IN THE UK COVID-19 PUBLIC INQUIRY

BEFORE BARONESS HEATHER HALLETT

IN THE MATTER OF:

THE PUBLIC INQUIRY TO EXAMINE THE COVID-19 PANDEMIC IN THE UK

STATEMENT OF HELÉNA HERKLOTS CBE, FORMER OLDER PEOPLE'S COMMISSIONER FOR WALES

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1. Introduction

- I am the former Older People's Commissioner for Wales. This is an independent, statutory role with the remit to protect and promote the rights of older people in Wales. The role is established in the <u>Commissioner for Older People (Wales) Act 2006</u> ("the 2006 Act") which provides that "older person" means "a person aged 60 or over". The 2006 Act also states that "in considering, for the purposes of this Act, what constitutes the interests of older people in Wales, the Commissioner must have regard to the United Nations Principles for Older Persons".
- 2. Although the 2006 Act refers to the Commissioner for Older People in Wales, the Commissioner is, in fact, known as the Older People's Commissioner for Wales.
- The 2006 Act sets out the functions of the Older People's Commissioner for Wales ("the Commissioner") which are to:
 - a. Promote awareness of the interests of older people in Wales and the need to safeguard those interests;
 - b. Promote the provision of opportunities for, and the elimination of discrimination against, older people in Wales;
 - c. Encourage best practice in the treatment of older people in Wales; and
 - d. Keep under review the adequacy and effectiveness of law affecting the interests of older people in Wales.
- 4. The legal powers of the Commissioner are limited to the areas over which the Welsh Government has competency. The Commissioner is however able to consider and make representations to the Welsh Ministers, the First Minister, and the Counsel General on any matter relating to the interests of older people in Wales and this can include non-devolved, as well as devolved, matters.
- 5. In summary, the legal powers of the Commissioner are:
 - a. Review of the discharge of functions of public bodies;
 - b. Review of advocacy, whistle-blowing or complaints arrangements;
 - c. Assisting an older person in making a complaint or representation to a public body;

- d. Examining the case of an older person in a matter that affects the interests of a wider group of older people;
- e. Issuing guidance on best practice to public bodies; and
- f. Undertaking or commissioning research and educational activities or giving assistance to another in order to do so.
- 6. The roles, duties and responsibilities of the Commissioner reflect the functions in the 2006 Act, as set out at paragraph 1.3 above, and include to:
 - Provide national leadership that will make a difference to older people's lives by establishing strong partnerships and powerful relationships with people and organisations to drive improved outcomes and influence policy, legislation, decision-making and practice that affects older peoples' lives;
 - b. Scrutinise Welsh Government, other public bodies or persons listed in Schedule 2 of the 2006 Act to ensure they deliver responsive services to older people; and
 - c. Champion the voice of older people across Wales and ensure their views and concerns are taken into account by working with older people's groups and networks across Wales.
- I was appointed Commissioner on 20 August 2018 and served as Commissioner throughout the Covid-19 pandemic ("the pandemic"). My term of office ended on 19 August 2024.
- 8. A requirement of the 2006 Act is that the Commissioner should appoint a Deputy Commissioner who "may discharge the functions of the Commissioner during a vacancy in the office of Commissioner or at any time when the Commissioner is for any reason unable to act". The current Deputy Commissioner also undertook the role of Chief Operating Officer in my team - she served throughout the pandemic and remains in this post. [HH3/01 – INQ000303296]

2. Overview of my work during this period is detailed within exhibit [HH3/02 – INQ000184905] which I explain as follows:

Working with older people in Wales

9. My engagement included: direct contact such as conversations with older people, their families and friends, and professionals caring for/supporting older people; setting up and

facilitating online sessions to hear directly, and gather evidence from, older people across Wales; conducting a survey into people's experiences in care homes; frequent and regular contact with the older people who chair the national older people's organisations; contact with older people's groups across Wales who we have worked with over the years.

Research and evidence

- 10. I undertook research and gathered evidence about the impacts of the pandemic on older people, including: the effects of decisions taken, or not taken, by the Welsh Government; the impacts of new legislation or suspended legislation; and the impacts of restrictions and lockdown.
- 11. I brought together evidence from older people and our expert analysis to set out what older people needed from, and could contribute to, the recovery from Covid-19.

Convening organisations and individuals, and setting up working groups

- 12. I brought together key individuals and organisations working with older people across the United Kingdom ("**the UK**") to enable us to: share information, expertise and understanding; generate ideas and solutions; and speak with a collective voice for older people when their rights were threatened.
- 13. I engaged with frontline voluntary, community and statutory organisations working with older people across Wales to hear their insights into the experiences of older people and good practice and ideas about what could improve the situation for older people.
- 14. I established advisory and action groups to bring together organisations and individuals across Wales to work with me: on key issues affecting older people, for example abuse; developments to improve older people's opportunity to age well, for example the development of age-friendly communities; and provide expertise on specific groups of older people, for example Black, Asian and Minority Ethnic older people.

Assessing the impact of the pandemic and the response

- 15. I undertook work to identify the risks to older people's health and wellbeing, and the impacts on older people, and on different groups for example, people living in care homes, those who were digitally excluded, and those at risk of or experiencing abuse.
- 16. A key focus throughout my work was protecting and promoting the rights of older people.

17. I drew on evidence, expertise, knowledge and insights held by me and my team, and through ongoing contact and engagement with older people.

Scrutinising and influencing Welsh Government and other public bodies

- 18. I brought before the Welsh Government, experiences, concerns and ideas, from older people.
- 19. I held the Welsh Government to account through questioning and scrutinising their actions.
- 20. I responded to Welsh Government consultations to influence their policy and guidance.
- 21. I engaged with key officials in the Welsh Government, particularly those with responsibility for policy on older people, social care, health, safeguarding, violence against women, domestic abuse and sexual violence ("VAWDASV"), digital inclusion and poverty.
- 22. I attended and contributed to working groups established by the Welsh Government.
- 23. I also engaged regularly with key bodies including Public Health Wales, Care Inspectorate Wales, Health Inspectorate Wales, the Welsh Local Government Association, the Welsh NHS Confederation, to raise issues about older people, share information and understanding, and propose courses of action.

Engaging with the members of the Senedd and its Committees

- 24. I prepared and gave evidence to Senedd Committees on the impact on older people of the pandemic and decisions of the Welsh Government, proposing actions and changes.
- 25. I provided briefings on the impacts of the pandemic and recommendations for action for Members of the Senedd.
- 26. I provided and signposted Members of the Senedd to information for their constituents and to assist in their surgeries.
- 27. I responded to issues and concerns raised by Members of the Senedd through my Advice and Assistance Service.

Providing information, advice and assistance to older people, their families and friends, those that work with them and the wider public

- 28. Through my Advice and Assistance Service, I helped individual older people, their families and friends drawing on their experiences and insights in the conduct of my work.
- 29. Identifying the areas of concern and where there was a lack of clarity, I developed 'Q and A' documents so that people could access trusted and clear information.
- 30. I helped to promote public health messaging and advised the Welsh Government on how their communications with older people could be improved.
- 31. I engaged with the media to amplify the experiences of older people, to ask questions, and to propose action to better support older people and uphold their rights.
- 32. I ran information campaigns to get key messages out to older people, their families and friends, and professionals working with older people.

3. Working with the Commissioner for Older People in Northern Ireland

- 33. The Commissioner for Older People in Northern Ireland and I had some calls to keep in touch with developments in our respective nations and the work we were both doing and kept in touch via emails and occasional WhatsApp messages. It was helpful to discuss the work we were doing and our approach, as the only two Commissioners for Older People in the UK.
- 34. Most of the contact I had with the Commissioner for Older People in Northern Ireland was through the UK Network of Older People's Organisations that I established. He was a co-signatory to the letters and press statements, which we agreed collectively.
- 35. The Commissioner for Older People in Northern Ireland accepted my invitation to participate in an online roundtable on the rights of older people in care homes held on 23 April 2021. From this, I established my Older People's Rights in Care Homes Group.
- 36. We both spoke at an online British Geriatrics Society seminar on 30 April 2021 on addressing ageism.

<u>4. Overview of the impact of the pandemic on the physical and mental health of older people and those that work with them in their homes</u>

- 37. The pandemic had significant and long-lasting impacts on older people in need of care and support and those who care for them. These impacts are explained in:
 - My response to the Equality, Local Government and Communities Committee consultation on 'The impact of the Covid-19 pandemic and its management on health and social care in Wales', [HH3/03 – INQ000181716];
 - b. My paper 'The Health and Wellbeing of Older People, Recommendations and Action: August 2021' [HH3/04 INQ000184992]; [HH3/04a INQ000184990]; [HH3/04b INQ000184991]; [HH3/04c INQ000184993]; [HH3/04d INQ000184994]; and in
 - c. My reports '*Care Home Voices*' [HH3/05 INQ000181725] and '*Leave No-one Behind*' [HH3/06 INQ000184908].
- 38. I also refer to Age Cymru's "*Tell me More*" engagement pilot project with care home residents.

Care homes

Older people living in care homes

39. In my paper '*The Health and Wellbeing of Older People Recommendations and Action: August 2021'*, I summarised the impact of the pandemic on older people living in care homes as follows:

> 'Lockdown and stringent infection control measures have seen families separated, people unable to participate in the care of their loved ones, increasing numbers of people living with bereavement, and growing recognition of the vital role families and friends play in the wellbeing of care home residents.'

40. I also referred to the findings of Age Cymru's '*Tell Me More*' engagement pilot project with care home residents, which showed that:

'residents are missing visits; visitor and volunteer support are also missed; the impact of losing close friends; spirits have been eroded; residents are scared; wellbeing routines have been broken.... One resident said, 'the worst thing was seeing all the empty chairs.'

41. An enquirer to my Advice and Assistance service described the impact of the different restrictions on people living in care homes compared with those in their own homes as follows:

'Not so long ago I could see mum all the time because we were in a bubble together – now she cannot see her grandchildren face to face. All this is taking a toll on her emotional well-being and her cognitive functioning'.

42. As set out in my 'Care Home Voices' report, one resident summed up how they felt:

'We still want to live'.

