

Research Prioritisation Project: How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?

Project update, February 2021

Introduction

Ten research priorities relating to the care and support of people in Wales aged 65 and over have been developed through a joint project between Health and Care Research Wales and Social Care Wales in 2020, on the topic: “How can we best provide sustainable care and support to help older people live happier and more fulfilling lives?”

The project was run in association with the [James Lind Alliance](#) so that the priorities were developed through meaningful engagement with hundreds of older people, carers and social care practitioners.

This report in February 2021 launches these Top 10 research priorities and gives an update on our progress in getting research on them commissioned. Further details about how the project was run can be found on the [Health and Care Research Wales website](#).

The Top 10 research priorities relating to care and support for older people

[Click on each topic for further information]

1. Does **early care planning and/or early or regular contact** by social care services, help prevent problems and result in better experiences for older people than waiting until there is a crisis?
2. How can we **reduce isolation and stress amongst carers** of older people and prevent burn-out?
3. How can social care and health services, including the voluntary sector, **work together more effectively** to meet the needs of older people?
4. How can social care for older people be **tailored to the interests and needs of individuals**, including better involvement in decisions about their own care?
5. How can social care best support older people with **complex needs** (e.g. people who need support from a range of health and social care services)?
6. How can social care for older people be **funded in a sustainable way**?

7. What **barriers** do older people experience in accessing services (e.g. access to information, waiting times, access to online technology, communication, costs)? How can access be improved?
8. How can **terms and conditions**, including wages, be improved for staff providing social care to older people? Will this attract more people to the profession?
9. How can social care for older people be kept at a consistent **high quality**?
10. How can home and community-based social care enable older people to socialise, reducing **loneliness and isolation**?

#1 Does early care planning and/or early or regular contact by social care services, help prevent problems and result in better experiences for older people than waiting until there is a crisis?

The priority:

Older people and their carers reported that receiving daily or weekly phone calls during the COVID pandemic had made them feel safe and less isolated: “Regular contact is vital as there is nothing worse mentally than feeling you are alone in the world and no one else is interested in you and your problems”. This was especially important for people without family. Some suggested that older people should be regularly approached to ask if they need care or support, rather than waiting for the point at which they realise they can no longer cope. Some thought this might prevent finding people “collapsed or dead in their home”.

Carers need support before they reach the point of emotional or financial crisis, as their stress will also have a negative impact on the older person they care for. This makes it important to get information to carers sooner about the services available to them.

Care workers were concerned that currently they only respond to crises, and are choosing the ‘least worst’ options, rather than doing ‘meaningful work’. They questioned whether their interventions are ‘too late’, and if “catching problems when they are small would prevent them growing into a big problem”. They suggested that research is needed to find out whether earlier action is successful and/or saves money in the long term.

Early planning for social care was thought to be particularly important when older people are in hospital, to ensure support is in place when they return home. In addition, planning for the move to a care home at an earlier stage could help to make the transition gentler, and give older people and their families more time to obtain all the information they need and to fully understand the options available.

The view from researchers:

Researchers felt this was a topic that would benefit from further research as current evidence is limited. They proposed this could focus on some **scoping work** to explore the exact form of approaches (interventions) relating to regular or early contact that could be

tested in a trial, how such a trial could be set up, and what outcomes to measure. The interventions might cover different forms of engagement, such as face-to-face or telephone contact, or communication via Apps.

The researchers also felt it was important to do a **rapid review** early on that looked at which interventions/packages are most effective at developing engagement with people, as the degree of engagement was felt to be an important determinant of whether people would feel the early or regular contact was a benefit.

#2 How can we reduce isolation and stress amongst carers of older people and prevent burn-out?

The priority:

Older people, carers and care workers agreed carers are underappreciated and without them social care services would be under even greater strain than they are now. Waiting lists for support for carers mean carers are often reaching crisis point. Stepping in to support carers earlier would do much to save “a lot of heartache and resources down the line”. Often they simply “don’t know who to turn to or what help is available”.

