

**Anne's Law**  
**Consultation: analysis of the**  
**responses**  
**Part 1 - Strengthening the**  
**Health and Social Care**  
**Standards**  
**Part 2 - Delivering Anne's Law**  
**Final Report**

February 2022

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## Executive summary

### Introduction

This report contains a summary of the responses to two consultations (Parts 1 and 2 of Anne's Law):

- Part 1: Consultation on Strengthening the Health and Social Care Standards to support people who live in adult care homes to maintain family and friendship connections
- Part 2: Consultation on Proposals for Delivering Anne's Law: supporting people who live in adult care homes to maintain family and friendship connections

In Part 1, the Scottish Government is proposing to strengthen the Health and Social Care Standards to enable people who live in adult care homes to have rights to see and spend time with the people who are important to them. The Health and Social Care Standards set out what people should expect when experiencing health, social care, or social work services in Scotland. This is in advance of the legislation planned to be introduced as Anne's Law under Part 2 of the consultation.

### The respondents and the responses

In total, there were 156 Citizen Space responses to Part 1 of the Consultation, 127 (81%) of these responses were from individuals and 29 (19%) were from organisations. There was one non-standard written submission.

There were 283 Citizen Space responses to Part 2 of the Consultation, 247 (88%) of these were from individuals and 35 (12%) were from organisations. There was one non-standard response provided.

The organisations that responded to Part 1 and Part 2 included care home providers, health and social care partnerships, local authorities, care home provider representative groups, professional representative organisations, academics, third sector organisations, and family representative groups.

There were also three engagement events held in September and October as part of the Part 1 consultation process and five for Part 2. The discussions at these meetings are summarised in Appendices 1 and 2. The summary tables are provided in Appendix 3.

The consultation was designed and delivered by the Scottish Government and PwC was subsequently appointed to conduct an analysis of the Consultation responses.

## Overview of findings

Part 1: Consultation on Strengthening the Health and Social Care Standards to support people who live in adult care homes to maintain family and friendship connections

There was virtually unanimous support for the overall aim of the consultation, i.e., that people living in adult care homes should have the right to see and spend time with those who are important to them to support their health and wellbeing. Many of the responses referenced the extreme emotional distress experienced by their relatives in adult care homes who were not able to have visitors during periods in the pandemic. There were also many references to visitation rights as a basic human right and the need to prevent restrictions recurring.

A third (34%) of the 151 respondents to Q2 stated that a new Standard is required, and a similar proportion (28%) said that the existing Standards should be strengthened. A quarter (25%) stated that both actions should be taken and 8% said “We don’t need to do either”. There was a view that the current guidelines are applied inconsistently. There was also a preference amongst many for legislation rather than guidance.

Unprompted comments on strengthening the Standards referred to quality of life and specific rights of access and communication.

When asked about the four suggested Standards, individuals (42, 37%) tended to select: “If I am an adult living in a care home and visiting restrictions are needed to prevent infection, my named visitor (and substitutes) are supported by the service to be fully involved in supporting my health and wellbeing at any time”.

Organisations (11, 39%) tended to select: “If I am an adult living in a care home and visiting restrictions are needed to prevent infection, my named visitor (and substitutes) are supported by the service to continue to see and spend time with me, as long as it is safe”.

There was also a general view that the proposals should apply more widely than adult care settings. A range of settings were suggested, including hospitals, supported housing and children’s homes. Many respondents stated that the proposals should apply in all settings.

Respondents suggest that the proposals would have a number of benefits, including quality of life for residents; protection of their human rights; and mental, emotional and physical health and wellbeing. Challenges include the need for all homes to apply the standards consistently and a perceived blame culture. The key risk was identified as the introduction of infections into care homes. Many, however, thought this risk was minimal given vaccinations, increased testing, and enhanced Infection Prevention Control. Similar themes were raised in the consultation workshops, with

the need to promote awareness and the importance of the Standards being a common suggestion.

## Part 2: Consultation on Proposals for Delivering Anne's Law: supporting people who live in adult care homes to maintain family and friendship connections

As with the Part 1 Consultation, respondents were almost unanimously in agreement with the overall aim of the consultation, i.e., that people living in adult care homes should have the right to see and spend time with those who are important to them in order to support their health and wellbeing. Again, the main reason was to protect the mental, emotional, and physical well-being of residents. Respondents emphasised the importance of quality of life and shared their personal stories. The majority of respondents thought that the right should be for both residents and visitors, although some of the organisations that participated expressed concerns over adult protection and whether there is a risk that some named visitors could exercise undue control.

The benefits, challenges and risks were similar to those identified in Part 1 of the Consultation. Again, there was a strong focus on quality of life as well as the support that family members can offer care home staff, by taking on some elements of care like feeding or washing, as many did prior to the pandemic. The impact of restrictions on residents with dementia was also noted. Challenges included compliance (from both the perspective of the care home and from families (i.e., on the use of PPE), a perceived blame culture and potential additional costs on care homes. Risks included the introduction of infection into the home (although many thought that this should now be minimal given testing and widespread vaccination) and potential ambiguity in the language of the legislation.

In terms of managing risk, there was a strong view that the residents' rights should be paramount. It was noted on many occasions that some visitors may test more regularly than staff. Other themes included: the need for individual needs assessment; for appropriate IPC measures and a partnership approach with the home.

Again, around three quarters of individuals and organisations suggested that the legislation should be applied more widely than adult care homes, including, as with Part 1, hospitals, children's settings and, as many noted "all settings".

Further comments on the proposals tended to relate to the importance of:

- The proposed Law, given the impact on the emotional, mental, and physical well-being of residents
- Early implementation of the Law

Respondents also took this opportunity to comment again on their own experiences of family members being isolated in care home settings over the course of the pandemic and to reiterate that a similar situation cannot arise again.

## Introduction

This report presents an analysis of a two-part consultation on Anne's Law which took place between September and November 2021. There are around 1,000 care homes for adults and 33,000 residents aged 18 years and over in care homes in Scotland. Throughout the pandemic, the overriding priority in care homes has been to safeguard and protect staff and residents from infection, many of whom are particularly vulnerable to the impact of COVID-19 due to their underlying multiple long-term medical conditions as well as frailty. However, at times, that meant that residents were unable to see their loved ones as they would have liked, causing anguish for many.

Social connections and meaningful activity are important for the wellbeing and quality of life of people living in adult care homes as well as their friends and family. Guidance for the care home sector recognises the importance of enabling people to connect with their loved ones and care homes are encouraged to take steps to facilitate opportunities for connection using all the protections in place to do this safely.

The consultation on Anne's Law sought views on the Scottish Government's proposals to ensure that people who live in adult care homes have rights to see and spend time with the people who are important to them.

The consultation was in two parts. Part 1 sought views on the Scottish Government's proposals for strengthening the Health and Social Care Standards to enable people living in adult care homes to maintain family and friendship connections to support their health and wellbeing. Part 2 sought views on the Scottish Government's proposals for delivering Anne's Law in primary legislation, to ensure that people who live in adult care homes have rights to see and spend time with the people who are important to them.

The development of Anne's Law follows a Care Home Relatives Scotland Petition: PE01841 which was lodged by Natasha Hamilton, who was unable to see her mother, Anne Duke, for prolonged periods during the height of the pandemic. The petition called on the Scottish Parliament to urge the Scottish Government to allow a designated visitor into care homes to support loved ones.