43. Also, staff in care homes described the impact on residents:

'Another impact it has had is on the emotional well-being of our residents. Many feel that they have been abandoned by their family and cannot understand why we need to keep them away at the moment.' Care Home Worker

'When any individual is symptomatic all service users are advised to isolate in their bedrooms for 14 days regardless of results of Covid test. This can happen within days of being able to access communal areas due to people being vulnerable to chest infections and similar. This has had a huge impact on the mental health and wellbeing of individuals, people eat and drink less when isolated and there is a decrease in mobility.' Care Home Manager

Families and friends of residents

44. Families and friends of residents, many of whom were older people themselves, also experienced emotional distress. For example, as described in my Care Home Voices report:

'Mum has Alzheimer's and is immobile and prefers to stay in her own room which means she is stimulated by and values family visits. I personally worry that we may never see my Mum again, and her current life experience during lockdown.' Family Member

45. The limited availability of testing in the early months of the pandemic was a cause of worry and concern for families and friends:

'My Dad is 92, my Mum is 89. Dad says why wasn't Joyce important enough to have a test?'

Staff in care homes

46. In my '*Care Home Voices*' report, staff in care homes shared their anxiety and distress. Some also shared that they felt they were not valued for the caring and skilled work they do:

'I got more anxious about my family, colleagues, friends, residents and future. I'm scared every day that I'll bring that virus to my workplace or home.' Care Home Worker

'Testing of staff and residents would have saved a lot of anxiety within the workplace' Care Home Worker

'I have worked in care and support services for 20 years and 10 of those as a care home manager, in this time I have never felt so desperate, tired, stressed, frustrated as I have over the past 9 weeks. I have cried as much as I have these last couple of months for my residents and staff. the staff that stayed have been amazing.' Care Home Manager

'I have had many sleepless nights and have been constantly working to ensure that all [is] okay within the home I feel mentally and physically drained...I don't think my mental state will ever be the same and when I do have time on my own I often cry which is definitely not a thing that I have done.' Care Home Worker

'I earn less than the cashier at Lidl, and I risk my and my family's life every day.' Care home Worker

Communication Issues

47. In my '*Care Home Voices*' report, older people living in care homes and staff raised the impact on communication from wearing face masks, and the barrier that it can create:

'It has impacted me in my job because we now wear face masks and residents struggle to see our facial expressions. They rely on being happy and smiling to trust us with personal care. It's difficult for them to recognise that we are helping them when they can't see our faces.' Care home worker

'Lockdown has to be done but I don't like the facemasks as I miss their smiling face.' Care Home Resident

48. In this report, I highlighted the impacts of face masks and gave an example of how one care home tried to deal with this:

'The use of PPE – particularly paper masks – causes particular issues for people with hearing loss who rely on lipreading, and people living with dementia, who may become distressed if they are unable to 'read' emotional cues from the faces of their carers, and it was interesting to hear that one of the care homes we spoke to had purchased facemasks with a transparent panel so residents could see their carers' mouths.'

49. The ability to be in contact with loved ones through video calls was very important and many homes facilitated this, but it did not suit everyone. It was also an additional task for staff:

'We are able to make regular calls on WhatsApp or Skype with a carer holding the phone as my mother cannot manage this. She is well cared for and treated very kindly and well.' Family Member

Domiciliary care and support in people's own homes

50. In my report, '*Leave No-one Behind*', 'Margaret' describes the impact of the beginning of the pandemic and lockdown:

'I am writing this on my 88th birthday. I have shared lockdown with my husband who has dementia. I am his sole carer, have a neurodegenerative disease and use a walking aid, but between us we make one good one. Sometimes! Lockdown pulled the rug from under us overnight, taking away the secure network of support I have cobbled together to keep us safe in our own home.'

- 51. The key issues that older people and their carers faced were:
 - a. Closure of day centres and other respite services;
 - b. Unavailability of domiciliary care or changes to care 'packages';
 - *c.* Cancellation of domiciliary care by families worried about the risk of Covid being brought into the home; and
 - *d.* Increased pressures on unpaid carers including when a loved one was ready to be discharged from hospital.
- 52. For older people isolated from their families and friends and unable to go out, the mental health impacts included loss of confidence, fear of going out, and anxiety, all of which threated their ability to live independently and had long term consequences.

53. In my paper '*The Health and Wellbeing of Older People, Recommendations and Action: August 2021'*, I refer to an Age Cymru survey showing a sharp increase in the number of unpaid carers during the pandemic and the pressures on them:

'The preliminary analysis of an Age Cymru survey found that 23% of respondents had taken on additional caring responsibilities during the pandemic. For some older unpaid carers, and those caring for people living with dementia the combination of the closure of respite facilities such as day centres, combined with lockdown restrictions, has pushed them towards breaking point.'

- 54. The need for care after hospital discharge was also a problem experienced by older people and their families. Through my Advice and Assistance service, I was aware of instances where an older person had been discharged from hospital without any support in place, other than that provided by family members, and without a Care and Support Assessment or a Carer's Assessment for their family members.
- 55. There were also problems caused by older people having to remain in hospital because of a lack of domiciliary care. For example, an enquirer's mother experienced a six-week delayed hospital discharge as there were no domiciliary carers available to support her needs.
- 56. Some enquirers to my Advice and Assistance service felt that they had no other option other than to pay privately for domiciliary care in order for their loved one to return home from hospital.
- 57. I summarised these impacts in my response to the Equality, Local Government and Communities Committee on '*The impact of the Covid-19 pandemic and its management on health and social care in Wales*',:

'Older people, carers, families and friends have been significantly affected by Covid-19 itself and by the impact of the pandemic on health and social care services, including specialist support services for people suffering abuse, and prevention and early intervention services for people experiencing deconditioning silently in the community. Infection control measures and staffing pressures have disrupted normal relationships and communication with relatives and their contribution to the care and support of their loved ones. This has intensified people's frustration, worry and distress at a difficult time, caused some people to suspect discrimination in how their relatives were treated and fuelled a demand from some people to know more about their rights.'

5. Liaison and communication with the Welsh Government

Overview of meetings with the Welsh Government

- **58.** Throughout the period, I met regularly with Julie Morgan MS, Deputy Minister for Health and Social Services ("the Deputy Minister for HSS") and Albert Heaney, Deputy Director General for Health and Social Services ("the Deputy Director General for HSS") (from June 2021 the Chief Social Care Officer) and his team. These meetings provided me with an opportunity to: question the Welsh Government on its response in respect of older people; discuss the experiences and issues being faced by older people and the concerns they were raising with me and my team; and propose changes in the policy and actions of the Welsh Government to better support older people and uphold their rights. Issues concerning the care of older people featured prominently in these meetings.
- **59.** The meetings were also a forum for the Welsh Government to inform me of developments, discuss emerging issues with me, and also provide an opportunity for us to work constructively together on a number of issues affecting older people.
- 60. On 9 April 2020, I met the Deputy Minister for HSS and raised concerns about the situation for residents and staff in care homes. On 14 April 2020, I wrote to the Deputy Minister for HSS following this meeting reiterating my concerns and the anxieties being experienced and calling for action to be led personally by the Deputy Minister for HSS [HH3/07 INQ000349334]
- 61. On 21 April 2020, the Deputy Minister for HSS responded to my letter of 14 April 2020 [HH3/08 INQ000184940] but this did not give me assurance that anything was going to change, and in my opinion, it indicated a lack of urgency and priority. In her letter, the Deputy Minister for HSS acknowledged the impact on older people living in care homes and their families but stated that:

"...the Social Care Sub-Group chaired by the Deputy Director General is working to

address the many issues which are arising across the social care sector – including those referred to in your letter – as a matter of urgency".

- **62.** This letter invited me to join the Social Care Sub-Group and confirmed there would be a care home workstream as part of the Social Care Sub-Group. The Deputy Minister for HSS further stated in her letter that an additional plan of action over and above these arrangements will not "*add value*".
- **63.** I was very troubled by this response by the Deputy Minister for HSS, which, whilst saying that matters were being dealt with urgently, did not give me assurance as the mechanisms appeared to be a weekly meeting and a workstream of a sub-group that had not yet been established. In my view, the response suggested that the Welsh Government did not appreciate the need to set out action publicly to help older people and their families know what was happening, and also to reassure them that the Welsh Government was aware of their situation and taking action. The Welsh Government did not, at this time, take my advice on the need for a published care homes action plan.
- **64.** I was particularly concerned about the delays to introducing testing for Covid-19 for residents and staff in care homes. I raised this in my meetings with the Deputy Minister for HSS and by letter to the Welsh Government.
- **65.** Following my public statement on 21 May 2020 in which I called for action by the Equality and Human Rights Commission ("**EHRC**"), to "examine and scrutinise the action taken by the Welsh Government, as part of a wider inquiry that looks at older people's experiences and the action that has been taken across the UK" [HH3/09 INQ000181746], I was invited to a meeting on 28 May 2020 to discuss the issues I had raised. The meeting was attended by the Deputy Minister for HSS and a number of officials including the Chief Medical Officer for Wales and Chief Nursing Officer for Wales.
- **66.** During this meeting, the Welsh Government officials and the Deputy Minister for HSS outlined the measures they had put in place for care homes and the actions that had been taken. They also updated me on the progress being made on testing and the work underway on visiting. I raised the issues that I was concerned about including GP support for care homes, visiting, and access to hospital care. I asked a specific question on whether those at the meeting thought that care homes were safe. The Chief Medical Officer responded to say that they were safer than they were and on an improving

trajectory. However, he went on to say that if he was working at home, he would take a relative into his own home from a care home.

- **67.** I updated the meeting on the work that I was doing to hear from residents, family and friends and staff working in care homes (which formed the basis of my '*Care Home Voices*' report).
- **68.** The Deputy Minister for HSS invited me to send across any other questions and sought to reassure me that the Welsh Government was committed to making life as good as possible for people living in care homes [HH3/10 INQ000253855].
- **69.** On 3 June 2020, I emailed the Deputy Minister for HSS, copied to the Deputy Director General for HSS, to follow up on our discussions and the questions I had raised, ahead of the next scheduled meeting the following day [HH3/11 INQ000185018].
- 70. On 17 June 2020, I emailed the Deputy Minister for HSS ahead of a meeting with her on 18 June 2020 highlighting concerns I had on the roll-out of testing for Covid-19 and asking for an update [HH3/12 -INQ000185017].
- **71.** As I explain in Section 7 below, I wrote to the Minister for HSS jointly with the Head of the EHRC in Wales on 20 July 2020. A number of meetings were held and correspondence exchanged, during the remainder of 2020.

Membership of Welsh Government Groups

72. Members of my team attended, and contributed to, several working groups established by the Welsh Government. These included groups that were set up to: share information; develop policy and guidance; and consider responses to the issues being faced by people in need of care and support. Our involvement in these groups provided us with the opportunity to feed in the experiences and issues being raised by older people. For some of these groups, members of my team stated that they were attending in an observer capacity – the degree of our involvement and participation depended on the purpose and role of the particular working group.