Older carers in particular struggle to cope with their caring responsibilities. Some carers described their role as ‘relentless’ needing to provide support 24/7 with few breaks. Looking after older people with dementia whose behaviour can be challenging is especially difficult for all involved. Carers reported feeling a “mixture of guilt for feeling trapped and unable to move on with their lives, while loving their families”.

Providing opportunities to socialise with other carers was thought to be important to prevent isolation. Respite is needed before carers “reach the end of their tether” and needs to be appropriate for the person being cared for. Carers need a break so they can return to their caring role feeling energised and refreshed. Care workers work shifts, take holidays and have their sick days covered – the same protections should be offered to unpaid carers to maintain their health and wellbeing. Care workers concluded that “money spent on research to understand the best ways to support carers would be money well-spent”.

The view from researchers:

Researchers identified that a lot of research evidence about carers already exists, and many single interventions to support carers have been tested in trials. To take this priority forward, researchers suggested a **realist review** could help us to answer the question “what interventions work for what type of carer in what circumstances?” This should include an analysis of the cost-effectiveness of these interventions. **New research** might be needed to plug any gaps identified by this review, for example on how to support particular types of carer (BAME, disabled, rural etc).

Researchers also felt that, because different types of carer will need different types of support at different times, **new research** could help us understand “how can ‘centres’ be

organised to support carers?” – NB “centres” could refer to either a bricks-and-mortar-centre, or a virtual network, or other form of support network.

Some **knowledge mobilisation** activity is also needed to support social care practitioners to use academic tools that already exist that can help identify carers who are stressed, at risk, or vulnerable.

#3 How can social care and health services, including the voluntary sector, work together more effectively to meet the needs of older people?

The priority:

Care workers, carers and older people all concluded that health and social care services need to work together more effectively, including to ensure:

- care workers and health professionals know about all the care and support available in their area and can signpost older people and their families to services
- assessments in health services lead to the provision of appropriate social care and someone takes responsibility to check that all needs are met
- funding and resources are distributed across all sectors to avoid voluntary services being forced to provide social care “on the cheap”
- social care workers are members of multi-disciplinary teams caring for older people in hospital
- voluntary sector services are valued and respected for the essential care they provide
- health professionals and care workers coordinate their care successfully to provide the best possible care for the older person
- health and social care services communicate with each other, refer older people to each other’s services and provide seamless care

Some suggested that health and social care services should be combined, but emphasised the culture and values of social care should take priority, “To the health staff my mother at 90 was a problem that needed to be disposed of rather than a person who had her own views. This was in marked contrast to the attitudes of the social care staff.”

Care workers and managers reported they are generally working well with their colleagues in health services, but this could still be improved. A range of standards and good practice are being used, and research could usefully identify what works well and should be continued, and what isn’t working well and should be stopped.

The view from researchers:

Researchers felt there is a large existing evidence base (and several evidence syntheses) on integrated working but it is hard for practitioners to make sense of it. The key question is how to mobilise existing knowledge about integrated working (e.g. service improvement

projects, leadership training etc.) – not just amongst health and Local Authorities, but also social care providers – in such a way that practitioners can know which good practice examples to extract and try to apply in a different location. A **knowledge mobilisation research** project should test the best way to go about this.

Researchers also felt we could usefully **synthesise existing information** on the type of signposting approaches that work best for people with health and social care needs, to answer the question “What approaches to improve signposting works best, for whom, in what circumstances and why?”.

A new **evidence synthesis** is also needed on the mechanisms / interventions that local areas implement to improve communication between health services, social care services and social care providers.

#4 How can social care for older people be tailored to the interests and needs of individuals, including better involvement in decisions about their own care?

The priority:

Older people said they wanted to be “listened to and heard” by care workers, so they can have an “equal say in the care they receive”. They wanted to be respected and understood as a unique, whole person with particular interests and needs, and to be supported to live their lives in the way they wish, “such as being part of my church and playing music in a band”. Some asked whether advocates add value by empowering individuals to understand their options and make choices. They wanted to know how best to make the individual’s needs central to the care they provide.

