged from hospital. In response to this, Carers Trust Wales co-produced hospital discharge guidance with carers and NHS health professionals.
The guides below contain specific practical guidance about working with carers (e.g. patient confidentiality issues), and how services can be structured to better meet carers’ needs (e.g. someone with specific responsibility in every MDT meeting). This will be of interest whatever your area of work, to draw on practice examples of supporting carers more effectively - which ultimately benefits everyone: the carer, the patient, and the professional teams.

- Good practice guide for hospital discharge: a policy guide for strategic and senior staff involved in planning services (18 pages)

- Involving unpaid carers in hospital discharge / transfer of care: a practical guide for frontline clinical staff (4 pages)

Carers Trust Wales can help with carer-specific issues, providing further resources, advice, and free Carer Aware training. (wales@carers.org) https://carers.org/carer-aware-project
Part 5. Next steps and further support

5.1. A few thoughts to conclude

Your keywords on this co-production journey are **patience** and **learning**!

**Patience**, because we are addressing urgent problems that have real impacts on people’s lives, so it’s natural to feel we have to do it all at once; but keep it simple, and take it steady step by step. It builds stronger and ultimately ends up quicker that way. The main thing to remember is that it’s a journey, with relationships as the operating principle, and relationships grow at the speed of trust. Whether you get to spend 10 minutes with someone you might not see again for a year, or your co-production project is a short-term ‘task and finish’ intervention, it’s part of a longer term relationship and development of trust between your organisation and its service users and carers: it builds on what came before, and will create the conditions for what comes after.

**Learning**, because there are no one-size-fits-all silver bullets: the only way is to learn by doing. Adopt the PDCA cycle: Plan, Do (test), Check (learn), Adjust… and test and learn again! Try to bring more curiosity and less defensiveness to the whole process. The stakes are high, and that is all the more reason to take this transformative approach with a growth mindset (“I can learn this” instead of “I’m either good or bad at this”).

We hope that this toolkit will help you to take some steps along the co-production path.

5.2. Further support

Carers Trust Wales can help with carer-specific issues, providing further resources, advice, and free Carer Aware training. [https://carers.org/carer-aware-project](https://carers.org/carer-aware-project)

You are also invited to join the **Carer Aware Professional Learning Network**: it is a supportive space open to all professionals supporting unpaid carers and working in health and social care settings in Wales (both in statutory health organisations and in third sector roles connected with health, like carer champions and carer leads), who want to share, learn and develop their practice with regards to co-production - regardless of current experience or knowledge of co-production. What is essential is having an interest in improving the opportunities available for unpaid carers to design and develop the services available to them.

Register your interest via this form, or get in touch for an informal chat. [https://docs.google.com/forms/d/e/1FAIpQLSefAgTnbCXulvswMzRKesODQaUAc2r8C1ROC8_PlzgbQ1S5g/viewform](https://docs.google.com/forms/d/e/1FAIpQLSefAgTnbCXulvswMzRKesODQaUAc2r8C1ROC8_PlzgbQ1S5g/viewform)

To contact us please email [wales@carers.org](mailto:wales@carers.org)