The Social Care Planning and Response Sub Group

73. I was represented on the Social Care Planning and Response Sub-Group by my Heath and Care Lead and we had observer status on the group. My Health and Care Lead attended the meetings regularly and it was a helpful source of information and intelligence. The Sub-Group discussed issues including care home visiting, Covid-19 outbreaks in care homes, hospital discharge to care homes, and vaccinations. We were able to highlight issues that older people and their families had contacted my Advice and Assistance service about.

The Social Care Stabilisation and Reconstruction Board

74. I was represented on the Social Care Stabilisation and Reconstruction Board by my Health and Care Lead, and we had observer status on the group. The issues we raised included how the pandemic had impacted the resilience of older people and carers, the need for services to be more joined up for older people, and issues brought to our Advice and Assistance service.

The Care Home Visiting Guidance Stakeholder Group

- 75. The Care Home Visiting Guidance Stakeholder Group was set up by Care Inspectorate Wales and was an important and useful way of bringing together the different and competing perspectives and expertise as part of the policy development process. I attended the first few meetings of this group in June 2020 and thereafter, was represented by staff from my office who attended regularly.
- 76. My staff raised questions, particularly concerning the rights of older people; proposed ways forward; and contributed to the discussions, drawing on the experiences of older people and their families that were being shared with us. Specifically, my staff advocated for the human rights of residents, including the right to a family life, questioned suspension of outdoor visiting when infection rates were low, and opposed imposition of blanket bans on visiting. Between the meetings, my staff reviewed and commented on the many different versions of the guidance on visiting which evolved with the changing situation.

The Covid-19 Moral and Ethical Advisory Group

77. I was invited to join the Covid-19 Moral and Ethical Advisory Group ("CMEAG") on 3 April 2020 by Dr Heather Payne, Senior Medical Officer, and Name Redacted Head of Equality, Welsh Government, and attended the first meeting on 6 April 2020. I, or my Health and Care Lead, subsequently attended the regular meetings.

- 78. I provided comments to the draft values and principles document produced by CMEAG and then published. Thereafter, working with three other members of CMEAG, I produced a discussion paper for the CMEAG meeting on 14 May 2020 on the role of CMEAG over the coming weeks and months. [HH3/13 – INQ000185044]
- 79. I sent a position paper entitled 'Care Home Visiting in Wales: Position Statement' to Dr Heather Payne, Chair and Name Redacted Secretary of CMEAG on 30 September 2020. [HH3/14 – INQ000185055]
- 80. For the CMEAG meeting on 23 October 2020, I produced a brief paper on Clinical Ethics Committees and older people. [HH3/15 – INQ000185046] [HH3/15a – INQ000185045]
- 81. Throughout the lifetime of CMEAG, I commented on draft papers and contributed to discussions in meetings. It was a very valuable group, bringing together different expertise and perspectives, and I was able to raise issues concerning older people, as well as highlight relevant areas of my work. For example, in August 2020 my 'Leave No-one Behind' report was circulated to CMEAG members and discussed at a subsequent meeting.
- 82. CMEAG provided me with an opportunity to comment by email on 10 December 2020 on the draft surge guidance about which I had significant concerns, and I raised a number of concerns and questions. [HH3/16 – INQ000185011]

6. Overview of UK Network of Older People's Organisations and Older People's Rights in Care Homes Group

- **83.** In addition to establishing regular contact with older people and their networks, I wanted to engage with organisations and individuals working with older people across the UK. I therefore established, in March 2020, an informal UK Network of Older People's Organisations. This network was for those of us in the UK who were leading older people's organisations and would have a public and evolving role over what, I anticipated at that time, would be the following few months. The aim of this initiative was to support each other and share information and ideas. We also used our meetings to discuss how the different governments and agencies were responding to issues affecting older people, for example policies and approaches to visiting in care homes.
- **84.** The membership of the group included colleagues from England, Scotland and Northern Ireland: Age UK; Independent Age; Age Cymru; the Commissioner for Older People in

Northern Ireland; Age Northern Ireland; Scottish Care; Age Scotland; **I&S** (for the first two months).

- 85. The first meeting of the UK Network of Older People's Organisations was held on 26 March 2020 via Zoom. We decided that we needed to speak out together, urgently, on the rights of older people, especially with regard to access to medical treatment. Consequently, we issued a joint public statement on 30 March 2020: '*The rights of older people to treatment during this pandemic*'. [HH3/17 INQ000181736]
- 86. On a number of occasions during the pandemic, and in order to maximise impact, the UK Network of Older People's Organisations issued joint public statements calling for action at a UK level or highlighting issues of common concern and risks to older people. For example, on 6 April 2020, we issued a statement on treatment decisions and Do Not Attempt Cardiopulmonary Resuscitation ("DNACPR") [HH3/18 INQ000181738]
- 87. On 16 April 2020, we wrote to Rebecca Hilsenrath, Chief Executive of the EHRC setting out our serious concerns about the issues affecting older people and the infringement of their rights. These included issues about: blanket policies restricting access to treatment; DNACPR; and restriction of access to hospital treatment if living in a care home. We asked to meet as a matter of urgency and we met on 11 May 2020.
- 88. Following the meeting on 11 May 2020, the EHRC issued a welcome statement on 14 May on older people's rights indicating that it would consider using all its powers to protect those rights. [HH3/19 – INQ000184943]
- **89.** The Older People's Rights in Care Homes Group developed from two online 'roundtable' meetings held in March and April 2021. The meetings were held to bring together organisations from across the UK to gather perspectives on what could be done to strengthen the rights of older people living in care homes now and in the future. Their purpose was to look at, and identify, common areas of concern from across the UK and discuss ideas on practical changes that might be made to improve rights, as well as identify wider structural changes required to make change happen.
- **90.** The membership of the Older People's Rights in Care Homes Group included: Age Cymru, Age UK; Association of Directors of Social Services Cymru; Care Forum Wales; Care Inspectorate Wales; Commissioner for Older People in Northern Ireland; Equality and Human Rights Commission Wales; the National Care Forum, the Relatives and

Residents Association (now Care Rights UK); Scottish Care; Social Care Wales; and Professor John Williams, Emeritus Professor of Law, Aberystwyth University.

- **91.** The Older People's Rights in Care Homes Group initially identified the following areas to work on:
 - a. Raising awareness of the rights of older people living in care homes;
 - b. Producing information about Human Rights and legal rights;
 - c. Promoting dignity, respect and the upholding of rights;
 - d. Working with service and workforce regulators to embed Human Rights in inspection frameworks and within social care practice;
 - e. Increase residents' security of tenure;
 - f. Increasing care home residents' access to independent advocacy, in particular for those residents without family or friends;
 - g. Develop a strategic approach to using complaints data to improve practice;
 - h. Influencing policy and legislation; and at a later stage
 - i. the need to carry out work on access to healthcare for older people living in care homes.

7. Working with the Equality and Human Rights Commission

- 92. On 20 July 2020, I wrote to the Minister for HSS jointly with the Head of the EHRC in Wales, expressing concern about the rights of older people in care homes and requesting information on the Welsh Government's decision-making processes. [HH3/20 INQ000185026]
- 93. Specific information was requested on:
 - a. Equality impact assessments and scientific evidence for all decision making linked to care homes;
 - Evidence of how due regard was given to the three needs of the public sector equality duty in the decision-making process around protecting care homes by the Welsh Government; and
 - c. Details of the arrangements in place to review and revise policies to ensure they comply with the public sector equality duty and specific duties.
- 94. On 21 July 2020, the Head of the EHRC in Wales and I issued a joint statement announcing our joint work to scrutinise Welsh Government decision-making. [HH3/21 INQ000181751]

- 95. On 30 July 2020, the Welsh Government announced its Care Home Action Plan. I was pleased that a public action plan had been announced, following my calls for this from 14 April 2020, but disappointed that it had taken this long to be developed and announced, and that the Welsh Government had initially rejected my advice stating that it would add "*no value*". [HH3/22 INQ000336948]
- 96. On 7 August 2020, we received a letter from the Minister for HSS confirming that a full response would be provided by the Deputy Director General for HSS and there was a joint meeting on 19 August 2020 with Welsh Government Ministers and officials. [HH3/23 – INQ000136959]
- 97. On 10 September 2020, the Head of the EHRC in Wales and I met with the Deputy Director General for HSS and members of his team. The meeting was held as the Welsh Government wanted to discuss and clarify the scope of the information that we had requested in our letter of 20 July 2020 to Ministers.
- 98. Following this meeting, on 14 September 2020, the Head of the EHRC in Wales and I received an email from the Deputy Director General for HSS stating that the Welsh Government was approaching its engagement with us in the spirit of co-operation and was:

"...committed to learning from the initial phase of the pandemic to better tackle the challenges in the months ahead." [HH3/24– INQ000185034]

- 99. This email set out what the Deputy Director General for HSS and his colleagues felt was a "fair reflection of conclusions from the meeting" and the three areas that we had highlighted, which the Welsh Government response would, therefore, prioritise. These were "testing in care homes", "the provision of PPE to care homes" and "guidance related to visits to care homes".
- 100. A further joint meeting took place with the Deputy Minister for HSS on 16 September 2020.
- 101. On 17 September 2020, the EHRC in Wales and I wrote to the Deputy Director General for HSS in response to the meeting held on 10 September 2020 and his email of 14 September 2020. In this letter, we agreed and further clarified that,

"...the Welsh Government response would focus on care homes, specifically: decisions on testing (including decisions made to discharge people into care homes from hospital without testing); the provision of PPE; and visits to care homes.