A commitment to developing Anne's Law was outlined within the Fairer, Greener Scotland: Programme for Government 2021-22 published on 7 September:

We will strengthen residents' rights in adult residential settings and bring in 'Anne's Law' – giving nominated relatives or friends the same access rights to care homes as staff while following stringent infection control procedures, as called for by Care Home Relatives Scotland

One of the main drivers for introducing legalisation to cement the rights of residents to see friends and family is a recognition that families and friends play an essential

role in the health and wellbeing of people who live in care homes (in terms of both practical and emotional support). Prolonged isolation from family and friends is likely to be detrimental to the welfare of the resident.

Introducing legislation takes time and therefore the Scottish Government proposed short term measures to support the commitment including the strengthening of the Health and Social Care Standards. A consultation on strengthening the Standards was launched on 16 September and closed on 2 November (Part 1). This was followed by a consultation on delivering Anne's Law which launched on 24 September and closed on 5 November (Part 2).

This document presents the results of both Part 1 and Part 2 Consultations.

## Part 1 Consultation - Strengthening the Health and Social Care Standards

Within the consultation, the Scottish Government proposed to strengthen the Health and Social Care Standards to enable people who live in adult care homes to have rights to see and spend time with the people who are important to them.

The Health and Social Care Standards set out what people should expect when experiencing health, social care, or social work services in Scotland. The Standards are used by services and support organisations as a guideline for how to achieve high quality care. They are also taken into account by the Care Inspectorate, in relation to registration and inspection of care services.

The Scottish Government noted in the consultation that strengthening the Standards around ensuring that people can spend time with their loved ones would allow regulators to refocus certain inspections practices in support of the wishes of care home residents and their nominated family or friends. The consultation paper acknowledged that there are many Standards which already contain references to connection with others (see below). However, the Scottish Government proposed that one or more new standards will be required to strengthen the rights of residents which would allow immediate work to support the Anne's Law commitment.

## Existing standards

1.10 I am supported to participate fully as a citizen in my local community in the way that I want

2.18 I am supported to manage my relationships with my family, friends or partner in a way that suits my wellbeing

2.19 I am encouraged and supported to make and keep friendships, including with people my own age

2.22 I can maintain and develop my interests, activities and what matters to me in the way that I like

5.15 If I am an adult living in a care home I can choose to see visitors in private and plan for a friend, family member or my partner to sometimes stay over.

### Part 2 Consultation - Delivering Anne's Law

The consultation on delivering Anne's Law outlined an aspiration that people who live in adult care homes will be able to have direct contact with people who are important to them in order to support their health and wellbeing, regardless of circumstances. The consultation indicated that legislative provisions on Anne's Law could be included in the National Care Service Bill for which a consultation was underway at the same time. Within the consultation for Anne's Law, views were invited on the potential aims of and proposals for legislative provisions to support Anne's Law.



## The respondents and responses to Parts 1 and 2

This section of the Consultation Analysis presents an overview of the number of responses received by respondent type and the format of those respondents.

### Responses received

This consultation was in two Parts. The first part explored views on strengthening the health and care standards around human rights and a right to visits in care homes while Part 2 addressed the issues around the implementation of Anne's Law and the associated benefits, challenges, and risks. The response breakdown is as follows:

	Number
<b>Part 1 Health and Social Care Standards</b>	
Citizen Space responses	156
Non-standard responses	1
Workshops/engagement meetings	3
Total	160
<b>Part 2 Delivering Anne's Law</b>	
Citizen Space responses	283
Non-standard responses	1
Workshops/engagement meetings	5
Total	289

These figures include responses to the Easy Read questionnaire which were inputted by the Scottish Government into Citizen Space.

### The respondents and the responses

In total, there were 156 Citizen Space responses to Part 1 of the Consultation, 127 (81%) of these responses were from individuals and 29 (19%) were from organisations. There was one further non-standard written submission.

There were 283 Citizen Space responses to Part 2 of the Consultation, 247 (88%) of these were from individuals and 35 (12%) were from organisations. There was a further non-standard response provided.

Organisations that responded to these consultations included: care home providers, health and social care partnerships, local authorities, care home provider

representative groups, professional representative organisations, academics, third sector organisations, and family representative groups.

There were also three engagement events held in September and October 2021 as part of the Part 1 consultation process and five events for Part 2. The discussions at these meetings are summarised in Appendices 1 and 2.

Please note that the overall figures include some Easy Read responses that were data entered by the Scottish Government into the main dataset. Please also note that figures in this report may not sum to 100% due to rounding.

### Comments on the Consultation

Overall, 55% of the respondents to Part 1 and 56% of respondents to Part 2 stated that they were satisfied with the consultation process, approximately a third in each case said neither/nor and 14% and 12% respectively said they were dissatisfied. Comments raised included the need for more publicity around the Consultation and difficulties in ranking the proposed standards in terms of preference.

The Scottish Human Rights Commission highlighted that the period for the consultation was short at five weeks and that it was difficult to comment in the absence of an analysis of the issue.

## Part 1: Strengthening the Health and Social Care Standards

### Introduction

The consultation document asked respondents if they agreed with the overall aim that those in adult care homes should have the right to see those important to them to support their health and wellbeing. It then sought views on whether existing Health and Social Care Standards should be strengthened or new Standards developed. It asked respondents to indicate their preferences on a list of suggested new standards. Finally, respondents were asked whether the proposals should only apply to those living in an adult care home and to consider the main benefits, challenges and risks involved with an update to Health and Social Care standards for those in care.

#### Q1 Views on the overall aim of the consultation

Nearly all participants agreed with the overall aim that people living in adult care homes should have the right to see those important to them to support their health and wellbeing. A total of 155 participants responded with 98% of individuals and 100% of organisations agreeing.

<b>Q1 Do you agree with the overall aim that people living in adult care homes have the right to see and spend time with those who are important to them in order to support their health and wellbeing?</b>			
	<b>Individuals</b>	<b>Organisations</b>	<b>Total</b>
Yes	124 (98%)	29 (100%)	153 (99%)
No	1 (1%)	0 (00%)	1 (1%)
I don't know	1 (1%)	0 (0%)	1 (1%)
<b>Total</b>	<b>126</b>	<b>29</b>	<b>155 (100%)</b>

The same number of respondents gave a reason for their response. These reasons tended to relate to:

- Basic human rights and dignity, including access to loved ones
- The extreme emotional and mental distress caused by enforced isolation, including those families who lost loved ones in care homes during the isolation period
- The close relationship between mental and physical health and the deterioration in physical health attributed to lack of visiting rights
- The impact of families not being able to contribute to care
- The difficulty of relying on technology

For some respondents, there was a sense that the question should not really have been needed to be asked and there was genuine and deep-seated anger on the part of many:

“I never again want to have to sit behind police tape and watch my mum - who has dementia - being restrained from coming near me. The way this country (and others) has treated residents and their families has been barbaric” (Individual respondent)

“It is not only their right, it is their voice and protection from neglect. Care homes can only do so much, and I have seen a totally unacceptable level of care provided to residents when they are isolated from those who speak for them.” (Individual respondent)

“My mum (88) has vascular dementia and has been in a Care Home for eight years. I had to stand on bricks outside her window and watch while she lay there gravely ill with Covid. I had to stand and watch on another occasion when she was unresponsive. I had to stand there when she was saying 'C'mon in hen' to me on the outside. I had to stand and watch from outside as she struggled for 20 mins to try and get her food on her fork when there were no staff available to help her. The days she recognised me were the worst. Those were the days she pleaded with me to come in, those days broke both our hearts.” (Individual respondent)

“Of course they have that right! Care home residents live in their OWN HOME and carers work in their home - residents do not live in their workplace!! No one has the right to deny contact with relatives and friends who play a major part in their health and wellbeing. Lives have not been protected during the pandemic - they have been destroyed. What is the point in extending residents' lives if their lives are not worth living? Residents should have the same rights as everyone else in the community to spend time with those dearest to them”. (Individual respondent)

The difference in practice across the country in terms of the variations in interpretation of the guidelines was also noted.

