

# Meaningful Connection

Report on engagement visits to care homes carried out

from March to May 2023





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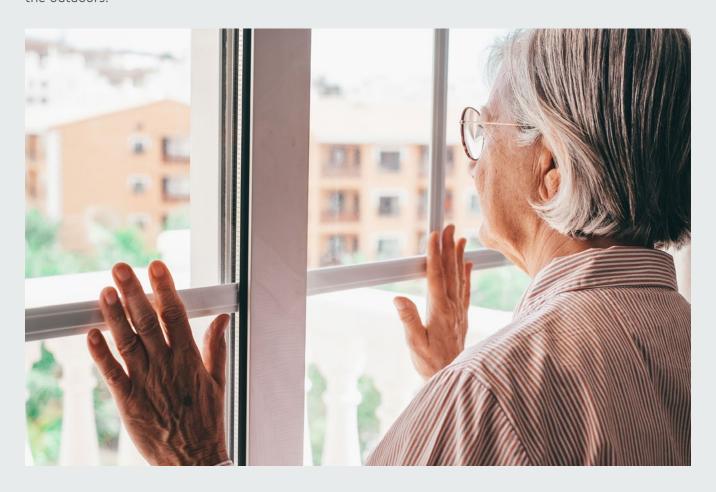
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# **Executive Summary**

We visited 20 care home services across Scotland between March and May 2023. The purpose was to gather views and experiences from people experiencing care, their families and friends, and care home staff about what matters to them in terms of meaningful connection, what works well, and what challenges exist. These were the key findings.

- People described powerfully the impact on health, wellbeing and relationships of the visiting restrictions and isolation associated with the Covid-19 pandemic. Many expressed the hope that visits would always be supported in the future, even if restrictions were needed.
- People described a range of important relationships, including with families and friends, peers, staff, and the wider community, which enhanced day to day life and supported identity, personhood and wellbeing.
- Conversations with family carers further reinforced the importance of their role as partners in care, and the factors which they valued in helping support meaningful connection with their loved ones.
- People benefited from meaningful activity and involvement with the wider community. However, some services experienced difficulty re-establishing links which had existed prior to the pandemic.
- There was an overall increased use of technology compared to pre-pandemic, and people benefited from this when it was used in creative, person-centred ways.
- Many examples of good practice were highlighted, which supported people to meaningfully connect and enriched their lives.

Barriers and challenges were also identified, which included staffing issues, organisational factors and access to resources both within and outside the care home; this often affected people's ability to access the outdoors.



### Introduction

The Meaningful Connection, Visiting and Anne's Law Project was set up with funding from Scottish Government to support and promote the importance of all types of meaningful connection for people who live in adult and older people's care homes, as well as helping prepare the sector for the implementation of Anne's Law. The project's work is based on the core principle that experiencing connection which is meaningful and person-centred is essential to everyone's health, wellbeing and personhood, and fundamental to human rights.

Two inspectors from Care Inspectorate are seconded to work on the project for a year. The remit includes producing resources for the care home sector, including guidance and training, to support services in ensuring that people experience connection which meets their needs, helping everyone to get the most out of life. A <u>literature review</u> was carried out at the start of the project to provide a clear narrative for the work and ensure a sound knowledge base. The literature review presented key themes and subthemes about meaningful connection and discussed potential barriers and enablers to support people in their decision making within a human rights-based approach.

Although the literature review gave a clear narrative of key themes, we wanted to build on this to ensure we were gathering direct views and experiences from people in Scotland. To inform our work, we arranged visits to 20 care home services across Scotland. This allowed us to hear a range of voices about why meaningful connection is important to people, what opportunities people have to make and sustain relationships, what works well to facilitate connection, what the barriers and challenges are, and ideas for how these can be overcome.

This report outlines the methodology used and discusses the themes arising.

We would like to thank the care homes who welcomed us into their services, and all the people experiencing care, families and friends, care home managers and staff who generously gave their time to speak to us. Their input was much valued and appreciated and their contributions have brought a richness to the report.

