Cafodd yr ymateb hwn ei gyflwyno i ymgynghoriad y Pwyllgor Iechyd a Gofal Cymdeithasol ar Flaenoriaethau'r Chweched Senedd

This response was submitted to the Health and Social Care Committee consultation on Sixth Senedd Priorities

HSC PSS 52
Ymateb gan: | Response from: IDEAL

Blaenoriaethau cychwynnol a nodwyd gan y Pwyllgor
Initial priorities identified by the Committee

Mae'r Pwyllgor wedi nodi nifer o flaenoriaethau posibl ar gyfer ei waith yn ystod y Chweched Senedd, gan gynnwys: iechyd y cyhoedd a gwaith ataliol; y gweithlu iechyd a gofal cymdeithasol, gan gynnwys diwylliant sefydliadol a lles staff; mynediad at wasanaethau iechyd meddwl; arloesi ar sail tystiolaeth ym maes iechyd a gofal cymdeithasol; cymorth a gwasanaethau i ofalwyr di-dâl; mynediad at wasanaethau adsefydlu i'r rhai sydd wedi cael COVID ac i eraill; a mynediad at wasanaethau ar gyfer cyflyrau cronig tymor hir, gan gynnwys cyflyrau cyhyrysgerbydol.

The Committee has identified several potential priorities for work during the Sixth Senedd, including: public health and prevention; the health and social care workforce, including organisational culture and staff wellbeing; access to mental health services; evidence-based innovation in health and social care; support and services for unpaid carers; access to COVID and non-COVID rehabilitation services; and access to services for long-term chronic conditions, including musculoskeletal conditions.

C1. Pa rai o'r materion uchod ydych chi'n credu y dylai'r Pwyllgor roi blaenoriaeth iddynt, a pham?
Q1. Which of the issues listed above do you think should be a priority, and why?

1.1 Introducing IDEAL

The Improving the experience of Dementia and Enhancing Active Life (IDEAL) Programme is a longitudinal study of people with mild-to-moderate dementia and their carers living in the community. A large cohort study, we began with 1547 people with dementia and 1283 carers. The programme began at Bangor University, and has been running since 2014 with participants across Great Britain. We recruited from two specific NHS sites in Wales: Betsi Cadwaladr and Hywel Dda, and have Welsh participants in the programme.

1.2 As one of the major research programmes working with people with dementia living in the community (rather than in care homes), we believe our research findings can help Wales move towards a position of 'Home based care and self management' which is part of the vision for 2028 in A Healthier Wales: our plan for health and social care. Our research focus is on what helps people with dementia and carers to live well with the condition. Our recommendations come from this large cohort study and we want to use our research evidence to enable people affected by dementia to live as well as possible for as long as possible, mirroring Chapter 5 of the Dementia Action Plan for Wales.

1.3 IDEAL is based at the University of Exeter and funded by Alzheimer's Society as a Centre of Excellence. The IDEAL team comprises 10 Universities, 2 partner organisations (Alzheimer's Society and Innovations in Dementia), 30 researchers and a wider network of advisers (including people with dementia and carers), affiliates and artists. IDEAL has been collecting evidence since 2014, so is in a unique position to evaluate the impact of the COVID-19 pandemic on people with dementia and their carers.

1.4 The IDEAL programme conducted two studies specific to COVID-19:

- The IDEAL COVID-19 Dementia Initiative (IDEAL-CDI) funded by NIHR, which collected evidence May-June 2020
- The INCLUDE project, a rapid-response project funded by ESRC, which collected evidence September 2020-April 2021. Further qualitative interviews were conducted with a small subset of participants January-May 2021 to assess the situation post vaccine roll-out.

1.5 As a dementia research programme, our submission relates solely to how people with dementia and carers can be prioritised by the Committee during the Sixth Senedd. However, this particular group is a necessary priority: Wales's first Dementia Action Plan 2018-2022 'recognise[s] that dementia is a significant health and social care issue which impacts not only on those living with dementia, but on their families, friends and carers too'.