Practitioners asked how often older people’s needs aren’t being met because services are under-resourced: “You can’t give people what they want, if you haven’t got the money to do it”. This issue is discussed under Priority #6.

Carers wanted social care services to better meet the older person’s needs, rather than them having to fit in with the service, for example, being able to get up and dressed at the time they wish, rather than during the only timeslot available. Carers also wanted to have their say about the care package provided, when they may be impacted by the decision and have a good understanding of the older person’s needs.

Older people, carers and care workers emphasised the importance of understanding and respecting the cultural backgrounds and values of older people receiving care, avoiding prejudice and racism, and providing the food they prefer. Some care workers suggested diversifying the workforce to better meet older people’s needs in different communities as well as educating staff about how “African-Caribbean people interact with authority, and show or don’t show distress”, and to learn about the experiences of the “population that are 3rd and 4th generation Black Welsh”.

Others identified communities where older people may need additional support to ensure good communication with care workers, including Welsh-speaking and Deaf communities. They asked how care packages could be tailored /developed to reflect a community's way of life, for example to allow older Travellers, Gypsies or Roma people with dementia to stay living on site with their families.

The view from researchers:

Researchers felt there was evidence on how to facilitate shared dialogue for decision-making in primary care, mental health and dementia care that could potentially be applied in various settings for the care of older people. They proposed the first step would be an **evidence synthesis** to pull this together, with a focus on identifying barriers and facilitators at different levels (including at system levels) and looking at different models to address these barriers. This synthesis may then identify gaps that **new research** could fill, relating to facilitating shared decision-making for particular types of service users, such as Black, Asian or Minority Ethnic older people, or those with sensory loss.

#5 How can social care best support older people with complex needs (e.g. people who need support from a range of health and social care services)?

The priority:

When older people have both physical and mental health problems, it can be challenging to get all their different needs met in a combined care package. As people live longer with multiple conditions, it seems likely that older people needing care and support are going to have complex needs and may be struggling to manage for example, "taking 14 different medications per day". Some asked whether managing complex needs should become standard in any social care needs assessment. Others asked whether research could identify the best way to care for people with specific complex needs for example, veterans with post-traumatic stress disorder and dementia.

Care workers and managers described how care workers seem to be taking on responsibilities that used to belong to nursing roles, especially when caring for people with complex needs. This means there is less time and funding available for basic core elements of social care such as taking older people to social events.

Complex care packages take a long time to set up, require additional training for staff and more oversight once they are running, but may not be commissioned at a higher cost than basic homecare. Research could helpfully identify a fair price for this care to recognise the increased complexity of this work and reward care workers accordingly.

The view from researchers:

Researchers felt this area could tie-in with research relating to shared decision-making (#4) and integrated working (#3). However there are specific challenges – and an evidence gap – in understanding how to best support people with complex needs whose care pathways involve both health and care practitioners. They felt a **research programme**

could explore and test “How to develop the competencies of care workers to specifically work in the area of older people with complex needs so they can provide a helpful link between service-users and specialist expertise and support”. In the short term, a **research review** could usefully determine what “complexity” means to different groups (older people, carers, practitioners) in different parts of a pathway, as this would help inform the above programme, including informing what outcomes need to be measured in order to establish whether the impacts of complexity has been reduced following the intervention.

#6 How can social care for older people be funded in a sustainable way?

The priority:

Funding for social care is currently a national concern and many people fear the situation will only get worse given the “social care time bomb associated with an aging population”. If funding is not addressed, it will be difficult to address any other issue facing social care.

Care workers argued more funding needs to be made available, since current funding limits the care and support that can be offered and may mean it doesn’t reflect older people’s best interests. Some were also concerned that older people are going into residential care rather than being supported at home, when homecare is often cheaper. Better planning and use of funds also needs to be explored.

Many services are closing through lack of funds and “You can’t give people what they want, if you haven’t got the money to do it”. Some suggested that tax increases are required and the public would understand the need for this because “Families are already topping up their loved ones care in order to provide adequate or better care”. Some thought it would be fairer to share the cost across the whole population, rather than only the people in need. Participants felt research could provide important evidence for policy-makers.

