



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

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/carers-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/carers-aware-project/resources>

- Meredydd Owen (2'48") <https://www.youtube.com/watch?v=NPENe0gKEOU>
- Isabella Jones part 1 (3'11") <https://www.youtube.com/watch?v=sUT2b98kPOY>
- Isabella Jones part 2 (3'10") <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:

- Full report (28 pages) <https://carers.org/downloads/carers-trust-report-final.pdf>
- Executive summary (4 pages) <https://carers.org/downloads/carers-trust-summary-english-final.pdf>

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) <https://carers.org/downloads/involving-unpaid-carers-in-hospital-discharge---policy-guide-for-service-planners-final-may23-eng.pdf>
- Involving unpaid carers in hospital discharge / transfer of care: a practical guide for frontline clinical staff (4 pages) <https://carers.org/downloads/involving-unpaid-carers-in-hospital-discharge---guide-for-clinical-staff-final-may23-eng.pdf>

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