A number of comments noted that this is not just about mental wellbeing but also physical wellbeing, with some suggesting that residents' physical health had deteriorated as a result of, for example, not being able to go out for a walk with friends and family. There were also a few comments that referenced that while normal activities have resumed for the general population (visiting or getting a visit from a hairdresser was one example), this is not always the case for people in care.

Eighteen organisations provided comments on this question, many highlighting the human rights aspects of the proposals.

“COSLA recognises that social care support is essential for many people to fulfil their human rights. COSLA promotes a human rights-based approach, drawing on the PANEL principles of Participation, Accountability, Non-discrimination and equality, Empowerment and Legality. Social care support protects people's human rights by

ensuring they are connected with, and able to contribute to, society, and are supported to live as independently as they wish to. This includes the right to a family life and for carers to have a break and a life beyond caring.” (COSLA)

COSLA also highlighted Article 19 of the UN Convention on the Rights of Persons with Disabilities (UNCRPD) which indicates that “disabled people have a right to live in the community, with the support they need and can make choices like other people do”. Social Work Scotland also highlighted Article 8 of the Human Rights Act.

Nearly all the organisations that responded to the consultation explicitly mentioned the importance of social interaction for mental wellbeing. Scottish Care also highlighted the need to provide support to those residents who do not have friends or family that are able to visit.

“For many people having contact with family and friends is a critical part of their health and wellbeing and this should be encouraged and enabled but at all times the individual choice and autonomy of the resident must be respected. Scottish Care agrees that families and friends play an essential role in the health and wellbeing of people whilst also recognising that there are many for whom there are no family and friends able to visit and therefore other activities and supports are fundamental to the wellbeing of those individuals.” (Scottish Care)

The Coalition of Care and Support Providers in Scotland cited Alzheimer Scotland’s report COVID-19: The Hidden Impact and the Scottish Human Rights Commission’s COVID-19, Social Care and Human Rights which it says described the adverse consequences of this decision in terms of health, wellbeing and the limitation on human rights.

“The government’s support of the right to meaningful contact is a welcome return to the Health and Care standards. CCPS supports changing the standards to give this right greater weight when balancing it against necessary public health considerations.” (Coalition of Care and Support Providers in Scotland)

## Q2 Health and Social Care Standards

There was a total of 151 responses to the question asking whether Health and Social Care Standards should be developed, or existing ones strengthened. Individuals (34%) and Organisations (38%) agreed that a new standard was required. Improving existing standards followed closely with 27% of individuals and 35% of organisations agreeing, individuals (29%) also agreed that both needed to be done in similar numbers. Only a very small number stated that nothing needed to be done.

<b>Q2 Do you think that a new Health and Social Care Standard (or Standards) should be developed, or should the existing Standards be strengthened?</b>			
	<b>Individuals</b>	<b>Organisations</b>	<b>Total</b>
A new Standard is required	41 (34%)	11 (38%)	52 (34%)
The existing Standards could be strengthened	33 (27%)	10 (34%)	43 (28%)
We need to do both	35 (29%)	3 (10%)	38 (25%)
We don't need to do either	8 (7%)	4 (14%)	12 (8%)
I don't know	5 (4%)	1 (3%)	6 (4%)
<b>Total</b>	<b>122</b>	<b>29</b>	<b>151</b>

Reasons given included:

- Existing rights and guidelines should be respected and enshrined in law
- Current guidelines are insufficient and applied inconsistently
- Current guidelines should be strengthened and enforced - with more oversight from the Care Inspectorate in general
- There should be explicit mention of the right to see a “loved one”
- There was a view amongst some that the standards are fine - the problem is in the interpretation and implementation - others indicated that there should be a new standard which explicitly refers to contact in the context of a public health outbreak
- Residents and families do not have a strong enough voice: there is a need for input from them

Selected responses are provided below:

“Care homes are not prisons. They should not be paid to treat residents like prisoners. Care standards should be adjusted to accept the fact that everyone in a care home is at end of life - their death is not the tragedy - every effort should focus on quality of end of life NOT preventing end of life” (Individual respondent)

“When a person enters a care home, that becomes their home, therefore it should be treated as such. Loved ones should be able to, (by law) offer comfort to family/friends in care as and when needed. This should not be left to the discretion of anyone other than the loved one and those in care” (Individual respondent)

“I think these could be expanded with the help of residents in care, their family and staff. The standards should focus on things that will benefit the residents with a focus on their physical and mental wellbeing. Family and friends have played a huge part in the person's life and no one should have that taken away from them because of policies!!” (Individual respondent)

From an organisational perspective, there were mixed views as to whether a new standard should be created or existing standards should be strengthened, or both. Several highlighted the need for simplicity and also the need to address “extreme circumstances). There were 22 responses from organisations to this question.

“I think it'd be easier to add in a new standard, developed from what is intended and be clear and concise. People/staff understand the current standards; they are simple and clear without jargon, and so there would be no point changing them when they are already known. Adding in one new standard of the same simple context for all to understand is quicker given the ‘forever changing’ circumstances.” (Care home respondent)

“The current standards are written for life out-with a pandemic and the associated restrictions. For absolute clarity there should be an additional section for “extreme circumstances.” (Care Home Relatives Scotland)

“A new standard being developed would give greater importance to the need to ensure that even due to circumstances such as a pandemic, that risks to residents, visitors and staff are assessed and when safe to do so, residents should have access to see their families and friends. A blanket approach to prevent face to face physical access should be avoided and a measured multi-disciplinary approach should be taken to risk assess and ensure the residents wishes along with safety are at the heart of the decision making. The standard may also be able to address the use of technology/ social media platforms to maintain access to family and friends when it is deemed not to be safe to be in the home in person.” (NHS Ayrshire and Arran).