102. We requested further evidence to demonstrate how decisions were made by the Welsh Government in relation to these three specific areas. We also stated that:

"...overall we would like to see evidence of how the rights of older people living in care homes were considered from the beginning of the 'delay phase' 13 March 2020 to 18 June 2020 (the end date stated in the annex to our letter of 20 July 2020) in terms of the actions take to protect and support them across Welsh Government." [HH3/25 – INQ000184950]

- 103. On 28 September 2020, the Head of the EHRC in Wales and I met with the Deputy Minister for HSS and officials to discuss human rights during the pandemic and future planning. In the meeting, the Deputy Minister for HSS updated us on the Welsh Government's work to respond to our information request as set out in our letter of 20 July 2020. We were advised that the Welsh Government aimed to respond by the second week of October, but this could be delayed because the officials working on the response were also dealing with the increased spike in Covid-19. I stressed the importance of the work so that lessons could be learnt and shared. The Head of EHRC in Wales also stressed this and the importance of Welsh Government's leadership role. The Deputy Minister for HSS sought to assure us that older people were high on the Welsh Government's agenda and that it is important that older people's rights are at the heart of decision-making.
- 104. On 2nd November 2020 (received by email 4 November 2020), the Deputy Director General for HSS wrote to me and the Head of the EHRC in Wales, setting out the Welsh Government's approach to impact assessments during the pandemic. [HH3/26 – INQ000338266]
- 105. On 27 November 2020, the Head of the EHRC in Wales and I wrote jointly to the Minister for HSS to state that the evidence provided to us was not sufficient to address the concerns highlighted and the EHRC would write separately in the performance of its regulatory role. We also requested a meeting. [HH3/27 – INQ000185013]; [HH3/27a - INQ000185014]

- 106. The EHRC in Wales wrote to the Minister for HSS on 30 November 2020, requesting further information and requiring a response by 8 December 2020. On 8 December 2020, the Head of the EHRC in Wales and I both received a letter from the Minister for HSS accepting the request to meet to discuss how lessons could be learned to ensure older people's rights are protected and promoted. [HH3/28 INQ000184926]
- 107. I am aware that on 16 December 2020, the Minister for HSS wrote to the EHRC in Wales in response to concerns raised in relation to the evidence provided previously by the Welsh Government.
- 108. On 17 December 2020, the Head of the EHRC in Wales and I attended a further meeting with the Minister for HSS, the Deputy Minister for HSS and Welsh Government officials. This was following the letter from the Minister for HSS on 8 December 2020 and focused on lessons learnt and how they were being applied. The Minister for HSS said that lessons were being applied and impact assessments were now being carried out on a more regular basis. The Welsh Government officials updated me that internally there was recognition that there were gaps in the early stages of the pandemic, including the reporting of impact assessments. An exercise had been undertaken to ask policy leads to explain the thinking that they had applied to the impact of policies they had undertaken. Officials were now particularly trying to address the recording of impact assessments. A new group had been set up to raise staff awareness and training to share good practice.
- 109. I am aware that on 21 December 2020, the EHRC in Wales wrote to the Minister for HSS. On 22 December 2020, the Head of the EHRC in Wales and I wrote jointly to the Minister for HSS welcoming the Welsh Government's recognition that it needed to improve its practice to ensure that older people's rights are upheld when decisions are being made. We both welcomed the steps being taken by the Welsh Government to do this and stated that the EHRC in Wales would continue to work with Welsh Government to review its processes and compliance with the Equality Act 2010. [HH3/29 – INQ000185005]
- 110. The EHRC in Wales also carried out work resulting in the publication of its report entitled 'Equality and Human Rights in residential care in Wales during coronavirus' in October 2020. I participated in a roundtable held as part of developing this work. This report set out a series of recommendations to the Welsh Government. [HH3/30 – INQ000253853]

- 111. I met a number of times with the Head of the EHRC in Wales to discuss our work with the Welsh Government. At the conclusion of this work, we agreed an (unpublished) statement about the work we had carried out to scrutinise Welsh Government's equality and human rights record during the Covid-19 pandemic between April 2020 and December 2020 and to summarise what we found and what happened as a result.
- 112. Our summary was as follows:
 - a. There were shortcomings in the Welsh Government's decision-making processes with regards to equality and human rights considerations during the first months of the pandemic. This includes an absence of Equality Impact Assessments as legally required by the Public Sector Equality Duty;
 - b. There were shortcomings in the evidence that Welsh Government provided and they were not able to adequately evidence the appropriate consideration of older people and their rights;
 - *c.* Welsh Government was unable to evidence that its decisions were taken within a human rights legal framework; and
 - *d.* There was insufficient attention given to older people living in care homes and upholding their rights.
- *113.* As to what had happened since and what action was being taken, our conclusions were as follows:
 - a. Welsh Government has improved its consideration of human rights following the scrutiny by the Commissioner and the EHRC including setting up an internal working group to help embed practice;
 - Welsh Government continues to engage constructively with the EHRC, including the provision of training to officials by the Equality and Human Rights Commission;
 - *c*. Welsh Government is undertaking Equality Impact Assessments as part of its policy and decision-making processes;
 - *d*. There is an explicit commitment to the rights of older people in the new Strategy for an Ageing Society and the Commissioner will be scrutinising the actions that flow from this; and
 - *e.* The Commissioner, working with the EHRC and other organisations in Wales and the UK, is leading work on how to improve the rights of older people living in care homes.

114. I continued to meet and work constructively with the EHRC in Wales throughout the pandemic and the Head of the EHRC in Wales became a member of my Older People's Rights in Care Homes Group.

8. Discharge of patients from hospitals

- 115. On 13 March 2020, the Welsh Government announced that it was moving from 'contain' to 'delay' phase in its response to the pandemic, which included:
 - a. Expedite discharge of vulnerable patients from hospital;
 - b. Fast-track placements to care homes by suspending the protocol which gives the right to a choice of a care home; and
 - c. Relax targets and monitoring arrangements.
- 116. The concerns raised with me by older people, their families, and those working in social care were: the lack of testing for Covid -19 of patients before discharge from hospital; the lack of PPE for social care workers (in care homes and domiciliary care); and concerns related to discharge to care homes and discharge to people's own homes, or homes of relatives.
- 117. For example, as described in my paper 'The Health and Wellbeing of Older People':

'The Commissioner's office has heard from people who have felt pressured into having their older relatives stay with them after discharge. The team has heard that clinical staff have been "a bit abrupt" with them and that clinical staff have told relatives that support would be in place for when their relative went home; support which has not necessarily been forthcoming. One inquirer said that the local social support service refused to attend her father, who had been diagnosed with Covid-19, as they did not have PPE. This meant that the inquirer had to provide the care herself. A week later her father became unwell and had to be admitted to hospital, where he died a few days later.'

- 118. The discharge of older people from hospitals to care homes without testing for Covid 19 infection was a key concern in the early weeks and months of the pandemic, which I recollect I discussed at my meetings with the Deputy Minister for HSS. Indeed, the issue of testing for older people in care homes was one of the factors in my call for the Equality and Human Rights Commission to take action.
- *119.* At a meeting with the Deputy Minister for HSS on 10 December 2020, the Deputy Minister for HSS and her officials outlined the Welsh Government's proposed changes

to discharge guidance and duration of outbreaks in social care, giving me an opportunity to respond and raise any questions.

- 120. On 11 December 2020, I received a follow up letter from Anthony Jordan, Deputy Director, Inclusion and Business ("Deputy Director for Inclusion and Business"), with an opportunity to provide my views on the two Consensus Statements: "testing criteria for discharge to care homes" and "defining the duration of outbreaks in closed settings" by 15 December 2020. [HH3/31 INQ000185021]; [HH3/31a INQ000185024]; [HH3/31b INQ000056319]; and HH3/31c INQ000227902].
- 121. I responded to the Deputy Director for Inclusion and Business by email on 14 December 2020, raising a number of questions and concerns [HH3/32 – INQ000185048]. My understanding was that the proposed change in policy involved some increased risk to older people in care homes and there was uncertainty about how the change would work in practice. I was concerned that a policy change may take place to deal with pressures in hospitals, but which would potentially transfer pressure and risks to care homes.

I asked whether the policy change would be tested out/piloted before being rolled out more widely, what information patients in hospital would be given about the risks and decisions on discharge, and how would they/their advocates be involved in decisions about their discharge. I also questioned the use of the term 'closed setting' to describe care homes.

122. The Deputy Director for Inclusion and Business responded to my email on 14 December 2020 and specifically to the questions I had raised. However, I had some outstanding concerns and questions which I raised in an email to the Deputy Director for Inclusion and Business dated 16 December 2020, including a request for information on how the Welsh Government would closely monitor the impact of the changes and how my views, and those of other stakeholders, would be reflected in that monitoring. [HH3/33 – INQ000185049]

9. Management of the pandemic in care homes in Wales

- **123.** My work concerning care homes focused on the following key areas:
 - **a.** Responding to concerns and enquiries from, and providing advice and information to, families and friends of older people living in care homes through my Advice and Assistance service;

- b. Gathering and sharing the experiences of people living in care homes, working there, or with loved ones in care homes, through my '*Care Home Voices*' report and sharing this with policy- and decision-makers;
- **c.** Working to improve visiting arrangements and encouraging families and friends of older people living in care homes to share their experiences of visiting arrangements with me;
- **d.** Pressing the Welsh Government on the availability and speed of testing for care homes; the roll-out of the vaccination programme in care homes; raising issues concerning hospital admissions and discharge, and access to health services; and
 - e. Increasing awareness of older people's rights in care homes.
- 124. I identified the need for a published action plan for care homes, raising this in meetings and in writing with the Welsh Government, and issued a public statement on 15 April 2020 [HH3/34 – INQ000181739]
- **125.** My serious concerns about what was happening to older people living in care homes led me to call on the Equality and Human Rights Commission to take action as I have explained in Section 7 above.
- **126.** In my '*Care Home Voices*' report, I outlined some of the challenges staff working in care homes shared with me in the early weeks of the pandemic:
 - a. 'A number of responses from care home managers and staff highlighted the difficulties they had faced in accessing crucial information and guidance to support them in minimising the spread of the virus and protecting residents and staff. Particular issues were highlighted about the amount of rapidly changing information that care homes were receiving, often from multiple bodies, which was often confusing or contradictory.'
 - **b.** "To have better communication and guidance from the start. I felt that Care Homes were left to deal with this life-threatening pandemic on our own at the beginning." Care Home Worker
 - **c.** "It took almost 4 weeks for agencies to get together to co-ordinate sending information through. The information ran to so many pages it took all our time to read it, digest it and put it in a useable form for our staff to understand and

implement quickly. It was geared towards clinical setting and not to care homes and some entirely inappropriate." Care Home Manager

- **d.** "We would like more direct information, so many reports aren't a true reflection of what is happening. We are sent endless emails every day from 2-4 sources repeating the same information making it impossible to trace the important information needed, or you just don't get the information needed." Care Home Worker
- 127. Some care home workers and owners/managers also highlighted a lack of practical guidance to support them in their work:
 - a. "More training, I feel that if staff were made aware and had in-depth training, we would be better equipped to handle the Covid-19 pandemic. A clear communication between the workers and the service so we are kept involved in decisions as they happen and have a voice in the decisions." Care Home Worker.
 - b. "Clearer guidance from Welsh Government, Care Inspectorate Wales, Public Health Wales and local authorities - which all reflect clear messages with practical advice. Not being bombarded with loads of info (some conflicting) from loads of sources." Care Home Manager.
 - c. "More in depth guidelines on PPE and action plans ready in place by organisations to ensure we are ready for our next crisis." Care Home Worker.