# Methodology

### Sample

Care homes were asked to volunteer to be involved in the project via Care Inspectorate mailings to all services, and most visits were arranged through this process. A few services were approached directly following signposting examples of good practice.

We visited a total of 20 services, primarily care homes for older people, but also including services for people with learning and physical disabilities and mental health issues, including addictions. Of the 20 services, 18 were registered as care homes for older people (including one which also provided care for adults under 65 with physical or mental health conditions), one care home for people with learning disabilities, and one addictions service. This reflects the current demographics in Scotland, with residents in care homes for older people accounting for 91% of residents in all adult care homes (Public Health Scotland, 2022). The homes were based in mainland urban and rural locations, with a mix of larger and smaller settings. The providers ranged from large corporate groups, local authority homes, small independent providers, sole providers and third sector services (figure 1). The number of registered places per service varied between 10 and 120.



Figure 1: Provider type

During these visits, we spoke to a total of 277 people. This included 105 people experiencing care, 72 families and friends, 20 service managers and 80 other staff, including care, nursing and activities staff (Figure 2). There was some overlap in that some managers and staff also had experience as family carers, and some family carers worked in other care services. They have been recorded according to their role in the service we visited.

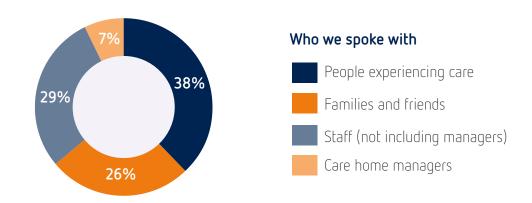


Figure 2: Percent of participants

### Data collection

People were offered the opportunity to be spoken with either individually or in small focus groups, as appropriate to the situation and their personal needs and preferences. We used a semi-structured interview format which was flexible and responsive to the individual needs of the people we spoke with. Not all questions were asked if deemed unsuitable to the situation or discussion. We wanted the discussions to be informal conversations, rather than an interview style. We were mindful of the distress caused by Covid-19 restrictions on people when they were separated from their loved ones. To prevent causing additional trauma, we agreed to let conversations about people's experiences happen naturally; this meant people only shared what they were comfortable with, rather than being asked specific questions that had the potential to cause harm.

The semi-structured interviews were developed considering what we wanted to establish and had these aims.

- Why connections/relationships are important to people (families, peers, staff, wider community).
- What opportunities do people have to make and sustain relationships?
- What works well to facilitate connection?
- Are people able to connect with things important to them, such as their belongings, the outside, meaningful locations, events?
- How can barriers be overcome? (Experiences or ideas that can be shared.)

We also wanted to gather examples and quotes that would enrich the data. We have included selected quotes from the people we spoke with to illustrate the themes. Informed consent was discussed at the time of the interviews; however, we have anonymised all quotes and removed any identifying details in order to maintain confidentiality further. The quotes have been coded as follows.

- R Resident
- **F** Family carer
- **S** Staff member (other than manager)
- HM Home manager

The term "family carers" has been used throughout this report to refer to immediate and extended family, friends and other close contacts who play ongoing roles in the lives of people who live in care homes. The term "people experiencing care" has been used to refer to people who live in adult and older people's care homes.

Most interviews were voice recorded and transcribed verbatim to allow the richness of the data to be maintained. Some conversations were recorded as field notes and key themes considered as part of the data.

Colleagues from the Scottish Government's Directorate for Social Care and National Care Service Development joined us for four visits near the end of the planned visit schedule. This was to enable them to observe and listen to the conversations and assist them in gaining insight into people's experiences. As the interviews were carried out informally, their presence in an observational capacity did not hinder the quality or consistency of data collection.

### Data Analysis

Due to the large volume of qualitative data collected, we needed a robust framework to allow systematic analysis of the data. The 'Framework Analysis' approach was selected as it is particularly suitable for use in this type of research. Framework Analysis was developed by Spencer et al. (2003) as a specific technique for qualitative data and has been used to ensure robust standards for government social research. It allowed exploration of people's experiences in depth, and as data was gathered from multiple sources and by both inspectors.