“There appears to have been variation across the country around the interpretation of guidance and some areas have had ‘blanket bans’ around visiting which has been detrimental to residential clients and families/friends. A standard around visiting emphasises the residents right to autonomy and self-determination which should not be interfered with unless authorised by law, guidance and proportionate but will also require shared understanding of when these rights can be overridden.” (Shetland Islands Council)

### Qs3-5 Suggestions for strengthening the existing Standards

Unprompted responses to suggestions for strengthening the standards included (Q3):

- The need for enforcement of standards and particularly whether they are being consistently and meaningfully applied
- A focus on quality of life
- Specific references to rights of access and communication
- Specific references to the inclusion of those with Power of Attorney in decision-making
- Access to basic healthcare (e.g., GPs, dentists, chiropodists etc)

Please note that this list is not exhaustive. Many also expressed a preference for legislation rather than guidance. However one of the care homes that responded stated:

“The existing standards do actually cover this, I think the accompanying guidance could be more specific”. (The Glade Care Home)

When asked to rank the four provided options of what a new standard could be (Q4), if living in a care home with restrictions to prevent infection, having a named visitor (and substitutes) being fully involved in supporting my health and wellbeing at any time was ranked as the top choice by a third (35%) of all respondents. For organisations, this figure was 29% which was second behind visitors being able to spend time with someone in care as long as it is safe (39%).

<b>Q4 If you think a new Standard is required, what do you think of the following:</b>			
Respondent Type	Individual	Organisation	Total
	Rank 1	Rank 1	Rank 1
If I am an adult living in a care home and visiting restrictions are needed to prevent infection, my named visitor (and substitutes) are supported by the service to be fully involved in supporting my health and wellbeing at any time	(42) 37%	(8) 29%	(50) 35%
If I am an adult living in a care home, I can nominate a named visitor (and substitutes) who I am able to see and spend time with at any time to support my health and wellbeing which meets my needs and preferences	(32) 28%	(3) 11%	(35) 25%
If I am an adult living in a care home and visiting restrictions are needed to prevent infection, my named visitor (and substitutes) are supported by the service to continue to see and spend time with me, as long as it is safe	(15) 13%	(11) 39%	(26) 18%



If I am an adult living in a care home, I can nominate a named visitor (and substitutes) who I am able to see and spend time with to support my health and wellbeing which meets my needs and preferences	(11) 10%	(0) 0%	(11) 8%
I don't like any of them	(15) 13%	(2) 7%	(17) 12%
I don't know	(0) 0%	(4) 14%	(4) 3%

Comments on Question 4 tended to reference:

- The fact that well-being of residents should be the priority
- There was some debate over the concept of a named visitor: there was a view amongst many respondents that people should be able to see whoever they want as a basic human right<sup>1</sup>
- A blanket ban should not happen again
- The need for unambiguous language i.e., “as long as it is safe”. It was suggested that thresholds should be provided so that decision-making was not solely at the discretion of care home managers. One referenced “substitutes” (i.e., in the plural) as another area of potential ambiguity
- The sensitivity of language and the need for the terminology to reflect the fact that residents are in their home
- The need to provide family and friends with PPE.

When respondents were asked whether they have an alternative suggestion for a new standard (Q5), standards suggested included:

- I am supported by staff to maintain my physical, mental, and emotional health
- Wording in c) with this sentence at the end: as long as they know and understand the risks of spending time with me and are provided with the same protection and regular testing that staff are.
- If I am an adult living in a care home and general visiting restrictions are needed to prevent infection, my named Essential Care Giver (and substitute) is permitted open access into my personal residential setting, on the same grounds as care provider staff (following all the same PPE and safety protocols applicable to them), to support both my health and wellbeing and theirs, at any time and without limitation on length of visit.

<sup>1</sup> There were very many comments about human rights in the course of both consultations. The Scottish Human Rights Commission (SHRC) has provided an analysis of the human rights issues associated with this Consultation which is published alongside this report. It also notes that: “the absence of detailed analysis of the problems the proposed legislation is intended to cure limits our ability to make strong fact-based recommendations”.

- If I am an adult living in a care home, I am able to see anyone who is important to me and spend time with at any time to support my health and wellbeing which meets my needs and preference.
- If I am an adult living in a care home and visiting restrictions are needed to prevent infection, my named visitor and myself are fully supported to communicate and given timely information by the service
- I suggest a statement that gives a minimum contact requirement for essential visitors would make this workable for all concerned: for example: statement (a) with an additional phrase
- If I am an adult living in a care home, I can nominate a named visitor (and substitutes) who I am able to see and spend time with to support my health and wellbeing at times which meet my needs and preferences. In the case of a time of crisis or need for infection control, I would be entitled to see and spend time with my named visitor for a minimum of four hours a week and have a minimum of two contact periods a week. My named visitor (or substitute) would be required to follow the same health and safety standards required of care home staff at such a time in order to ensure the safety of all residents
- A care home will at all times be supported to ensure **meaningful contact** is maintained between a resident and family or friend. Adhering to the same IPC rules as staff members this contact must never be completely denied.
- If I am an adult living in a care home and visiting restrictions are needed to prevent infection; I will be asked what my preferences are, indoor visit, outdoor visits, home visits or videocall/telephone calls at any time. I can change my preferences at any time and as many times as I choose. I want my named visitor (and substitutes) to be supported by the service to uphold my choice and be able to remain fully involved in supporting my health and wellbeing

Please note that the list above is indicative and not exhaustive. There were 42 responses to this question. Selected verbatim responses are provided below.

“I feel having one nominated person could cause a lot of family tension and conflict trying to decide who the one nominated person is, family dynamics can be complex. I don’t see the need to have a limit on it. If my Grandma was still alive in her care home and I was her nominated person (as her POA I have a duty of care and responsibilities that come with that) I would be visiting and then coming home to the same house as my mother and brother. (Individual respondent)

“It is an absolute standard to see who you want without interference. Work from that premise.” (Individual respondent)

“We would do well to consider and include in any standard that these institutions are the residents' home and should be treated as such. They should always have

access to family and to necessary services, they should be allowed outside and indeed this should be facilitated at every opportunity, we should remember they are people not just statistics or a way for the home to make money” (Individual respondent)

A small number of respondents did suggest that some restrictions might be appropriate in certain circumstances, but this was very much the minority view.

### Q6 Application to settings

A total of 145 respondents answered the question on whether proposals should only apply to adults living in a care home registered with the Care Inspectorate. The majority of individuals (74%) and Organisations (89%) disagreed with this statement.

<b>Q6 Should the proposals apply only to people who live in an adult care home (residential and nursing) registered with the Care Inspectorate?</b>			
	<b>Individuals</b>	<b>Organisations</b>	<b>Total</b>
Yes	13 (11%)	2 (7%)	15 (10%)
No	87 (74%)	24 (89%)	111 (77%)
I don't know	18 (15%)	1 (4%)	19 (13%)
<b>Total</b>	<b>118</b>	<b>27</b>	<b>145</b>

There were 95 open-ended responses to this question. There was a general view that the eventual proposals should be applied to all residential settings including: children’s homes; settings for adults with learning disabilities, sheltered housing; and care at home. Hospitals were mentioned several times. Specific comments included:

“I was at home and separated from my family during lockdown and there seemed to be no point in living anymore”. (Individual respondent)

“Of course not!! ANYONE living in so called 'care' has the right to see and spend time with the most important people in their lives - otherwise what exactly is the point of their lives??” (Individual respondent)

“All adults should be supported to maintain contact with those who are important to them, not just those registered with CI”. (Individual respondent)

“It should possibly be applied to all areas registered with the Care Inspectorate, the issue of access to loved ones and support are equally important to people living with a learning disability, with mental health issues and to children and young people in terms of their wellbeing and remaining connected.” (Organisation respondent)

“This would only add to the disconnect that the H&SC is for limited settings so absolutely NO” (Aberdeenshire Health and Social Care Partnership)

“The standards apply across all Health and Social Care settings, therefore to ensure equity across the sector, consideration may be required for the application in other care and health settings.” (Organisation respondent)

## Q7 Benefits, challenges, and risks of the proposals

Respondents were asked what they saw as the main benefits, challenges, and risks of a proposal to update the Health and Social Care Standards to support people living in adult care homes to have the right to see and spend time with those who are important to them (Q7). This was an open-ended question and 111 responses were provided. These are summarised below under the headings of benefits, challenges, and risks.