Infection prevention and control measures

- **128.** Within my '*Care Home Voices*' report, I gave examples, shared with me by staff in care homes, residents and their families, of the impact of infection prevention and control measures on the health and wellbeing of residents. For example, the impact of residents having to isolate in their rooms:
 - **a.** "When any individual is symptomatic all service users are advised to isolate in their bedrooms for 14 days regardless of results of Covid test. This can happen within days of being able to access communal areas due to people being vulnerable to chest infections and similar. This has had a huge impact on the

mental health and well-being of individuals, people eat and drink less when isolated and there is a decrease in mobility." Care Home Manager

- 129. While the need to use PPE was understood by the older people we spoke with, the barriers it can create between residents and staff were also highlighted:
 - a. "Lockdown had to be done but I don't like the facemasks as I miss their smiling face." Care Home Resident
 - b. "It has impacted me in my job because we now wear face masks and residents struggle to see our facial expressions. They rely on being happy and smiling to trust us with personal care. It's difficult for them to recognise that we are helping them when they can't see our faces." Care Home Worker
- 130. The use of PPE particularly paper masks caused particular issues for people with hearing loss who rely on lipreading, and people living with dementia, who may become distressed if they are unable to 'read' emotional cues from the faces of their carers, and it was interesting to hear that one of the care homes we spoke to had purchased facemasks with a transparent panel so residents could see their carers' mouths.

Testing of residents for Covid-19

- 131. "During [the] early part of pandemic, difficulty accessing PPE for staff, a lot of staff off sick but no testing available, which delayed people coming back and others working with Covid-19 spreading infection. No government guidelines on transfers of residents from hospital our staff going to other homes to help staffing levels, maybe transferring infection back to our home." Care Home Worker
- 132. As set out in Section 5 above and in the work I undertook with the EHRC in Wales described in Section 7, I was very concerned about the delays to introducing testing for Covid-19 for residents and staff in care homes and the consequences of this.
- 133. As I state in my 'Care Home Voices' report:
 - a. The Welsh Government's policy on testing was heavily scrutinised, and gradually shifted over a period of several weeks following calls from myself, and many others, for testing to be made available to all care home residents and staff in Wales.
 - b. Access to testing both for residents and care home staff was a key issue highlighted by many of those who responded. It was clear from the responses that

testing was seen as a crucial way to keep residents and staff safe, and that the limited availability of testing was a cause of significant worry and concern.

- c. "My Dad is 92, my Mum is 89. Dad says why wasn't Joyce important enough to have a test. We have all cried many tears and I personally feel care home residents have been sacrificed." Family Member / Friend
- d. "Care homes have been totally neglected in this pandemic I feel and lack of testing available to care home residents is shameful." Care Sector Professional
- e. "Testing of staff and residents would have saved a lot of anxiety within the workplace." Care Home Worker
- f. "Access to staff for testing when supporting people with Covid this was only available if symptomatic which left staff feeling vulnerable." Care Home Worker
- 134. Responses also indicated that despite changes in testing policy, care homes still experienced difficulties in accessing testing for residents and staff:
 - a. "When we had a resident who was symptomatic and we requested testing straight away via Public Health Wales – [the Health Board] decided that the resident at that time was not a priority for testing, this was a particularly anxious time for the resident, her family & staff, it was most unhelpful." Care Home Worker
 - b. "More testing at homes. We have tried for weeks to get tested and hopefully this will now happen in the next 7 days." Care Home Worker
 - c. "We had to "fight" health agencies to get tests for our residents." Care Home Manager
- 135. In addition, concerns were shared about difficulties in obtaining test results, the turnaround times for testing and the potential impact of delays in results being received.
 - a. "Not being able to get testing results, the care home manager was tested a week ago and still no result. Blanket staff testing is not happening despite a resident being tested positive earlier this week." Care Home Worker

Restrictions on access by/to healthcare professionals

136. Ensuring appropriate access to healthcare professionals and healthcare services for older people living in care homes, and support for staff, is a longstanding issue. During the pandemic, the main issues raised with me were: a lack of visiting and support from healthcare professionals, particularly GPs; problems with access to hospital care; and issues with discharge of patients from hospital to care homes.

Restrictions on Access (Visiting)

- 137. I was particularly concerned about the impact of the restrictions on visiting, (both indoor visiting and outdoor visiting), and on older people being able to go out from care homes.
- 138. I raised these issues in my meetings with the Deputy Minister for HSS, with Welsh Government officials, and also with Dr Giri Shankar, Professional Lead Consultant for Public Health Wales ("the Professional Lead Consultant for PHW").
- 139. In my opinion, the initial decision making on visiting, under public health guidance, was based on the risks of Covid-19 infection, but did not take account of the harm to health and wellbeing from older people being isolated within their home and not being able to see loved ones. I also felt that it did not take adequate account of the human rights of older people, for example the right to respect for private and family life. I believe that the focus should have been on how to enable safe visiting and the support that would be needed by care homes to help make this happen.
- 140. My role in the meetings I had at this time was to push for improvements in visiting, based on a better understanding of the impact of the restrictions on older people and their families.
- 141. A significant early problem appeared to be a lack of clarity about where accountability and responsibility lay for the imposition and withdrawal of restrictions in care homes. This was compounded by the rapidly changing guidance and apparent variations in how the guidance was interpreted locally.
- 142. In my opinion, there was a lack of understanding about care homes and the rights of older people living in them, amongst some key policy and decision makers, which needed to be overcome in order to make progress.
- 143. I wrote to the Professional Lead Consultant for PHW on 21 September 2020 in advance of a meeting on 23 September 2020, about the suspension of outdoor visits in

areas where outbreaks had occurred. I was concerned that this may have been a disproportionate response which would be very damaging to the health and wellbeing of older people living in care homes and their loved ones. [HH3/35 – INQ000184951]

- 144. On 25 September 2020, I emailed the Professional Lead Consultant for PHW and Andrea Street, Welsh Government, following up from our meeting on 23 September 2020 and enclosed my paper entitled 'Care home Visiting in Wales – a Position Statement', dated 25 September 2020. [HH3/36 – INQ000185008] [HH3/36a – INQ000184909]
- 145. I sent my paper entitled 'Care Home Visiting in Wales a Position Statement' to the Deputy Minister for HSS and issued a public statement on 28 September 2020. [HH3/37 – INQ000181756] The aim of this paper and public statement was to enable a review of the current position on visiting and how progress could be made collaboratively. I also emailed this paper to the Chair of CMEAG, welcoming her views on the statement and asking if this was an issue where CMEAG might have a role to play.
- 146. I wrote to the Professional Lead Consultant for PHW on 8 February 2021 following contact from a relative of an older person in a care home about indoor visits to care homes being permitted under "*exceptional circumstances*". I was concerned that the relative had been wrongly prevented from visiting their relative and the advice given to the care home by local public health professionals contravened the Welsh Government's guidance in relation to indoor visits for exceptional circumstances. [HH3/38 INQ000184986]
- 147. I received an email reply from the Professional Lead Consultant for PHW on 9 February 2021 and an invitation to meet.
- 148. On 19 February 2021, I issued a public statement welcoming the First Minister's announcement that the Welsh Government would be examining ways to enable more visits to care homes. I stated that the Welsh Government should work with key organisations to develop and publish a route-map so care homes, older people and their loved ones had time to plan and prepare. [HH3/39 INQ000181769]
- 149. I emailed the Deputy Minister for HSS on 2 March 2021 asking for an update on progress made by the Welsh Government towards enabling more routine indoor visits

to care homes and urging an announcement from Welsh Government as soon as possible. [HH3/40 – INQ000184989]

- 150. On 5 March 2021, I welcomed the statement from the Deputy Minister for HSS that indoor visits to care homes would begin again from 13 March 2021 [HH3/41 – INQ000181770] and the First Minister's confirmation on 12 March 2021 that indoor visits would be allowed from the next day. [HH3/42 – INQ000253847]
- 151. On 26 May 2021, I issued a public statement urging anyone facing difficulties with care home visits to contact me and share their experiences. [HH3/43 – INQ000181784] This followed a change to the Welsh Government's Care Home Visiting Guidance to remove the "*two designated visitor*" rule.
- 152. Through my Advice and Assistance service, I continued to hear about problems being experienced by families and friends regarding visits to their loved ones in care homes and I had concerns about a gap between the issued guidance and the reality in practice on the ground.
- 153. On 20 December 2021, I issued a public statement following the Welsh Government's updated guidance concerning visits to care homes which was published in response to the emergence of the Covid omicron variant, its transmissibility, and the increase in cases. [HH3/44 – INQ000181779]
- 154. Much of the development of the national guidance was discussed at the Care Home Visiting Guidance Stakeholder Group. This was an important and useful way to bring together the different and competing perspectives and expertise as part of the policy development process. Staff from my office regularly attended meetings of the Care Home Visiting Guidance Stakeholder Group where they: raised questions particularly concerning the rights of older people; proposed ways forward; and contributed to the discussions, drawing on the experiences of older people and their families that were being shared with us.
- 155. I discussed care home visiting at many of my meetings with the Deputy Minister for HSS who was understanding of the distress being experienced by older people and their loved ones, and the harms that this was causing. The Deputy Minister for HSS was keen to find ways for safe visits to be enabled, including providing Welsh Government funding for care home visiting 'pods' before indoor visiting was allowed.

Vaccinations of people living and working in care homes

- 156. On 16 December 2020, I made a public statement welcoming the beginning of the vaccination of older people living in care homes [HH3/45 INQ000181759].
- 157. On 1 February 2021, I wrote to the Minister for HSS to question the speed of the roll-out of the vaccination programme for people living and working in care homes and requesting information and data, given the Welsh Government's targets for vaccinations had not been met. [HH3/46 INQ000184985] I was also raising these concerns in my regular meetings with the Deputy Minister for HSS and the extent to which there were problems with the available data.
- 158. I received a letter from the Minister for HSS dated 15 February 2021 responding to the specific questions that I had raised in my letter of 1 February 2021. [HH3/47 – INQ000184988]
- 159. I had a further meeting with the Deputy Chief Medical Officer for Vaccines in Wales on9 February 2021, to discuss care home vaccination rates and communication.
- 160. During 2021, my Health and Care Lead regularly attended the Wales Vaccination Stakeholder Board meetings. This was very useful for keeping up-to-date with developments and issues and also enabled me to raise questions and concerns from older people.