The overarching themes were extracted from the literature review to provide a clear structured approach. However, the flexibility of the approach also helped identify additional sub-themes, allowing us to gather new insights and build on the previous data.

Table 1 shows the pre-existing themes from the completed literature review, and new sub-themes which emerged from the visits.

Overarching Themes	Subthemes	New subthemes
The health and wellbeing outcomes associated with social connection.	<ul> <li>Social isolation and loneliness in care homes</li> <li>Emotional wellbeing</li> <li>Mental wellbeing</li> <li>Physical wellbeing</li> <li>Quality of life and thriving</li> <li>Strategies and recommendations for improving connection</li> </ul>	
The types of relationships experienced by people who live in care homes and why they matter.	<ul> <li>Relationships with peers</li> <li>Relationships with staff</li> <li>Relationships with the wider community</li> </ul>	Staffing methods
The roles and involvement of family carers and why they matter.	<ul> <li>Social and emotional support</li> <li>Advocacy and monitoring</li> <li>Providing direct care</li> <li>Barriers and enablers</li> </ul>	Barriers and enablers subthemes:  Feeling welcome Being included Being able to visit flexibly Relationships with staff Communication Trust Lack of information Engaging families Rebuilding relationships
The role of technology in facilitating connection.	<ul><li>Communication technology</li><li>Other forms of technology</li></ul>	

**Table 1:** Themes from literature review with additional subthemes

# Health and wellbeing outcomes

### Impact of separation on people's health and wellbeing

Many people told us about their experiences of restrictions during the Covid-19 pandemic, and how these had affected people experiencing care, families, and staff. People described the emotional, mental, and physical impacts of separation and isolation on health and wellbeing. As these subthemes are so interlinked, we have combined them in this discussion.

While effects varied from person to person, and not everyone appeared affected, many people experiencing care were described as feeling distressed and abandoned, sometimes likening the situation to being in prison or enduring wartime.

"In the beginning he thought he was in prison. He said, 'what did I do?'"(F)

"Yeah, it was very bad. We were in our rooms with the door closed and we weren't allowed out. It was a bad time." (R)

"We were isolating people and they hated it. They were so distraught and upset and you know, a lot of them were saying, I'm my own person. You can't do this. I've got the right to be where I want and do what I want. And you can't keep me in here and you know, I've been through the war. And yeah, it was terrible." (HM)

"We had several residents saying why am I here? Why they're not coming anymore, do they not love me anymore? Or they've just dumped me here, you know?" (S)

In many instances, and in addition to the emotional impact, staff and relatives were aware that people experiencing care's nutritional intake, mobility, and cognitive abilities declined. This was often perceived to be due to the impact of separation and isolation.

"We had a lady that just refused to eat. She saw her daughter every single day of her life and when that stopped, she just stopped eating. She wouldn't eat, she wouldn't drink. We thought we were going to lose her." (HM)

"You could see a lot of them declining and getting themselves into a little bubble. And then obviously, you know, they had to be confined in their rooms if there was a break out. So it was just, I mean, the mobility, the mental health, nutrition and everything just went downhill. Yeah, it was just a shame to see it." (S)



People experiencing care, their families and staff also described their experiences when visiting resumed, either at windows or indoors or outdoors with distancing in place. For many, these visits were not experienced as very meaningful and, in some cases, caused increased distress, both for people experiencing care and their visitors. The lack of touch and close contact was particularly difficult.

"Eventually, she actually said to me, you know, give me a hug. I said, well I don't really want to in case I pass anything on, and she just said I would rather get Covid and die than not be able to give you a hug. You know, I mean, she was 92." (F)

"The mum was three metres distance from the daughter and the mum couldn't see, couldn't hear. So what was that for? That wasn't a visit." (S)

"We had window visits and we were able to use the ground floor rooms and that was nice, but it was almost more torture for some residents that just wanted to cuddle and things like that." (HM)

Families also described the traumatic emotional impact of being unable to see their loved ones, particularly near the end of life, feeling that precious time had been lost.