### Benefits of the proposals

The following benefits were cited:

- Quality of life for residents
- A focus on human rights
- Mental and physical health and wellbeing of residents
- Human contact and family connections
- Removes the discretionary decision-making of individual homes
- Greater clarity around the standards and more support for care home managers and staff

### Challenges of the proposals

The following challenges were identified:

- All homes applying the same standards
- A fear of blame and making a mistake
- The individual care home culture
- Staff shortages
- The need for extra hygiene measures and controlling infection

### Risks

The following risks were identified:

- Introduction of infection into home (although many thought this risk was minimal given testing and vaccination)
- Visitors should have an awareness of their potential impact on other residents and may “bend the rules” i.e., in relation to nominated visitors
- Some thought risks outweighed by benefits and that visitors brought no more risks than staff

Selected quotes are provided below.

“[The] benefits are obvious - this will help with both residents and relatives/friends mental wellbeing... Challenge will be to ensure all care homes apply the same standards. Risks - I have never understood why I as a ‘visitor’ poses more risk to my relative than the several members of staff who may attend to my relative any one day. As long as all infection prevention protocols are adhered to, there is no more risk from a visitor than from a member of staff.” (Individual respondent)

“The challenge is obviously to support these rights while still minimising the risk. However, I strongly believe the biggest risk of infection transmission is and always was staff. Staff live in the community, socialise, come into work and work with vulnerable people. Families have so much at stake and will moderate their behaviour accordingly in order to be able to see and support relatives. Obviously, you cannot exclude staff and it was all too easy to exclude families, who were never the problem in my view.” (Individual response)

“The benefits: the individual receives the presence, touch and smell of their loved one. They get to hear their voice, share memories, laugh, cry, and just sit and be with each other. Their fundamental need to be with their ‘family’ is fulfilled. Staff are supported to carry out their roles by sharing the caring role with those who have family to help. Risks: the family member may catch the infection if it’s in the home. They may introduce it unwittingly, both minimised by treating staff and family the same way in terms of regular testing and education on hygiene control measures.” (Individual respondent)

“There are no risks. The risk is lives ruined by failing to act. I've had to accept the loss of my father, knowing he spent months at a time isolated from family. This cannot be allowed to happen again in what we consider to be a modern society.” (Individual respondent)

“It is a fundamental human right to spend time with loved ones, those who care about you and want to see you... for all those who do have people wanting to spend time with them it is often the main thing that makes life worth living. Putting them into isolation and removing this right for an extended period in the name of safety, is just cruel and barbaric. Having been through this crisis, we now have the experience required to prevent such a thing happening again.” (Individual respondent)

“If a visiting standard was introduced it may encourage homes who have been reluctant or anxious about visitors coming back into the Care home to support visiting particularly when they have concerns about bringing in infection during a pandemic. Home managers have had an unprecedented amount of extra responsibility added to their workload and I can understand the cautiousness of some particularly if they have tragically lost residents to Covid. Managers need to feel supported and not blamed and this may help to do that.” (Care home respondent)

“There is a wide range of evidence internationally that social connectedness is required for good health. Strengthening health and social care standards would help reduce social isolation, poor mental health and associated effects on physical health. This creates a more efficient and effective service as there are less care needs for staff to manage and residents, carers and staff are happier, thus reducing risk of complaints and calls from anxious relatives/friends etc.” (Health body)

## Q8 Other comments

Of the 155 respondents to Part 1 of the consultation, 75 provided additional comments at Q8. These referenced issues such as:

- The very substantial emotional and mental impacts on residents and their families of isolation over the last 18 months, often manifesting in significant physical deterioration for both
- The urgency of implementing standards or legislation so that the experiences of the last 18 months are not repeated
- The need to treat residents in care homes in the same ways as other members of society and to protect their human rights
- The importance of friends and family in caring for residents in care homes
- The importance of standards or legislation in providing clarity for all
- The constraints of staff shortages and an undervalued workforce

Many of these respondents also referenced their personal experience of the emotional costs and loss over the course of the pandemic, with personal stories of bereavement and loss of loved ones without being able to spend time with them.

## Part 2: Delivering Anne’s Law: supporting people who live in Adult Care Homes to maintain family and friendship connections

Overall, there were 283 respondents to Part 2 of the Anne’s Law consultation, one non-standard response and five workshop events.

### Q1 The overall aim of Anne’s Law

Nearly all participants agreed with the overall aim that people living in adult care homes should have the right to see those important to them to support their health and wellbeing. A total of 280 participants responded with 99% of individuals and 97% of organisations agreeing.

<b>Q1 Do you agree with the overall aim that people living in adult care homes have the right to see and spend time with those who are important to them in order to support their health and wellbeing?</b>			
	<b>Individuals</b>	<b>Organisations</b>	<b>Total</b>
Yes	243 (99%)	33 (97%)	276 (99%)
No	1 (0%)	1 (3%)	2 (1%)
I don’t know	2 (0.8%)	0 (0.0%)	2 (1%)
<b>Total</b>	<b>246</b>	<b>34</b>	<b>280</b>

Of the 280 respondents to this question, 260 provided a reason for their response. The main reasons given were:

- The mental and physical wellbeing of residents and their loved ones
- Quality of life is paramount
- The importance of family connections
- The need for residents in care homes to have the same human rights as other members of society
- The specific negative impact of the restrictions on care home residents with dementia

Care Home Relatives Scotland presented a number of scenarios experienced by residents and relatives in the pandemic:

“Our group (current membership 2012) was established In August 2020 to support the growing number of friends and relatives, who for the previous 6

months had been totally denied any opportunity for meaningful contact with their loved one in residential care. The outpouring of anxiety, guilt, grief, sadness, anger, despair and heartbreak has been immense. The voices of the residents in care sadly remained silent and unheard.

- Daughters were forced to watch from a distance as carers held a dying mother's hand
- Elderly husbands peered through windows to see their distressed wife reaching out for a familiar touch
- Children and young adults were left distraught and with no comprehension as to why they were "abandoned" by their family
- The use of prison style screens and intercom communication were cold, unfeeling and gave no comfort
- I-pads and online communication was impossible for the many residents with no understanding of zoom calls or facetime."

There were many comments on the impact of this isolation on the mental health of residents and their relatives.