The view from researchers:

The researchers recognised this is an area where UK and Wales Governments are considering policy options. They felt **new research** could provide useful information to policy makers on the impact of existing policy differences between the four UK nations (such as differences in free personal care / weekly cap on costs / lifetime cap on costs/ means testing thresholds) on behaviours (such as planning, saving, self-funding) and also outcomes (such as access, top ups, self-funding, quality of services, wellbeing). This research could also explore the impacts of policies in countries outside the UK.

A key concern for policy makers is likely to be whether increased investment in social care is going to lead to an increase in access to services, and also an increase in quality of those services. This is discussed under Priority #9.

The researchers also identified that **policy research** might be needed to look at different models of accountability for hypothecated funds raised centrally through taxation.

#7 What barriers do older people experience in accessing services (e.g. access to information, waiting times, access to online technology, communication, costs)? How can access be improved?

The priority:

One of the major barriers to accessing social care highlighted by older people, carers and care workers is that most information about services is now online, while not all older people have access to a computer or a smart phone, and may not be comfortable using technology. Research is needed to find the best ways to provide information to older people, which may be about using alternative media (e.g. TV, radio and newspapers) or about providing training and support to use IT. This was thought to be important because one of the common reasons older people and carers don't access services, is that they simply don't know what's available, or believe common myths such as "The government takes your house, if your relative goes into a home".

Participants at the workshop discussed how the availability of different types of accommodation and living in a rural area can also present barriers.

Carers and care workers identified major barriers for older people who have difficulty communicating or are unable to read, either because of a disability or from loss of sight and hearing associated with old age. These people might miss out on vital care and support, especially if they don't have family members to help them find information and navigate through services. Care workers suggested they might need training to know how best to overcome any such communication barriers.

Care workers reported they are aware of many other barriers to accessing services and want research to find ways to overcome them. The issues they suggested could be usefully addressed included:

- the stigma some older people feel in needing help and using social care services
- lengthy delays between referrals, assessments and action being taken e.g. 6-12 month wait for assessment for handrails
- being part of a community that is disadvantaged or marginalised.

The view from researchers:

The researchers felt that considerable research evidence already exists about barriers to accessing social care services, but we need more evidence on the solutions to those barriers and the cost-effectiveness of those solutions.

They proposed the first step would be a new **evidence synthesis** on the solutions to overcoming barriers to access, including consideration of equity issues (i.e. access to

services by those with protected characteristics and other disadvantaged/vulnerable groups).

They also proposed a **research review** that would explore the extent to which these barriers could be understood as a problem of supply (e.g. that services or accommodation are not available in a particular area).

They also proposed **scoping work** for a trial of interventions to overcome barriers to access, further **scoping work** for a trial of an intervention specifically to improve decision-making related to the choice of accommodation and to the purchase of assistive technology and aids.

#8 How can terms and conditions, including wages, be improved for staff providing social care to older people? Will this attract more people to the profession?

The priority:

Care managers expressed concern at the falling numbers of care workers due to stress and overload, which is then increasing the demands on those who continue to work in understaffed services. They suggested care workers taking traditional nursing roles, such as giving medicines, should receive increased pay in line with greater responsibilities. Better pay and conditions would result in “less stressed, tired and grumpy care workers”.

Older people and carers were concerned that since care work is paid at a minimum wage, not many people are attracted to the profession. They asked whether increasing wages would help to improve the quality of care, by helping to recruit older and more experienced staff. They thought it important that care workers are properly trained to support older people and have a better understanding of their caring role. Older people and carers would then have more trust and confidence in staff. This would ensure carers receive proper respite, knowing that the care provided will be high quality.

The view from researchers:

Researchers felt that a lot of research evidence and policy work relating to terms and conditions had already been done, and future research needed to build on this. A specific **research question** was proposed: “What is the relative value placed by staff providing social care to older people on different employment terms and conditions? How might this inform employment practices that promote recruitment and retention of social care workers?” Terms and conditions include those relating to pay, rotas, shifts, rewards, training and allotted time per client.