<u>10. Restrictions on access or no access to treatment for older people living in</u> <u>care homes</u>

- 161. The UK Network of Older People's Organisations issued a statement on 30 March 2020, '*The rights of older people in the UK to treatment during this pandemic*'. The final two paragraphs stated:
 - a. 'We strongly believe that decisions about treatment should always be made on a case by case basis through honest discussion between doctors, patients and their families that factor in the risks, benefits, and people's wishes. There is no reason to abandon this long-established good practice now; in fact the current health emergency makes it more critical than ever that we keep it.
 - b. In addition, the fact that someone is in need of care and support, in a care home or their own home, should not be used as a proxy for their health status, nor blanket policies applied – for example, over whether they should be admitted to hospital. To make such decisions without considering either an older person's

needs or their capacity to benefit from hospital treatment would be discriminatory and unfair.'

- 162. As a result of my concerns about older people in care homes being able to access hospital treatment, on 14 April 2020, I wrote to the Deputy Minister for HSS calling for a care home action plan to include action to:
 - a. '...ensure that residents are able to access NHS services and treatment that they may need (including for Covid-19) and that there are no blanket policies applied excluding care home residents from receiving hospital treatment if their condition warrants it. Ensure that all care homes are able to quickly access healthcare support and guidance including any need for training, for example, on infection control.' [HH3/07 – INQ000349334]
- 163. I followed this with a public statement issued on 15 April 2020 [HH3/34 INQ000181739]
- 164. In my meeting of 28 May 2020 with the Deputy Minister for HSS and a number of her colleagues, and also in my follow up email of 3 June 2020, I raised the issue of access to NHS services and whether residents in care homes had been able to access hospital care and treatment if their condition warranted it and asked for data on this [HH3/11 INQ000185018]. I met with the Deputy Minister for HSS on 4 June 2020 at which stage she had not seen my email of 3 June 2020, so I went through the issues that I had raised in that email. I understood from our discussion that I would receive a formal response from the Deputy Minister for HSS following the meeting, but this did not happen.

11. Do Not Attempt Cardiopulmonary Resuscitation

- 165. I outline below the experiences and concerns raised with me about Do Not Attempt Cardiopulmonary Resuscitation ("**DNACPR**") and the actions that I took. I do not know whether those affected were in receipt of social care support at the time.
- 166. On 1 April 2020, I issued a public statement and gave a television interview following the shocking letter sent on 27 March 2020 by a surgery to some of its patients saying that they would like to complete a Do Not Attempt CPR form ("a DNACPR form") for them. [HH3/48 – INQ000181737] The letter, sent to patients with serious health conditions, told them they were "unlikely to be offered hospital admission" if they

became unwell with coronavirus and "*certainly will not be offered a ventilator bed*". The letter further stated that the completion of the DNACPR form:

- a. "will mean that in the event of a sudden deterioration in your condition because of a Covid-19 infection or disease progression the emergency services will not be called and resuscitation attempts to restart your heart or breathing will not be attempted".
- 167. The letter also listed benefits to the completion of a DNACPR form, including that:
 - a. "scarce ambulance resources can be targeted to the young and fit who have a greater chance of surviving the infection".
- 168. This letter caused significant alarm and distress to older people and led to older people and their families contacting us about DNACPR and hospital treatment. My team and I continued to have these concerns raised with us throughout the pandemic. I was contacted by a Member of the Senedd concerning a constituent who had been contacted by her GP practice to ask if she would agree to DNACPR and, if hospital treatment was needed, would she agree to stay at home. The older person: had been self-isolating; had no immediate support; was living with depression; was hard of hearing and found this interaction extremely distressing. [HH3/49 INQ000217417]
- 169. I discussed the issue of DNACPR with the UK Network of Older People's Organisations and we issued a joint statement on 6 April 2020 calling on the governments and health services of the four nations of the UK to:
 - a. "...carefully consider they ways they can provide stronger leadership and guidance to ensure that people's rights are upheld." [HH3/50 INQ000282359]
 [HH3/18 INQ000181738]
- 170. I emailed a copy of this joint statement to the Deputy Minister for HSS and the Deputy Director General for HSS on 6 April 2020, for their information.
- 171. I met with the Deputy Minister for HSS on 9 April 2020 by Skype and our discussions included the issues about DNACPR. I sent an email to her following our meeting with a link to a letter on DNACPR from the Chief Nursing Officer and National Medical Director at NHS England to Chief executives of all NHS trusts and foundation trusts,

CCG Accountable Officers, GP practices and Primary Care Networks, and Providers of community health services. This letter stated that:

- a. 'The key principle is that each person is an individual whose needs and preferences must be taken account of individually. By contrast blanket policies are inappropriate whether due to medical condition, disability or age. This is particularly important in regard to 'do not attempt cardiopulmonary resuscitation' (DNACPR) orders, which should only ever be made on an individual basis and in consultation with the individual or their family.'
- 172. In my email, I suggested the need for a similar letter to be issued by the Chief Nursing Officer and Chief Medical Officer in Wales. [HH3/51 INQ000217418]
- 173. I was pleased that, on 17 April 2020, the Welsh Government's Chief Nursing Officer and Chief Medical Officer issued a letter to the Chief Executives, Medical Directors, Directors of Nursing, and Directors of Therapies and Healthcare Sciences in all of the Health Boards in Wales referencing the concerns that I had raised regarding DNACPR and the joint statement issued on 6 April 2020, setting out that:
 - a. "...age, disability or long term condition alone should never by a sole reason for issuing a DNACPR order against an individual's wishes".
- 174. I was also pleased to see the joint statement on 21 April from Healthcare Inspectorate Wales and Care Inspectorate Wales, and welcomed the establishment of the Covid-19 Moral and Ethical Advisory Group. [HH3/52 – INQ000221538] [HH3/52a – INQ000505862]
- 175. For some older people, concerns about DNACPR led to a breakdown in trust in the NHS and anxiety about whether they would get other treatment that they might need or whether this would be denied. An enquirer to my Advice and Assistance service shared his experience. His wife lived in a nursing home and he was contacted by her GP to ask him to agree to a DNACPR and to agree that she would not be admitted to hospital for any reason. The enquirer was seeking information from my team about DNACPR and Advance Care Planning. He had been told that he did not need to sign any DNAPCR documentation, that his verbal agreement was sufficient, and he was unsure if this was correct.

- 176. There were problems with regard to the discussion and communications about DNACPR decisions. As I stated in my written response to the Senedd's Health, Social Care and Sport Committee consultation on '*The impact of the Covid-19 pandemic and its management on health and social care in Wales'*, dated April 2022, 'several enquirers did not know whether a DNACPR order was in place.'
- 177. On 18 May 2022, a member of my team attended and presented at the Welsh Government's Advance Future Care Planning Group meeting to outline the issues and concerns that older people were raising with us and the need to improve the communications with older people, and where appropriate family and friends, about DNACPR decisions.

12. Commissioner's Reports

- 178. Older people are particularly at risk and vulnerable to Covid-19, and to the effects of the restrictions implemented by the UK and Welsh Governments during the pandemic. Within the older population, there are groups of people for whom these risks and vulnerabilities are heightened. This related not just to the health and medical status of older people, but also to, for example:
 - a. Where they lived and whether there were local services available to them;
 - b. Whether they lived in a care home;
 - c. Whether they were online and confident about using digital technology;
 - d. Whether they had family and friends to help them;
 - e. Whether they were at risk of or experiencing abuse of all kinds including domestic violence and financial abuse;
 - f. Whether they were Black, Asian or Minority Ethnic; and
 - g. Their financial position.
- 179. I used a range of methods to gather information and evidence of the impact on older people of the UK and Welsh Government's response to the pandemic and make recommendations for action, and published the following reports, papers and briefings:
 - a. 5 June 2020: 'Covid-19 Information Pack abuse of older people';
 - b. 21 June 2020: 'Care Home Voices';
 - c. 8 August 2020: 'Leave No-One Behind';
 - d. 18 December 2020: 'Accommodation and support for older people experiencing abuse';
- e. 15 June 2021: 'Support Services for Older People Experiencing Abuse in Wales';
- f. 12 August 2021: 'Accessing Health Services in Wales Transport Issues and Barriers';
- g. 1 October 2021: 'State of the Nation';
- h. 1 October 2021: 'Winter Stories'; and
- i. 18 November 2021: 'Ensuring access to information and services in a digital age: guidance for local authorities and health boards'.
- 180. I also established a Black, Asian and Minority Ethnic Advisory Group to advise me on how best to carry out research with older people from minority ethnic communities. The Group met from August 2021 and as a result of their advice I worked directly with organisations and individuals who work with and support Black, Asian and Minority Ethnic older people to gather their lived experiences. A report based on this work was published in May 2024.

Care Home Voices: A snapshot of life in care homes in Wales during Covid-19

- 181. I undertook rapid work to give voice to people living and working in care homes, their families and friends, during the first months of the pandemic. I issued a survey and responses were received via an online form, over the telephone, via email and by letter. [HH3/53 INQ000181730] In May/June 2020, I also held two online engagement sessions with older people living in care homes in north Wales and south Wales to enable more detailed discussions about their experiences.
- 182. I published this report on 21 June 2020 and shared it with Welsh Government Ministers including the Deputy Minister for HSS and officials as well as other key organisations including Care Inspectorate Wales. [HH3/05 – INQ000181725].
- 183. The report highlighted the issues and challenges faced, changes that were needed, and good practice. Below is a summary of the report's key findings:

a. The response to the pandemic:

- i. Fear amongst staff: "I'm scared every day that I'll bring that virus to my workplace or home.";
- ii. Many care home staff were extremely dedicated in unprecedented circumstances, such as dealing with the challenges of the variations in the

availability of Personal Protective Equipment ("PPE"). "In order to deal with the lack of PPE and testing in the early days of Covid-19, 39 of our staff agreed to 'lock down' in the home with our residents 24 hours a day for 12 days."