2.0 Evidence-based innovation in health and social care

2.1 At the heart of all IDEAL's work is the belief that anything offered to people affected by dementia should be based on both research evidence and the lived experience of people with dementia and carers. We work side-by-side with our ALWAYs – Action on Living Well: Asking You – involvement group of people with dementia and carers who guide and influence our research. Our recommendations throughout are based on what our significant body of research evidence reveals.

2.2 A fantastic example of co-production in Wales is the new All Wales Dementia Care Pathway of Standards, published March 2021. We are working with those involved and the Dementia Oversight Implementation and Impact Group (DOIIG), to feed into their evidence base. We encourage the Committee to explore the development of this pathway of standards as a case of best practice which could be replicated in other areas of health and social care.

3.0 Support and services for unpaid carers

3.1 The cost of dementia care falls disproportionately on unpaid carers. Our research found that unpaid care accounted for 75% of the total care cost per person with dementia. Attention should also be paid to the type of dementia that someone has, as this can make a significant difference both to the amount of care needed and its cost. For instance, we found that the costs of care for a person with Parkinson's dementia were nearly 2.5 times that for Alzheimer's disease.

3.2 Added to this financial element, there is also a significant emotional cost to caring for a person with dementia, especially without appropriate respite (of which more below). It is significant, then, that when statistically modelling all the different factors that affect a carer's ability to live well, that a carer's psychological health came out as the most dominant area of influence. Add to this the fact that we know caregivers are at particularly high risk of loneliness and you have group of people in significant need of proper financial, sometimes medical and community support.

3.3 Support and services for unpaid carers would pay further dividends, since how unpaid carers are faring affects the person with dementia for whom they care. Our research shows that people with dementia report lower 'living well' scores if their caregiver feels stressed. Similarly, feeling you have a good relationship makes a difference to the life satisfaction and well-being scores which people with dementia and carers individually report.

3.4 Alzheimer's Society's 'The Fog of Support' report, written before the COVID-19 pandemic outlined what was an already difficult situation for carers of people affected by dementia. The recommendations revolved around ensuring carers could receive prompt carers assessments and access respite regardless of where they live.

3.5 The situation worsened for unpaid carers with the COVID-19 pandemic, with Alzheimer's Society's 'Worst hit: dementia during coronavirus' report outlining the increased burden on unpaid carers. Their survey revealed that '92 million extra hours have been spent by family and friends caring for loved ones with dementia', with 95% of respondents reporting 'a negative impact on their mental or physical health'.

3.6 We urge the Committee to keep unpaid carers as a priority of the Sixth Senedd, knowing that this already-burdened group has faced further challenges in the pandemic. A better situation for unpaid carers of people with dementia will also improve the situation for people with dementia themselves. We recommend the Committee seek to understand the regional availability and quality of support and services, ensuring that no unpaid carer is left to face their burden alone. Raising the profile of carers nationally will also have benefits, since further IDEAL work found that how carers perceive their social status within their community and broader society affects their ability to live well.

4.0 Access to COVID and non-COVID rehabilitation services

4.1 Currently unpublished qualitative data from INCLUDE reveals that people with dementia feel they have experienced accelerated cognitive decline over the pandemic and associated lockdowns. This in turn led to psychological distress, affecting their confidence to interact and furthering their isolation: "I found that there'd been a massive impact on my communication skills. I couldn't deal with so many people anymore." Carers have been noticing and coping with the increased challenges of worsening symptoms without support.

4.2 INCLUDE asked specific questions around the pattern of health service use, seeking to determine how much face-to-face contact people wanted or were able to access, as opposed to telephone/video appointments. Unsurprisingly, contact at a distance was more common, though this comes with its own problems: one participant was aware that they have "difficulty […] pronounc[ing] words sometimes – especially now over the phone". Compared with IDEAL's pre-pandemic data, there was a significant increase in GP telephone appointments and decrease in in-person GP appointments.