"Emotional support from a loved one, family member, friend can be invaluable to residents. To completely restrict a resident from their family is detrimental to their health and as has been evidenced over the last 18 months, may contribute to overall decline in health. Safe and supported visiting should be encouraged at all times."  
(Organisation respondent)

"My own mother's mental health has suffered. Her communication levels have deteriorated to the extent she now basically says yes or no. Prior to the long periods of lockdown mainly due to staff testing positive, she was great at holding a conversation." (Individual respondent)

"Because it's a basic human right and one which is essential. This right is allowed and expected in every other part of our community so must be extended to care homes too. I note the words "living" and "homes" in this question - these are crucial to the implementation of Anne's Law - care home residents are 'living in their homes' therefore must have the same rights as any other member of the public who are 'living in their homes' too". (Individual respondent)

"I have personal experience of being barred from visiting my husband for two lockdowns - one of four months and one of six months. We had previously had daily outings together. Despite daily video calls, during each lockdown I had to watch my husband become more withdrawn and despondent. At the start of each lockdown, he could communicate on these video calls but a couple of months in he would no longer look at the camera and his conversation became monosyllabic and then non-existent. He also stopped eating and lost considerable amounts of weight each time".  
(Individual respondent)



Some responses from organisations referenced the benefits of family and friend contact for residents with dementia:

“Next of kin, family and friends can offer the unique support and reassurance to relatives in care that carers cannot. Their knowledge of past life experience is essential and has a positive response especially with those suffering from dementia.” (Individual respondent)

“There is extensive evidence to support the theory that contact with loved ones is a fundamental human need which can significantly impact on wellbeing. This is very important particularly for people with dementia which we know are a significant part of the care home population.” (Organisation respondent)

## Q2 Opinions on the main aims of Anne’s Law

Nearly all (278) of the respondents to Part 2 of the consultation provided a response to the question on the main aims of Anne’s Law. The main issues raised included:

- The need to protect human rights and ensure that meaningful contact is enshrined in law
- The need to maintain the right to family life
- The need to prevent restrictions recurring
- The need to provide clarity and guidance for residents, families, care home managers and staff
- The need to make sure that the response to infection prevention is proportionate and personalised

“People in care homes are living in their homes. Therefore, they should be entitled to have the freedoms we enjoy in our homes. My uncle went through weeks of solitary confinement in his room. We wouldn't accept this in prisons where there is a minimum amount of activity and outside exercise. Our care homes and nursing homes should never have their doors closed to those who have loved ones living there. It is immoral and dangerous. I fear what is going to come out over the coming years of what has gone on in some establishments.” (Individual respondent)

“To ensure residents/families are never again denied meaningful contact. By this I mean physical contact. There is no reason why families should be denied access to relatives in care homes, using the correct infection control procedures.” (Individual respondent)

“To ensure that homes have a safe code of practice to follow, with clear guidelines and support to facilitate safe visiting during any outbreak, infectious period and know that they will be supported by Local Authority, government, HSCP and Public Health to do so”. (Organisation respondent)

“My opinion [is that] all families should be allowed in no matter what the lockdown level is as our families need all of us not just one. If it had to be at different times I

can understand to an extent but we can not let our families finish their life this way restricting who they can and cannot see! No appointment system just needs a law to ensure our families can be with us when they need to be especially in a time of need! We can't predict when that is so we need law to ensure we can be with them at any time!" (Organisation respondent)

"The main aims for Anne's Law should be to ensure a consistent, fair approach is taken in relation to visiting across the sector in the whole of Scotland. This will ensure continuity of care and reduce variation between providers, areas etc. Achieving this minimum standard will support resident health and wellbeing." (Stirling Council)

The Law Society of Scotland highlighted that the rights of residents and others should be protected by existing legislation:

"Adults living in care homes already enjoy rights to family and private life under Article 8 ECHR. We do not believe that it is necessary to create a new right in legislation. What is required is effective protection for existing human rights in adult care home settings, to meet the aim of ensuring residents in care homes can spend time with those who are important to them in order to support their health and wellbeing... We recognise that the rights impacted are likely to be qualified, not absolute and their exercise needs to be balanced with the wider interests of public safety and the protection of individual and community health... We would suggest that the aim of Anne's Law should be to allow adults living in care homes to effectively claim their existing rights, and to ensure that those rights are restricted only in exceptional circumstances and in a way that is proportionate and non-discriminatory in according with national and international human rights law. Consideration should also be given to mechanisms to ensure effective protection of the human rights of adults living in care homes in all situations." (Law Society of Scotland)

### Q3 Visiting rights

The majority of individuals (83%) agreed that both residents and visitors should have the right to see those important to them in care (Q3). Combined with the residents percentage, practically all individual responses (99%) thought this should be a right. For organisations this was split between both residents and visitors (50%) and residents only (47%).

<b>Q3 Do you think this should be a right for residents or for the visitor(s)?</b>			
	<b>Individuals</b>	<b>Organisations</b>	<b>Total</b>
For both	204 (83%)	17 (50%)	221 (79%)
For resident	39 (16%)	16 (47%)	55 (20%)
I do not think there should be rights for either resident or visitor	2 (1%)	1(3%)	3 (1%)
<b>Total</b>	<b>245</b>	<b>34</b>	<b>279</b>

Reasons given included:

- The fact that access should already be covered in human rights legislation
- The impact on the mental and physical health of friends and family as well as residents
- The need for family members and care home staff to work together as partners in care
- The need to consider family sensitivities and circumstances in terms of named visitors, including some cases where respondents thought that residents should have the main say
- There was some disagreement with the concept of a single nominated visitor with some suggesting this may place undue pressure on families
- The importance of not relying on technology as many residents struggle to cope with it

Selected verbatims included:

“Care homes are only the place in which residents live, their family and friends should have the same rights as care staff to enter the buildings and spend quality time with them.” (Individual respondent)

“The care, comfort and contact of a visit is experienced by both the resident and the visitor and this right to human contact extends to both and will benefit both. Primarily the right may be viewed as being for the resident, but we must also consider the short- and long-term impact of children, partners, family members and friends being restricted or banned from visiting care home residents. Care Home residents are understandably on a restricted life time-line and without Anne's Law many will die without access to a family member/friend.” (Individual respondent)

“This should be a right for both residents and visitors. We are all entitled to hold and enjoy rights on an equal basis...In particular, the Article 8 right to family life is held by

both a care home resident and a family member of that resident. Note also that we consider that this includes all persons living in all residential health and social care settings whether voluntarily or involuntarily.” (Organisation respondent)

#### Q4 Balancing the rights of residents and others

Respondents were asked about how the rights of residents can be balanced against the rights of other people in the setting for example other residents, staff, visiting professionals (Q4). There were 265 responses to this question. Recurring themes included:

- Residents’ human rights should be paramount
- Visitors are tested more regularly than staff so should, according to the respondents, be less of a risk to residents
- Visiting rights to be included in individual care plans
- There should be appropriate IPC measures in place (including PPE) and proper risk assessment tools made available
- A partnership approach is required with good communication between the home, residents, and their families
- Consideration should be given to suitable separate areas for meeting within the home
- Mixed views on whether children should be allowed to visit and whether vaccination should be a requirement

Selected comments on this question about balancing the rights of residents, staff, visitors and others included:

“A person requiring support within residential accommodation must always have the right to spend time with those important to them and who in turn will be providing an essential part of their care. The importance of face to face contact cannot be underestimated. Many care home residents are unable to make their wishes known so rely on their Power of Attorney or close family to provide advocacy and ensure they receive the correct care from within the care home and wider services.” (Care Home Relatives Scotland)