- iii. The impact of the experience on the physical and mental health of care home staff was significant. "I have never felt so desperate, tired, stressed, frustrated as I have over the past nine weeks.";
- iv. Staff wearing face masks impacted on their ability to communicate effectively with all residents;
- v. The limited availability of testing was a source of anxiety;
- vi. Rapidly changing information and guidance from different bodies: "...was often confusing or contradictory".
- vii. Care Home staff do not get the recognition they deserve and the crucial work they do is not sufficiently valued.

b. Impact on older people's quality of life

- i. Restrictions on visits and difficulties staying connected seriously affected the health and wellbeing of older people. *"It is really difficult not being able to visit my mother and we can see a deterioration in her cognition and state of mind. She is often tearful and we think this is because she does not see her family.";*
- ii. Enforced separation meant that older people were concerned that they would not see their loved ones again;
- iii. Care home staff played a vital role in facilitating video calls, phone calls and passing on messages from loved ones to relatives;

- iv. Alongside safe visits, enabling older people to go out from care homes was also important; "I want to see my family again and go for walks.";
- v. Access to health services was limited, with particular difficulties relating to visits from GPs;
- vi. There was a significant impact on the mental health and emotional wellbeing of residents, particularly those having to isolate in their rooms; "Another impact it has had is on the emotional wellbeing of our residents. Many feel that they have been abandoned by their family and cannot understand why we need to keep them away at the moment."
- 184. The conclusions I drew in my report were that many felt there was not a sufficient focus on protecting and supporting people living and working in care homes in Wales, and limited understanding amongst public bodies in Wales about the policies and support needed to keep older people safe and well.
- 185. I concluded that more action was needed to tackle the disconnect between what was being promised at a policy level and what was being delivered on the ground. I stated that; "It also appears that many of the issues and challenges that have been shared with me could have potentially been avoided, through more effective planning and engagements with care homes at an earlier stage and the provision of clear, practical information and guidance".
- 186. I set out my short term and longer term calls for action which included:
 - a. Improved engagement with care home residents, their families and friends and staff;
 - Deportunities to share views and experiences with policy and decision makers;
 - c. Care home staff and managers to be consulted as policy and guidance for care homes is developed;
 - d. A Welsh Government Action Plan for Care Homes to be published to provide assurance to people living and working in care homes and allow constructive and responsible scrutiny of the decisions being made and the action being taken by the Welsh Government and other public bodies;

187. I used the findings of the report to continue to press the Welsh Government through my meetings with the Deputy Minister for HSS and her officials on the need to enable safe visiting in care homes and reiterated my call for a published action plan.

'Leave No-One Behind' - 18 August 2020 [HH3/06 - INQ000184908]

- 188. This report was based on information, experiences and ideas captured at 16 online engagement sessions I held with older people and those who work with, and support, them across Wales. I concluded that rapid action was still needed to ensure that older people who needed to be were protected and supported, as well as to enable older people to contribute their skills, energy and ideas to the recovery from the pandemic. *"There can be no successful recovery without engaging and enabling older people to play their part in it ... older people's rights need to be better protected, and where they have been removed, reinstated. The exclusion that many older people have experienced and felt must not be allowed to continue."*
- 189. The report addressed five key areas: social care and health services; the economy and older people; stopping the abuse of older people; strengthening communities; and improving communication and inclusion. I refer to social care and health services, stopping the abuse of older people, and improving communication and inclusion below.
- 190. Under each key area, I set out my recommendations for short-term actions for the following three months, as well as longer-term actions.
- 191. Social care and health services: "We are all feeling that if we do get ill, as older people, whether we will get the treatment that we deserve, or if we would be seen as 'dying soon', and if that would result in poorer treatment."
- 192. I called for the following actions to be taken immediately:
 - a. Publish and implement an action plan for care homes ahead of the winter;
 - b. Repeal sections of the Coronavirus Act 2020 that risk limiting older people's rights;
 - c. Reinstate the social support that has been suspended during lockdown;
 - d. Prepare for the winter support older people to access health services again; and Welsh Government to provide additional financial support to local government and the NHS for early preparation and planning for winter; and

- e. Establish a rehabilitation programme for older people to help older people who have experienced physical and mental health deterioration as a result of the pandemic and its restrictions.
- 193. I also set out my recommendations for longer term actions, including: establishing a major healthy ageing programme focused on supporting older people and helping people to age well; and appointing a Chief Social Care Officer in the Welsh Government to act as the head of the profession in Wales and to ensure that social care expertise is at the heart of decision making on a par with the NHS.
- 194. Stopping the abuse of older people: "Where these individuals can go is an issue as refuges may not be the best environment for people with complex needs. There is a lot of training that needs to be done for professionals as understanding of older people experiencing domestic abuse is lacking."
- 195. I called for the following actions to be taken immediately:
 - a. Raise awareness of the risk of abuse and where to go for support through the media and via public bodies and networks;
 - b. Roll out and promote training to professionals and key workers so they can identify abuse and know what help and support is available; and
 - c. Assess the availability of suitable accommodation and support for older people needing to leave abusive relationships and put in place what is needed.
- 196. My recommendations for longer term actions included: the Welsh Government should develop and publish an All Wales Action Plan to stop the abuse of older people and ensure appropriate resources are available to support its delivery.
- 197. Improving communication and inclusion: "So many feel disconnected, mainly because so many don't use social media. As many times as my group have been shown even basic use of tablets, phones, they don't feel confident to use them when alone. This of course makes many feel discriminated against as they don't get vital information."
- 198. I called for the following actions to be taken immediately:
 - a. Public bodies should take action to ensure that public health messaging is communicated more effectively to older people.

- b. Undertake community-level audits of older people who have been digitally excluded during the pandemic and provide user-friendly devices with access to the internet.
- c. My recommendations for longer term actions included: placing a duty on public bodies in Wales to demonstrate how they will engage with and serve citizens that are not online; and health boards and local authorities establishing outreach programmes to build digital confidence for older people to access digital public services.

'Accommodation and support for older people experiencing abuse' (Report exhibited at [HH3/54 – INQ000184912])

- **199.** My Abuse Action Group had discussed the difficulties for older people who needed to leave abusive relationships, and the lack of appropriate accommodation and support for them to move to. A member of this group initiated a survey of Directors of Social Services in Wales (19 out of 22 responded) and an online workshop was held on 4 November 2020 to provide an opportunity to share information and discuss the way forward. The Deputy Minister for HSS spoke at the online event and was very supportive of the work.
- **200.** This report which was based on the survey findings, the presentations, and discussions at the event, listed the immediate and longer-term changes needed: improve awareness; build the evidence; develop housing and support options; improve access to exciting services and develop more specialist services for older people; and improve access to justice.

'Support services for older people experiencing abuse in Wales' (Report exhibited at [HH/55 – INQ000184915])

- 201. I commissioned research to: undertake a comprehensive mapping exercise of the services throughout Wales to support older people experiencing or, at risk of, abuse; identify the availability and type of services being delivered in Wales; and consider whether the support currently available is sufficient to ensure older people can access the help they need, when and where they need it.
- 202. The information was used to develop a new abuse support services directory, which can be used by older people and stakeholders to find the services available in their area.

- 203. Key recommendations of this report covered: services and support; awareness and understanding of older people's experiences; data collection; training; and policy, strategy and legislation.
- 204. The above reports, combined with my work with the Abuse Action Group and Steering Group, helped to ensure the Welsh Government's commitment to produce a National Action Plan to prevent the abuse of older people, a draft of which was published for consultation on 8 August 2022. The Welsh Government also responded positively to my advice on the need for specific communications to raise awareness of the abuse of older people and how to get help and support. There were Welsh Government communication campaigns run in March 2022.

"Winter Stories" - 1 October 2021 (Report exhibited at [HH3/56 – INQ000181728])

- 205. I wanted to hear more in-depth experiences of older people through the winter months and commissioned a researcher to work with older people from all areas of Wales between December 2020 and March 2021, to capture their experiences of winter and the effects of the pandemic on their lives: "*It has given me more time to think about things, and there is something about the winter months which makes it worse, it's when you close the curtains, you know you are alone then, leaving you with time to think about those you have loved and lost. I've got a picture of my family in my hallway, my late wife, children and grandchildren are in it, and I say goodnight to them all every night before I go to bed."*
- 206. I did not make any recommendations to the Welsh Government or others in this report, but it was important to share it widely to increase understanding of the experiences of older people and the impacts of the pandemic and the response to it. I also used the report to inform my work and that of my team.
- 207. The report reinforced learning from earlier work and contact with older people in Wales, showing: the detrimental impact the pandemic and its restrictions had on people's health and wellbeing; how older people felt a loss of sense of purpose during this time; the importance of being online; and the value of support from family and friends and the wider community.

"State of the Nation 2021" – 1 October 2021 (Report exhibited at [HH3/57 – INQ000184918])

- 208. My 'State of the Nation' report brought together a wide range of data, evidence and research to provide a detailed overview of people's experiences of growing older in Wales and assessed how things had changed since the publication of my previous 'State of the Nation' report in October 2019.
- 209. The following is a summary of the report's key findings:
 - Accessing community services, particularly health and care, was difficult for older people;
 - b. Unpaid care increased significantly as social care services have been withdrawn or handed back by service users;
 - c. There was a significant deterioration in the physical and mental health of older people as a result of pandemic restrictions and reduced physical and social activities;
 - d. Older people were impacted financially by the pandemic, and those who wished to remain in the workforce were at higher risk of redundancy or exclusion from developing work practices;
 - e. The lack of available data on older people's experiences of abuse made it difficult to assess the impact of the pandemic but it is clear that criminals have been targeting older people for financial crimes and fraud;
 - f. Opportunities to engage with communities and volunteer were limited for older people during the pandemic and many older people said they did not feel like valued members of society;
 - g. Many older people were at risk of exclusion as public and private services accelerated the introduction of digital services; and
 - h. Older people showed resilience and determination throughout the pandemic and were generally optimistic about the future.

'Ensuring access to information and services in a digital age: Guidance for Local Authorities and Health Boards' - 18 November 2021 (Report exhibited at [HH3/58 – INQ000184920])

210. In light of the rapid shift by public bodies to the provision of information and services through digital means, and the feedback from older people about the difficulty of getting information and services if not online, I used my legal powers under Section 12 of the 2006 Act, to issue guidance to local authorities and health boards on how to ensure access to information and services in a digital age, which they must have regard to in discharging their functions.

- **211.** I required local authorities and health boards to provide details of the action they were taking to ensure older people can access information and services via non-digital means, and that older people who want to get online are supported to do so.
- **212.** At the same time, I issued an information booklet for older people '*Getting the information and services you need: Know Your Rights*'.
- 213. The challenges of being able to get on with day-to-day life for older people who are not online, were highlighted by the introduction of Covid passports as set out in my letter to the Minister for Health and Social Services, dated 19 November 2021. [HH3/59 INQ000184979]; HH3/59a INQ000184978].

Sharing the results of reports

- 214. The findings from this engagement, evidence gathering, reports and working groups were shared in a number of ways:
 - a. Reports were sent to the Welsh Government, and the findings and recommendations were discussed with relevant Ministers, Deputy Ministers and officials and followed up as needed;
 - b. Reports were sent to other policy and decision-makers and discussed with them, for example Care Inspectorate Wales and Health Inspectorate Wales;
 - c. Reports were published through the media, on my website and via social media;
 - d. Reports were sent to Members of the Senedd; and
 - e. Reports were sent to those who took part in the work and all other relevant stakeholders.