"I was the only one allowed in [as an essential visitor]. And I feel as a family, we were robbed of the last times with my husband." (F)

Many of the people spoken with had not directly experienced care home restrictions, as they or their relative had moved in once restrictions had eased or ended. They expressed the importance of being able to see their loved ones.

"That [not being able to visit] would definitely be hard. That would be, I would say, hell. We would both go downhill." (F)

"It makes a huge difference, I don't know if he necessarily knows when we were last in or if we're here, like just now, he's asleep, but just for us to know that we can be there. And we can see him and we can see his progress or not and just see how he's getting on." (F)

The impact on people experiencing care when visiting restarted was described by several members of staff and family carers. This powerfully illustrated the importance to people's emotional, psychological and physical wellbeing of being able to see their loved ones in person.

"You could see their mentality... just everything. You know, it's like they got a Christmas present given to them. You know it was just like, oh, so it was just so lovely to see it all. It's just lovely to get back to normal. It was a lot of hassle when they all first came in but just so good because the residents are just so happy." (S)

Some described longer term effects on people experiencing care's mental wellbeing and social confidence as a result of the pandemic.

"It was really challenging for a lot of people and there is still a lot of residual anxiety about going out and seeing people." (HM)

The vast majority of all those spoken with agreed that, in the future, it was important that in-person contact was maintained even in outbreak situations.

"For me it's just totally wrong. You've got an 89-year-old that's never been on her own, always had family round her, to having nobody. That can't be right." (F)

"An actual person, a personal visit is essential and not just relying on technology." (F)

"There's somebody every day, I keep on saying, for goodness sake. What do you think is going to come over me? I'm 94... not dead. I wasn't to be granny dumped, [I had a friend who said] he used to get so angry they would dump the old granny and forget to come back for her. Now, that's horrible. I think there's nothing worse than rejection." (R)

It's essential, it's a human right. It's all about the relationships." (F)



# Types of relationships and why they matter

### Relationships with peers

Some people experiencing care had developed valued friendships with others living in the care home. These enriched day to day life, helped people settle in and fostered a sense of belonging. Sometimes, these friendships had formed by chance, and sometimes staff had intentionally introduced people to each other who they thought might get on well. It is worth noting, just because people live together in a care home or have a shared interest, they may not naturally get on, and staff also described conflicts between people experiencing care.

"We got introduced at the start, she said I'll take you round a bit, show you what it's like. I couldn't do without her and she couldn't do without me.... She doesn't have family of her own but she's one of my family now." (R)

"Just a few girls in here and we have sort of matched together, we just have meals together all the time and we just do silly things, have a giggle. And that gets you through the day." (R)

"It depends on the type of person, right? We get a good inclination of the person before they come in. We're reading their assessment. Say one likes doing the garden, we've got another one that loves the garden, so we maybe say right? Well, there's a nice wee friend. She'll do the garden with you, or there's other projects. Some of them love knitting. So they all sit and they're all quite friendly." (S)

In some homes, many people experiencing care came from the same local area and had pre-existing connections or commonalities with each other, such as having worked in the same place, lived close to one another or attended the same church. This helped to foster a natural sense of community.

"People will come in and say, 'Is that Mr So-and-So?'. There are a lot of connections among people." (HM)

People described participating in activities and events which fostered connection. Some people experiencing care, who did not necessarily choose to participate in activities, described mealtimes as a particular point of social contact.

"I'll go to the bingo later. We'll have a laugh. I've got a friend there, she was 100 not long ago. It's amazing." (R)



Celebrating occasions, both general ones like Christmas or Easter, or personal ones like birthdays, could also help people to make connections. People experiencing care told us about the different types of meaningful events they were involved in and how this gave them a sense of purpose and enjoyment. As the visits took place around the time of the King's Coronation, many people spoke about how they had enjoyed preparing for the celebrations and being involved on the day. These conversations also sparked other memories and people seemed more engaged in the conversations when they had the opportunity to reminisce. People who had been more passive in the focus group joined in and shared in the conversation.