“If you look closely you will see there is a perfect balance around the world between risk and rights for everyone. Anne's Law is not about favouring one resident over another, it is about equality for all citizens regardless of their place in society. Don't forget, relatives of residents in care homes can also be staff in other care homes and professionals who visit other care homes. it makes no logical sense that they can pull on a uniform or flash a badge and be any less of a risk than if they were visiting their mum.” (Individual respondent)

“This is very difficult as everyone has rights and when we supported essential visitors for our residents, we encountered real anger and distress from relatives of

other residents who strongly felt no one should be allowed in the home”.  
(Organisation respondent)

“Trust, communication and effective infection prevention and control (which CI inspection reports show is sadly lacking in too many care homes).” (Individual respondent)

“Everyone's rights and needs should be considered. Proper risk assessments which consider not just physical harms. A risk enablement approach - what is important to everyone, how can we do this rather than automatic no. Active engagement with all parties working together.” (Individual respondent)

“The rights of individual patients should be the priority always and not seen as an inconvenience to work schedules of staff, perhaps more staff would be an idea. Designated visiting areas for residents and family.” (Individual respondent)

“The decision to restrict or limit visiting should always be done within a rights-based approach and under a risk assessment of the environment etc. This should be led by the public health message and in full consultation with public health professionals. Any limits to this should be for the minimum time, and always support essential compassionate visiting.” (Organisation respondent)

“This should be a right for the residents to decide who they see and when. The principles of the Adults with Incapacity Act should be followed for those who lack capacity to make these decisions. This should include what is in the best interests for the resident and takes into account previous wishes i.e. considering what their previous relationship dynamics were and whether contact was supportive or detrimental to wellbeing.” (Stirling Council)

## Q5 Benefits, challenges and risks

Question 5 addressed the main benefits, challenges, and risks of the proposal to develop legislation to support people living in adult care homes to have the right to see and spend time with those who are important to them.

### **Benefits**

The benefits identified by respondents to this question are similar to those identified in Part 1 of the consultation. Of the 283 respondents who took part in the Part 2, 271 provided benefits or other comments. These included:

- Quality of life
- Improved mental, emotional and physical health for both residents and their loved ones
- Supporting human rights
- Support for care home staff
- Maintaining family and other relationships

- Consistent visiting guidelines for care homes
- Legal protections and safeguards in event of disputes

The needs of residents with dementia were highlighted by many respondents as has been noted separately above.

“The greatest benefit will be that residents of care homes will no longer fear that they will be denied the right to see and spend time with those who are important to them in the closing months of their lives.” (Individual respondent)

“Main benefits are the continued family support for the resident through a difficult time in their life. Emotional contact with those they love would have a beneficial effect. Knowing that they are not abandoned, that reassurance is at hand whenever it is needed would make all the difference to those in care. Contact should not be restricted as at present.” (Organisation respondent)

“The presence of the designated caregiver is vital to the well-being of the person receiving care and support. The presence of the designated caregiver will result in a decreased risk of unintentional harms, including decreased risk of emotional, mental and physical harms.” (Individual respondent)

“There is a wide range of evidence internationally that social connectedness is required for good health. Anne’s Law would reduce social isolation, poor mental health and associated effects on physical health. This creates a more efficient and effective service as there are less care needs for staff to manage and residents, carers and staff are happier” (NHS Greater Glasgow and Clyde).

A number of respondents did state that the legislation should not be needed as the right to spend time with their loved ones should already be covered under the Human Rights Act 1998.

## **Challenges**

There were 255 responses to the question on the challenges posed by the proposed legislation. Again, these were similar to the challenges identified in Part 1 of the Consultation. These included:

- All homes complying with the legislation
- Family members complying with legislation or guidelines i.e., on the use of PPE or social distancing and getting all parties to agree safe visiting protocols
- The potential for family disagreements if there is only one designated visitor
- Staff shortages and the additional administrative time that logging visitors might take
- Spread of infection
- A fear of blame and making a mistake
- Sheltering other residents when visits take place
- The additional costs associated with the measures.

A substantial proportion of respondents said there were no challenges in their view, relative to the impact of no visitation on their families. Those that did cite challenges provided comments around the safety of other residents, staff and other visitors.

“Keeping people safe from infection. Staff trying to police this when people don't always follow guidelines. The time/resources, including providing for this. Adapting existing environments and procedures to make this possible. Anxiety about blame and guilt if people do get infection. Helping staff to feel safe and supported in new ways of working. Difficulties in managing e.g., who is going to be the designated visitor if only one is allowed.” (Individual respondent)

“In the case of Covid, the challenge is to allow this to happen safely whilst keeping other residents, staff and visitors safe and keeping the virus out. Also, without adding more work to stressed staff.” (Individual respondent)

“[Challenges include] the provision of education and relevant information to ensure that individuals rights are upheld; potential restrictions to funding may lead to lack of equity in access to resources required to facilitate safe visits; and application across all health and social care settings” (Erskine)

## **Risks**

There were 248 responses to the section on risks.

- Introduction of infection into home (although many thought this risk was minimal given testing and vaccination)
- Potential adult protection issues with the risk of “coercive” visitors
- Visitors may have an impact on other residents and may “bend the rules” i.e., in relation to nominated visitors
- Some thought risks outweighed by benefits and that visitors brought no more risks than staff
- Level of resources (i.e., staffing, PPE etc)
- Ambiguity in the language employed in the legislation which may therefore be open to interpretation
- Risk that there will be entitlement for access at all hours and the associated impact on operations and staff
- Insurance for care home providers

“More risk of infection from Covid as well as other infections, colds etc. But I think the benefits far out-weigh the risks.” (Individual stakeholder)

“We have some relatives who are actively anti vaxxers and will not wear a mask or test, the law needs to ensure we have the support to challenge these behaviours which are out of line with the expectations within the homes.”  
(Organisation respondent)

“Life is full of risks. Adult humans and their caregivers should have the right to determine their own risk.” (Individual respondent)

“The risk of not allowing visits is far greater than the risk of allowing visitors! Residents in care homes are at the end of their life - their death is not the great tragedy of this situation- their loneliness and despair is.” (Individual respondent)

““During normal times, we have an open visiting policy and we are currently open to visiting. However, this legislation appears to enforce full access to our home for designated visitors at particularly challenging times such as during the height of a Global Pandemic on the same basis as staff and with no right to cancel the visits for any reason or to restrict visiting times?” (Akam Care Ltd)

“The management of risk is at the heart of any potential change in the law. We believe that the right of access should be reasonable and proportionate at all times, reflective of the risks to the individual resident, to other residents and staff.” (Scottish Care)

## Q6 Settings

Over two thirds of respondents disagreed that proposals should apply to only those living in adult care registered with the Care Inspectorate, 73% of Individuals and 75% of organisations selected “No”.

<b>Q6 Should the proposals apply only to people who live in an adult care home (residential and nursing) registered with the Care Inspectorate?</b>			
	<b>Individuals</b>	<b>Organisations</b>	<b>Total</b>
Yes	26 (11%)	2 (6%)	28 (10%)
No	179 (73%)	24 (75%)	203 (73%)
I don't know	41(17%)	6 (19%)	47 (17%)
<b>Total</b>	<b>246</b>	<b>32</b>	<b>278</b>

There were 230 respondents who gave a reason at Q6. There was a very strong majority of respondents who thought that these rights should apply across all residential settings, including children’s homes, supported housing, retirement complexes and hospitals.