4.3 Other participants did not seek help for health issues because they felt such services were "not available to help". One person noted "it's been difficult to get through to [the] surgery, [it's] almost been obstructive". Such examples indicate that many people could not, or felt they could not, access healthcare services when they needed them. We need to understand why people feel their needs are not adequately addressed by existing services: are they not being listened to? do they feel staff are not able to provide for them? Meanwhile, people's medical issues may have developed into more serious problems which then require healthcare interventions. One participant explains the problem of waiting for someone to ask for help rather than proactively offering it:

> "It never occurred to me to actually talk to people about it. Because you've then got to specify exactly what you want. I don't need physical support. I don't need any domestic support. But it's interaction and stimulation."

4.4 When asked about which healthcare services stopped due to coronavirus, INCLUDE participants mentioned various services. Memory clinics were often cited, and perhaps their closures had a greater impact since these were previously regular appointments and as one participant said, "I enjoy it there". Several participants had had dental appointments postponed or cancelled, with one person noting "It took me about 18 months to get a dental appointment when normally I go once a year. I ended up having to have treatment". For another person living with dementia waiting to have an implant fitted, there was "an impact on quality of life as […] unable to eat without pain". Participants also cited other local groups, often charity- or community-provided, which had stopped. For example, singing groups, art groups, local libraries – all were serving different purposes for people (sources of support, information, entertainment, socialisation). Although not branded as health care services, all are important for living well and also provide essential respite opportunities for carers.

4.5 Beyond the individual health concern for which services are sought, there is a global impact to a person's capacity to live well with dementia from any one of these complaints. As IDEAL's 'living well' model shows, many factors contribute to a person with dementia feeling that they are 'living well', but the psychological domain exerts the most influence. Why is this relevant? People with dementia refer to feeling "forgotten about" due to limited healthcare appointments, or in one person's words "lack of reassurance – felt abandoned". Such negative expressions are cause for further concern given that we know that a positive outlook contributes to living well with dementia, and that loneliness and depression are both associated with lower living well scores. We have also found that as difficulties with everyday activities increase, the ability to live well decreases for people with dementia. This may be further contributing to pandemic-related struggles, since many everyday activities (such as shopping) were more difficult or disrupted.

4.6 Part of the recovery from COVID-19 must be the restoration and re-evaluation (to address changing needs) of those services which helped people with dementia and their carers to live well: from memory clinics to singing groups, from respite care to community classes. All of these social interactions help people with dementia begin to regain skills and confidence, and allow carers to recoup energy. One recently-released free resource to help with cognitive rehabilitation is 'My Life My Goals' from the GREAT-iP project. Cognitive rehabilitation allows people with dementia to keep doing the things they want to, and to retain independence. We urge the Committee to find out what is available to people affected by dementia across Wales and to raise awareness of resources such as this one. People with dementia and carers tell us often that what they want is hope – true rehabilitation from the pandemic for this group needs to foreground the offer of services and support.

Blaenoriaethau allweddol ar gyfer y Chweched Senedd

Key priorities for the Sixth Senedd

C2. Yn eich barn chi, pa flaenoriaethau allweddol eraill y dylai'r Pwyllgor eu hystyried yn ystod y Chweched Senedd mewn perthynas â:

a) gwasanaethau iechyd;

b) gofal cymdeithasol a gofalwyr;

c) adfer yn dilyn COVID?

Q2. In your view, what other key priorities should the Committee consider during the Sixth Senedd in relation to:

a) health services;

b) social care and carers;

c) COVID recovery?

Gwasanaethau iechyd

Health services

5.0 Personalisation

5.1 We encourage the Committee to consider scope for a move from person-centred care to personalised care. The Centre for Workforce Intelligence's 2013 report 'Big Picture Challenges: The Context' (which can be found on the Wales NHS website) identifies one such challenge as 'Delivering the personalisation agenda'. While the focus is mainly on English government outputs (pp. 15-16), this agenda remains at the heart of NHS England's long-term strategy with a Personalised Care Institute now set up. Personalisation seems to have dropped out of circulation somewhat in Welsh health publications except the Dementia Action Plan which acknowledges the need for 'personalised respite' support for carers.