#9 How can social care for older people be kept at a consistent high quality?

The priority:

Older people and carers expressed concerns that the care provided by one care worker may be of very different quality to that provided by another, and that when contracts change the quality of a care package may go down, even though the same care is supposed to be provided. They asked how best to keep the care consistent and reliable. Care managers concluded that variation in quality is linked to inadequate funding.

The view from researchers:

Researchers felt that there is considerable policy activity underway in both England and Wales to develop more robust systems of monitoring service quality. More research evidence is needed to test whether investment that increases pay and/or improves terms and conditions in the social care sector results in increased quality of care. Policy-makers need this information in order to make funding decisions. A specific **research question** would be “What is the effectiveness and cost-effectiveness of investment at increasing the quality of care?” Some preliminary work for this research would be needed to network of providers who may be willing to provide data on their charging structures, and also to determine what is meant by “quality” for service users vs. carers, practitioners, providers and commissioners, and how quality could be measured in the research.

#10 How can home and community-based social care enable older people to socialise, reducing loneliness and isolation?

The priority:

Finding the best way to reduce social isolation and loneliness was a key concern for older people, carers and care workers. Some had felt very lonely during lockdown describing “isolation as the worst thing anyone can bear”. They considered research in this area essential because helping older people to stay active in their community improves their mental health and wellbeing, and hopefully results in fewer demands on services in the long-term.

Some important ways to increase social activity in the community were thought to be increasing the availability of transport, public toilets, day centres and community events. While meeting with their peers is enjoyable, older people may want to be connected to other parts of their local community, including younger generations and people from different backgrounds. Suggestions for ways to help older people socialise at home or in residential care, included befriending services and home visits from volunteers.

The view from researchers:

The researchers felt a considerable body of evidence has been built in recent years relating to specific interventions that aim to tackle loneliness. However a new **evidence synthesis** is needed, and potentially some **knowledge mobilisation** work.

What is missing from the evidence base and requires **new research evidence** is something about the features of localities that either increase or decrease the levels of social support. There may be learning from the COVID pandemic in terms of what prompted connected local actions, what hindered them, and what could be sustained post-COVID. This research should also look at what Local Authorities (or others) could do at a system level in order to increase the levels of social support. This research could also link to the research on carers (#2) which looks at the best way of providing centres of support for carers.

There is also some **knowledge mobilisation** work needed to help social care practitioners to use academic tools that already exist to identify people who are at risk of loneliness and isolation.

Progress at February 2021 on getting research commissioned

Health and Care Research Wales is working closely with the potential funders to explore how the research priorities identified could be commissioned and funded. This work will continue throughout 2021.

Potential funding routes are dependent on funder priorities and the ongoing availability of funding/appropriate budgets. Across the different funding bodies there are a variety of different ways through which research could be commissioned and funded, and all of these are being explored.

- **Open researcher-led calls:** Researchers can submit a bid for funding on any topic that meets a grant scheme's eligibility criteria. (Often they will be asked to demonstrate why the topic is a priority, and may refer to the Top 10 priority areas.)
- **Commissioned or directive calls:** Funding bodies put out calls for bids on a specific topic (e.g. one of the Top 10). The researcher proposes the exact research question and methodology.
- **Specific commissions for scoping work, rapid review of evidence, evidence syntheses:** These can be commissioned and completed more rapidly than the open- or commissioned-calls.
- **Policy research:** Policy teams in Government tender a contract for specific research.
- **Knowledge mobilisation:** Projects helping to embed the use of research evidence in social care practice could be funded by a variety of organisations, not just research funders.

Our work to get research on the Top 10 commissioned and funded is at an early stage, but progress to date is encouraging as we have already identified potential funding streams

and commissioning options for each of the Top 10 priority areas. We hope to see significant progress in the next few months and will report back in November 2021.

For further information about the project, please contact the project manager [Emma Small](#)