"I was really young when the Queen came to throne. She came to [our local town] with her young sister as princesses, and her father and mother. I remember standing at the Borough Hall cheering them on. Lovely! Wow! It was a shame because their mother dressed them alike. Those matching tweed coats on and things like that." (R)

Some people, however, expressed that there were few people to talk to, often perceiving this as being a result of communication barriers. They said they would like more opportunity to socialise within the home. Some told us that they had stopped using shared areas such as lounges or going to the dining room for meals as they struggled to make conversation with people and preferred to remain in their room.

"I went down [to the lounge] and I didn't like it. Everybody sits elbow to elbow all the way round. Then they just watch television on the big screen. I'd talk to [name], but with a lot of noise, it's not necessarily easy." (R)

"There's not really anybody here you can talk to." (R)

Some people had identified smaller areas within the home where they liked to gather to meet their friends. People also enjoyed sitting outside.

"It's a nice little space for sitting in, having a blether". (R)

"We've got a big seat at the back and they get them out there and they sit out there. Two ladies go out the front and have a cup of tea and a biscuit. They chat [together], that was in morning and they sit out and talk about the world going by." (S)

Staff described how they tried to foster positive relationships between people experiencing care and described some positive examples of good practice. This was often around the time people moved into the care home, or if shared interests had been identified. Some services spoke about an informal "buddy up programme" where people were connected when they moved in.

"We do try and, especially when they first come in, try and find out things they have in common with others, introduce them to people we think they would get on well with." (HM)

"We just had [name] come in two days ago. And I saw that [name] and [name] had formed a friendship. So they came out for their lunch, and they just sat and newsed the whole lunch time, just newsing about times gone by, and things like that, so it was good to see. If you can form friendships. Because everybody needs somebody as well, and they don't want to feel alone." (S)

People discussed the impacts of loss and change, and supporting people experiencing care to maintain their relationships.

"We had a lady who came in and was quite mobile, and she always used to go through and see one of our ladies who has very advanced dementia. And she would sit with her and give her a bit of company. It was really nice. And then she actually went off her feet. So then as a staff every day, we'll take her along." (S)

"People might not remember but if we say look, your friend would want to meet you today for a cup of tea, and then they say oh yes I'll go through." (HM)

Some services had designated an area as a café or a pub where people could gather to chat and spend time together.

"It's a community and there's fishermen and farmers and things like that. So that's what they used to do, going to the pub at the end of the week and talking, so I created this little, you know, pub area. And we'll meet there and talk and have a quiz." (S)

Staff also expressed the difficulties that arose when people lost valued relationships due to bereavement. During one conversation with staff, they were moved when they started to recognise the impact losing a friend could have on someone.

"She's gone very quiet in herself. She had a sort of close bond with [another] resident, and then after that [death] she kind of lost herself a bit. So it shows you, it just shows you. Maybe we don't realise how much the residents are depending on the other residents, as well as just at the start." (S)

"We had three ladies and they never did anything without one another, you know, they ate the same thing, to the extent that somebody had to go onto a textured diet and they all wanted the textured diet. But, you know. One of them died. It was very difficult for the other ones." (HM)

Not all people experiencing care wanted or valued peer relationships, however.

"I like my own company and my own space... I'm fine here in my room." (R)

### Relationships with staff

People experiencing care described the qualities they valued in staff. Common words used to describe these important qualities included "genuine", "caring", "patient", "kind" and "approachable". Other factors that people told us contributed to good relationships were getting to know each other and having fun. People particularly enjoyed when they could share a laugh together with staff. A number of people mentioned humour and sharing moments of fun with staff as an important part of their day, as this brought joy.

"The staff are so lovely, genuine, caring, want to help you. You can have a laugh with them. You can ask them anything. They never make you feel like you're being a bother." (R)

"Some days we just have a 'stupidity time' I call it, we just have a laugh, and it brightens the day up. It's brilliant, it really is." (R)

"But like all people, some will go that extra mile, some even two extra miles. Most are very good. I like their approach to you... the way they speak to you as if you're an equal." (R)

A sense of reciprocity in relationships with staff was a contributor to positive relationships. Many people enjoyed hearing about staff's lives outside of work, such as their families and hobbies, which generated a more personal connection.