“It may be difficult to monitor those settings not registered although ideally the law should cover all” (Individual respondent)



“The rights of residents living in a care home should be those of the rest of society wherever this is possible. As this is a group living environment, there will be times when, following risk assessment and upon advice of public health, some freedoms may require to be limited to support the well-being of the collective resident group.” (194)

## Q7 Other comments

Question 7 sought further comments on the proposals tended to relate to the importance of:

- The proposed Law, given the impact on the emotional, mental and physical well-being of residents
- Early implementation of the Law

Respondents also took this opportunity to comment again on their own experiences of family members being isolated in care home settings over the course of the pandemic and to reiterate that a similar situation cannot arise again.

“The current guidance allowing a “named visitor” to have contact with their loved one during a “controlled outbreak” is a step in the right direction, but we know that care home companies can make their own final decision as to whether they will facilitate this. We are very aware that the pandemic still presents a risk to all, but our greatest fear is that we will once again be “locked out” and have to endure a repeat period of torture.” (Care Home Relatives Scotland)

# Appendix 1: Summary of consultation events: Strengthening the Health and Social Care Standards

## Introduction

Three workshop events were held with staff and providers to consider the proposals under Part 1 of the Anne's Law consultation between 30th September and 19th October 2021. There were 44 participants in total at these events. The events have been recorded in note form so it is not possible to attribute different perspectives to different categories or numbers of participant but, as with the written consultation, there was broad agreement across the events about the need to strengthen residents' human rights.

## The Health and Social Care Standards

There was a view across all three events that there is a need for clarity and that Care home staff need clear guidance. There is a particular need to avoid vague wording i.e., "as long as it is safe". There is also a need for consistency across all statutory bodies as following different sets of guidance was challenging for providers during the pandemic, including local authorities and health boards. Independent providers also need to be on board.

In one group, it was thought that there needs to be a balance between legislation and guidance and the independence of individual services. It was also thought that pressure on staff is overriding existing standards. There was a view in this group that standards need to have a clear reflection of what can be provided on the ground.

One group mentioned that the term 'visitor' should be described as someone providing meaningful contact.

## The implications for residents, staff and families and friends

Strengthening the standards will give families more confidence to work with the sector to ensure they can visit when an outbreak of any infectious disease.

One group suggested that there was a need to manage expectations and that care homes required resources to manage this process. Communications to residents and families should be in Plain English and available in formats that are suitable for people with visual or hearing impairments. Funding should be available for this. Carers need to be central to the process and should be given more of a voice

Residents should also be consulted much more. One group suggested that information, advice and decisions should be considered on the principle of "no decision about me without me". This group thought that the full set of measures,

including visitors being part of the care team was very enlightened and would welcome that.

There was a view that staff wages need to be increased and there should be more funding for recruitment

## Advantages and disadvantages of this approach

Overall, it was thought that greater clarity will help reduce fear amongst care staff and ultimately help them care for their residents. It will also result in happy residents and families and friends

A concern was expressed by some that nominated visitors would come to the home and refuse to follow procedures. Insurance was mentioned as an issue by two groups: if nominated visitors are like staff, would they be covered by insurance?

There was a message again around consistency and that all public health bodies need to get behind the fine detail of the standards.

## Application to settings

There was a general view that family connections are important in all settings so the standards should apply to all. Day centres and housing support, at home care and sheltered housing settings were also mentioned as these were also affected during the pandemic.

## Other comments

- Independent Review of Adult Social Care should be central to the process
- The guidance already covers connections and was applied inconsistently throughout the pandemic which has led to some cynicism in the sector
- Guidance should be fully shared and communicated: constantly changing advice is hard for service providers to follow
- The role of Public Health should be given consideration
- The level of scrutiny is difficult, especially police investigations
- Some concern over the consultation: one group commented that the questions are leading

## Appendix 2: Summary of consultation events: delivering Anne's Law

### Introduction

Five workshop events were held with people living in adult care homes, staff and providers to consider the proposals under Part 2 of the Anne's Law consultation in October 2021. Overall, 81 people participated in these events. The events have been recorded in note form so it is not possible to attribute different perspectives to different categories of participants but there is broad agreement across the events about the urgent need for Anne's Law. At the same time, as this is a summary of the notes taken by the Scottish Government, it is difficult to attribute weights to the views expressed. However, many of these views chime with the views stemming from the written consultation.

The structure of the events varied, but in the main considered the following issues:

- What difference should Anne's Law make?
- Who should it be for and what setting?
- Who should have the right to choose?
- How should it be enforced?
- Other comments and considerations

### The implications of the lockdown and lessons for the future

There was universal agreement amongst all the events that the impact of the lockdown on residents was immense and that there is a clear and overwhelming need to treat residents as individuals. There was a strong view that people's human rights had been violated and had caused physical and emotional harm and distress. There was also a strong sense that care homes should not have the power "to lock people out" and that residents should be treated as citizens.

It was also noted that care homes operate best when the family and staff work in partnership and that excluding family has impacted on operations. It was noted that friends and relatives can help support tired and overworked staff. They should be seen as a solution and in partnership with home.

There were several references to the need for national guidelines to create consistency across the country. Several pointed to the confusion a lack of guidance created for staff and between care home managers and headquarters. Anne's Law would provide a safety net for any future pandemics - need to protect managers as well as staff. Rights should be legal rights and not left to the discretion of the care homes. There is a need to build confidence amongst care home staff and to consider

how to mitigate against an outbreak if a designated visitor is the cause of an outbreak.

In two of the events, there was an expressed desire for open visiting rather than bookings and time based appointments.

It was also noted in one event that the situation should not have arisen as there is existing protective legislation and that, in the future, Power of Attorney arrangements should account for visiting rights. The importance of proportionate decision-making was also noted.

## The right to choose

The majority view appeared to be that the right to choose a named visitor or visitors should lie with the resident, with some provision for those with dementia or mental health conditions, where anyone with a Power of Attorney should be able to nominate a visitor. There were some suggestions that this named person could be varied to avoid an undue burden on one family member alone. It was emphasised that the right to family life is a human right and therefore should be available to all, regardless of setting or age.

## Views on next steps

Across the events, there was a view that the legislation needed to be amended as soon as possible. In one group it was thought that Anne's Law should be implemented in the same way as other emergency laws that were introduced during the pandemic. It was also mentioned that national guidance would be quicker to introduce than legislation, through the health and care standards. There should be a joined up approach with providers, care inspectorate and managers should all be on board. There was a view that it should be applied across all health and care sectors. In two of the groups, the need for access panels or visitor co-ordinators in each care home was raised. Other issues discussed included:

- More clarity around children visiting
- Training for care home staff
- Communication of Anne's Law implications to families The need for families to agree to PPE and testing and the need for reserves of PPE
- The implications of different types of infection
- Terminology is important. Should there be an Essential Contact as not everyone has a family member?
- The impact on small independent care homes
- The need for a digital standard across care settings: wifi was an issue and residents needed help with technology



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