5.2 Our living well maps both for people with dementia and for carers outline the many factors involved in living well, and how these factors influence people's lives is highly individualised. Dementia is such a multi-faceted condition that everyone's experience is necessarily different. The My Life My Goals resource mentioned, and GREAT Cognitive Rehabilitation offers that flexibility for people to choose how they wish to work with their condition. We encourage the Committee to explore the possibility of foregrounding personalisation in dementia care.

5.3 The IDEAL-CDI concluded a need for personalised health care, given that COVID-19 was experienced very differently by different groups. For instance, minority ethnic communities were less trusting of health care professionals. Building links between primary care and community leaders would help engage people from minority groups.

Adfer yn dilyn COVID
COVID recovery

a. Choice over how to connect to healthcare

b. A strong theme of INCLUDE’s qualitative evidence is a dissatisfaction with phone appointments for medical issues. Not all people with dementia are able to use the phone, or would prefer not to use it for medical issues. Indeed, 45 people with dementia declined to participate in the INCLUDE study because we had to move to remote data collection. In response to the question ‘Can you think of anything that would have made the situation more manageable and/or help you cope better?’, difficulties accessing healthcare services came up repeatedly among INCLUDE participants. It is of note that this question was asked before asking more structured questions about health and/or healthcare (which specifically encouraged participants to focus on this aspect of their pandemic experience). These responses, then, show that this aspect of the pandemic stood out for individuals as difficult:
    - “[I] have called over 100 times in past year and have been unable to get through and [my] health has declined.”
    - “Yes, seeing my doctor seeing face to face. Haven't seen him for a year. He rang at start of outbreak. My memory clinic review was postponed and then it was done over the phone but it’s not the same – having this face-to-face would have helped.”
    - “access to GP not eConsult and want to speak to them and proper prescription rather than just a cream for fibromyalgia.”
    - “disappointed with Dr service in terms of the phone calls – very quick call made me feel he didn’t have the time. Not the same as face to face visits.”

c. Those appointments which people with dementia and carers have been able to get during the pandemic has sometimes been a disappointment. There have been fewer opportunities for people with dementia to talk through their problems. Our researchers heard about several difficulties with medical appointments: not being asked enough questions, not being asked about mental health, and not being given personalised advice about what they can do to reduce the risk of cognitive decline. One participant had been waiting a long time for a dementia review. They received a call from the surgery at short notice and the carer was not present, and so the person with dementia did not get a full opportunity to discuss the problems they had been facing.

d. In order to allow people affected by dementia a proper recovery from COVID-19 and its surrounding circumstances, we encourage the Committee to inquire into appointment access, appointment choice, and whether practitioners are checking in with people affected by dementia to understand where they are now, and what they need.

8.0 A continuation of what is working

8.1 The COVID-19 pandemic offers a radical opportunity to overhaul systems for the better, where new ways of working improved pre-pandemic conditions. The IDEAL CDI found that those people who had received regular telephone calls from ‘just checking’ services (usually from voluntary agencies such as Alzheimer’s Society, Carers UK and Age UK) found these contributed to coping better. We would encourage the Committee to explore which of these types of services have helped those affected by dementia in Wales and to not only maintain these but further develop capacity.

Unrhyw faterion eraill

Any other issues

C3. A oes unrhyw faterion eraill yr hoffech dynnu sylw'r Pwyllgor atynt?

Q3. Are there any other issues you wish to draw to the Committee’s attention?

9.0 We are ready and willing to help the Committee in any way that we can regarding the significant population of Wales who are affected by dementia. While the hyperlinks embedded throughout are to full journal articles, our website hosts accessible summaries of each research paper which we can share directly with you as needed.