"The majority [of staff] you know have been here quite a while, you get to know their background and they kind of relate bits and pieces and you get to know each other a bit more, find out a bit about their lives." (R)

"Opening up about your own life helps to build trust with them. They sort of trust you, by letting them in, so they sort of let you in as well." (S)

People experiencing care valued a feeling of being included by staff in daily activities. Some people gained a sense of purpose through being involved in tasks or enjoyed when staff sat with them to complete their paperwork or electronic notes.

Sharing activities and occasions with staff also helped to build relationships, reciprocity, and supported people to get to know each other. A home manager described a baby shower held for a member of staff who was going on maternity leave, and how people experiencing care had enjoyed this and were facilitated to give small gifts.

"They reminisced about when their kids were small and they were just delighted to see all the baby things." (HM)

When speaking to a group of people experiencing care about a word game that staff were involved in, many described it as "really nice", "really lovely", "we were all in it together".

"Everybody was laughing. The men were shouting out answers." (R)

People often recognised though that staff were very busy, and sometimes had limited time to spend with them. But others spoke about and appreciated the time staff spent supporting them with care tasks which they could now no longer do independently.

"Staff are wonderful, actually. I mean, this morning somebody came along and put me in the bath and bathed me. A nice warm bath." (R)

The pandemic and its associated restrictions had impacted relationships with staff in various ways. Some staff referred to difficulties communicating with people experiencing care when personal protective equipment (PPE) was needed, particularly masks, as people often had difficulty hearing what staff were saying, recognising their faces, or seeing their facial expressions.

"Residents struggled with that, they can't make out what you're saying. It's more meaningful with the mask off, there's no getting away from it." (HM)

However, some staff felt that relationships with people experiencing care had been strengthened during the pandemic. Sometimes this was due to staff working in "bubbles" and hence getting to know people better, when previously they would have worked in different areas of the home. Staff also described spending more time with people when visiting was limited.

"I think we all became stronger. Relationships became better. We were always involved, but we became more, because for a while we were their only people." (S)

"They seem to confide in you more now, if they've got any worries or anything". (S)

Not all people experiencing care had family visitors or peer relationships. Staff described working one-toone with people who did not have families and/or preferred to spend most of their time in their rooms. However, not all services had staffing levels which facilitated this kind of interaction.

"I do one to ones with people, when the weather's nice like today I've taken a few people round the garden already, there's a lovely little spot where we stop and chat. We've got one lady who likes dominoes and jigsaw puzzles, there's a gentleman who I play Scrabble with, he's formidable, he wins every time." (S)

### Relationships with the wider community

We heard about the links people experiencing care had with the wider community, both in terms of getting out and about and in terms of bringing the community in. There were varied experiences of this, and many people described continuing effects as a result of the pandemic.

Some home managers and staff described striving to rebuild community links which had often fallen away during the pandemic. Some recounted difficulties in re-establishing links with external organisations.

"Our community engagement isn't what it was, churches and schools and that kind of thing. I've tried to chase them up over weeks and weeks." (HM)

"Very difficult for church and they have not come back into us and we've tried several different churches. They haven't been able, so we just use it on the telly, you can go through Netflix and get a service there on a Sunday." (HM)

The loss of work placements for people with learning disabilities, due to the pandemic, was something which had had significant effects on people's quality of life and ability to be active citizens.

"Meaningful work is a big part of having a good quality, full life." (HM)

Services described various ways of maintaining community links during the pandemic, both through using technology (for instance, watching live music performances remotely) or finding other ways of enabling more, albeit limited, community engagement. One service had set up a letter writing scheme via a local community group. Some had used outside space to enable more community contact.

"The nursery children came to our windows to sing their songs and wave to their special friends." (HM)

Several homes had good relationships with local schools and nurseries, Guides and Scout groups, and this intergenerational contact was enjoyed by many people experiencing care. One home shared part of their garden with a neighbouring nursery, and many people valued this contact with the children, while others enjoyed visiting nurseries to read the children stories.