13. Data on the deaths of residents in care homes

215. Initially, it did not appear that the published data on deaths from Covid-19 included older people who died in care homes. I recall raising this issue in some early meetings with the Welsh Government. The lack of published data meant that it was difficult to know the extent of loss of life from Covid-19 in care homes in the first weeks of the pandemic.

14. Concerns about infection prevention

216. The key concerns I was aware of regarding infection prevention and control measures for those providing care in the home, were regarding the availability of PPE in the early weeks of the pandemic. There were also some concerns from older people and unpaid carers about the risks from domiciliary care workers coming into their homes.

15. The Coronavirus Act

- 217. On 20 March 2020, I issued a statement on the Coronavirus Bill, reflecting the concerns that older people had raised with me about the impact that it could have on them and how the changes could affect health and social care. [HH3/60 INQ000181733]
- 218. The Welsh Government conducted a 'rapid engagement' on the Coronavirus Act 2020 in respect of supporting people with social care needs, which I responded to and discussed with the Welsh Government.
- 219. The '*Rapid Engagement on the 'Draft Guidance Consequent to the Coronavirus Act* 2020' proposed changes to the Social Services and Well-being (Wales) Act 2014 ("**the 2014 Act**"). In my covering letter of 17 April 2020 to the Deputy Director General for HSS, I raised a number of concerns about the impact on older people who were likely to be disproportionately impacted by the changes. I urged that any changes should be time-limited and used sparingly and that rights should be re-instated as quickly as possible to reduce the impact on the most vulnerable older people. I stressed that the duty in the Act to have 'due regard' to the UN Principles for Older Persons' remained unchanged. [HH3/61 INQ000184938]; HH3/61a INQ000184939]. In this letter, I recommended;
 - a. "Any decision by a local authority to operate under the modified duties must be subject to continuous review, with robust scrutiny from Welsh Government and a report made to the Senedd. As Commissioner, I would also expect to be informed if a local authority has entered into Stage 3 or Stage 4 of implementing the modifications as this will impact upon my scrutiny role and the support I provide to individuals who contact my Casework Team.
 - b. Clear communication to the public will be essential to ensure that they are aware of any potential changes to their care and support, and how decisions can be challenged during this period. Local authorities should be compelled to record

this information which should be used to inform the on-going review of the decision to operate under the modified duties."

- 220. In its response to my letter, the Welsh Government did not agree to require local authorities to inform me if they entered Stage 3 or Stage 4.
- 221. On 2 October 2020, the Welsh Government began its rapid engagement on the suspension or retention of part 15 and part 2 to Schedule 12 of the Coronavirus Act 2020. In my letter of 30 October 2020 to the Deputy Minister for HSS, I highlighted that; "...legislation to remove the rights of older and disabled people should have no place in Wales. It must be repealed to ensure that the rights of older and disabled people who need care and support are protected now, and in the months ahead".
- 222. I also stated that:
 - a. "Removing an individual's legal right to have their eligible needs for care and support met is not acceptable. Such rights are more important now than ever. The 'relaxation' or 'modification' of legal rights under the 2014 Act disproportionately impacts on older and disabled people, particularly those who are less able to pay for their own care and support.
 - b. Despite the Schedule 2 provisions not being formally enacted in Wales there are questions about whether they are having an effect on people's rights by their very existence.
 - c. Through my engagement with older people, I have been made aware of some long delays in assessments, the inability to access any form of respite, as well as older people being discharged from hospital without an appropriate care package. Older people are experiencing this at a time when their usual network of informal support may have been lost, leaving many older people to struggle to cope, especially those who provide care for their loved ones.
 - d. To severely ration the provision of care and support to only those in need of protection from abuse or neglect is an important but low baseline for the provision of social care. The removal of the duty to conduct care and support assessments may also serve to be counterproductive, with the potential for local authorities to fail to identify priority cases as a result. The lack of duty to assess may hide

cases of abuse, reducing a local authority's ability to protect those at risk of abuse and neglect and comply with their safeguarding duties under the 2014 Act (which remain unchanged by the Coronavirus Act 2020 modifications)."

- 223. I also highlighted my evidence to the Equality, Local Government and Communities Committee, and its subsequent report, which highlighted the inequality felt by older people in relation to the response to the pandemic from across public bodies, including that the fulfilment of their care and support needs were seen as, and continue to be seen as, non-essential. [HH3/62 – INQ000185007].
- 224. Although the Schedule 12 provisions were not formally implemented in Wales, I was concerned, from issues being raised with my Advice and Assistance service, that these provisions were having an effect on people's rights by their very existence. However, the lack of data makes it difficult to assess the full impact. As I stated in my response to the Equality, Local Government and Communities Committee;
 - a. 'The extent to which older people in receipt of social care and their carers have been impacted is unclear. Data on such changes may exist at a local level within local authorities, but the pause on national data collection in relation to social care as directed by the Chief Statistician for Wales means that the impact of Covid-19 on the delivery of social care will be less clear.'
- 225. On 22 January 2021, the Deputy Minister for HSS announced the outcome of the consultation was in favour of suspension and that the regulations to suspend would be laid in the first quarter of 2021.

16. Lessons Learned and Recommendations

Consideration of older people by the Welsh Government

226. It is my view that older people were not adequately considered by the Welsh Government when making decisions which affected older people living in care homes and those in receipt of domiciliary care, particularly in the early months of the pandemic. Although a considerable amount of work was undertaken by Welsh Government officials working on social care policy, this did not result in the rights of older people being upheld, and the Welsh Government overall did not give the necessary attention to older people living in care homes or requiring social care support.

- **227.** As the pandemic started, when older people receiving care services or requiring them needed greater protection and support, the Coronavirus Act removed people's legal right to have their eligible needs for care and support met, as highlighted in section 15.
- **228.** The discharge of older people from hospitals without testing for Covid-19 not only put older people at risk, but also those living with them and caring for them.
- **229.** The restrictions on visiting older people living in care homes, and the restrictions on residents being able to go out from care homes, caused great distress and harm, and measures to enable safe visiting took too long to be put in place. There was also inconsistency in their subsequent application.
- **230.** My work with the EHRC, as set out in section 7, identifies that the Welsh Government, between April 2020 and December 2020, gave insufficient attention to older people living in care homes and upholding their rights. More broadly the Welsh Government was not able to adequately evidence the appropriate consideration of older people and their rights.

Lessons learned

- 231. In my view, the decision-making of governments in relation to older people living in care homes, in receipt of domiciliary care, or needing other care and support, needs to be improved.
- 232. There is a need to improve awareness and understanding of the rights of older people, under the Human Rights Act 1998 and the Equality Act 2010, as well as specific legislation relating to social care. Rights do not diminish with age, yet the experience of many older people is that they do. There need to be improvements in the understanding and commitment to the rights of older people by governments and public bodies, particularly during times of crisis. It is positive that the Welsh Government's Strategy for an Ageing Society, published in October 2021, adopts a rights-based approach, which provides opportunities to protect and promote the rights of older people throughout Wales. I see no indication of any similar action from the UK Government.
- 233. As well as improving understanding and awareness of the rights of older people, it is also important to ensure that ageism plays no part in decision making. It is my view

that the pandemic and the response across the UK, revealed the ageism and age discrimination that exists in our society and the harms that this can, and does, cause. Research by the World Health Organisation states that one in two people hold ageist views against older people. There should be more serious attention given to ageism and age discrimination throughout governments and public bodies – through awareness raising and training, and embedding this in policy and decision-making processes.

- 234. When making decisions affecting older people in care homes and those receiving domiciliary care it is, in my view, imperative that governments draw on and listen to people with experience and expertise in social care. As social care is provided by three sectors public, private and voluntary it is important that the issues and challenges for each sector are understood.
- 235. It is also vital that the experience and expertise of those that use care and support services are listened to and contribute to decision-making. Describing people who use care and support services as 'recipients' can suggest a passive role, rather than people with legal rights who should be viewed as partners in their own care, and not merely passive recipients.
- 236. As well as ensuring that people with experience and expertise in social care contribute to decision-making, it is also important to increase the knowledge and understanding of the care sector amongst policy- and decision-makers. I was struck by the lack of knowledge and understanding of care homes and how they operate, amongst some senior policy- and decision-makers, outside of social care. For example, a lack of appreciation of the fact that care homes are people's homes, and that they are not healthcare institutions or clinical settings. This, in my view, was one of the reasons why it took considerable time to improve visiting arrangements.
- 237. In my view, there need to be improvements in social care data collection, analysis, insight and reporting in order to inform decision making. This should include data on older people's access to social care services and whether they are able to access the full range of services that they need.
- 238. Although the focus of this module is on 'recipients of care in nursing and residential homes and adults in receipt of domiciliary care', there are other vital social services and support, including day centres and respite care. The immediate closure of many of these services at the beginning of the pandemic caused significant problems for older

people and for unpaid carers. In my view it also meant that some people then needed domiciliary care, or increased levels of domiciliary care, because they had lost access to other forms of care and support. I believe that when governments are making decisions about social care, or particular social care services, they need to consider the totality of the social care sector and the interdependencies between different services. In addition, they should consider the cumulative impact of decisions on people in need of care and support.

239. The dominant narrative during the pandemic was about protecting the NHS and this included how social care could support the NHS. There appeared to be little attention given in policy and decision making as to how the NHS needed to support social care – for example by ensuring access to GPs and hospital treatment for people living in care homes.

Recommendations

- 240. I have been asked to set out any recommendations that I would ask the Chair to consider in order to improve the response of the adult care sector in the event of a future pandemic.
- 241. My recommendations reflect the issues outlined above:
 - a. Increased investment in the social care sector in order to increase capacity to meet the needs of those who require social care and to improve the resilience of the sector. This investment should include improving the terms and conditions of those that work in the sector, providing vital and skilled care and support.
 - b. Improvements in the support that the NHS provides to the social care sector, particularly to care homes, and monitoring of residents' access to medical treatment to ensure that they are not being disadvantaged.
 - c. Changes to government structures and processes to ensure that there is social care experience and expertise in policy and decision making at an appropriate level.
 - d. Improvements in social care data collection, analysis, insight and reporting both to inform policy and decision making and to understand the consequences of policies and decisions taken.
 - e. Better enforcement of older people's rights to social care, and human rights when drawing on social care and support, including, but not limited to, the right to see loved ones when living in a care home.

STATEMENT OF TRUTH:

This statement, consisting of [51] pages, is true and accurate to the best of my knowledge and belief.

| | Personal Data | | 0 10 011 |
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| SIGNED: | | DATED: | 2.12.24 |