"You can see the nursery children up there and they had their sports this year and I was there in the wheelchair, it was great." (R)

Several homes had visits from animals, including dogs, ponies, alpacas, tropical reptiles and owls, which many people enjoyed. This could be visitors bringing their own pets in, or external organisations. Some also had resident animals, including pigs, sheep, cats, chickens, birds and guinea pigs, which many people appreciated, and which afforded the opportunity for some people to be involved in taking care of them.

The nursery children came to our windows to sing their songs and wave to their special friends." (HM)

"I got to pet the ponies.... they were lovely." (R)

"My mum had a cat, so she's got an attachment to the cats that live here and that's made her more at home as well." (F)

Various services facilitated people's involvement in activities which benefited the wider community and/ or the care home community, such as planting, litter picking, or making and selling jam or pot plants to raise funds for charity or for the care home residents' fund. People appreciated the sense of usefulness, satisfaction and reciprocity which they derived from these types of activities, which contributed to active citizenship.

"We sold a lot of marmalade and raised some money, that was really good." (R)

Some services had forged positive links with other nearby services such as sheltered housing. This helped to build community links and widen people's social networks.

"We have good links with [sheltered housing service], we attend events there and they come here." (S)

"We have our community cafe once a month, which brings people from the community or friends. You've got lots of people that come from the sheltered houses." (S)

Various factors impinged upon services' ability to engage in the community. Some homes had their own minibuses, either entirely for their use or shared with another service, and made good use of these to get people out and about, although the numbers able to go at any one time were limited by the capacity of the bus and staff availability. People described going out to cafés or garden centres, coffee mornings, to local places of interest, or just for a bus run around the local area. Other services had their own car and some used local taxis

"We go around the coast and we stop at the café there and we have teas and coffees." (R)

"It's nice to get out as I get a bit of change of scenery." (R)

Others were reliant on sometimes scarce community resources to transport people, which limited their ability to get out and about.

"We do struggle with the transport for wanting to go and do things. Just to let folks go and see the town that they were in all their life and they can't get out to see now." (HM)

The location of the home was also a factor; some were close to the heart of the community with plenty of destinations within walking distance, while others were in less accessible locations, which could also make it harder for people's families and friends to visit. A very rural service used their mini-bus to facilitate people to access the care home by collecting and dropping them off at the bus station in the nearest town - this was offered 365 days a year.

Having more opportunities to get out and about was a recurring theme. Some people had little to no opportunity to go outside, and some stated they would love to be able to go out to the local shops to buy a newspaper or an ice cream.

"There was a bus trip. I'd like to go out more on the bus. I'd be the first one on the bus." (R)

"You feel quilty because there's so many people and they can't take everybody out, you know? They can only take three or four. You sit in your room saying it's a beautiful day, why can't you get out there?" (R)

### Staffing methods

Staffing was another factor which impacted on people's experiences of connection, and activities in general. We found every service was unique in how they planned and deployed their activities staff. While all the homes we visited did employ dedicated activities staff to varying degrees, this may not necessarily be the case in every care home service. Some services we visited were extremely limited in their provision of activity hours, and at times these hours were also used for routine care activities such as hair and nail care. This impacted the opportunities people had, with activities being cancelled, staff capacity to support people with activities being limited, and organised activities only being offered a few days a week. This meant there was an increased likelihood that not all people experiencing care would be supported to engage in meaningful occupation or activity throughout the week.

Other services had a real emphasis on activities, and it was evident when a service had embedded meaningful activities as a core value of the care home. Some services had multiple staff covering seven days a week, and had also allocated additional roles to help in creative ways such as technology, oneto-ones, and holistic therapies such as Namaste. Services also varied in the provision of hairdressing, barbering, and beauty treatments, and for people who were unable to go out, some had made it into a real experience for people. We saw some incredible examples of people being given opportunities to get the most out of life which supported relationships; this included going out to visit older parents, or doing a gym session with their children.

"The hairdresser is in six days a week...maybe they'll have a day about, say, the salon and the beauty. So somebody's getting their hair done and somebody else is getting their nails done. And then on a Friday she turns it into the barber shop, she's got her own pole [which goes up]. They often have a Prosecco or an Advocaat, or even a nice coffee — so it's a real experience for them." (HM)

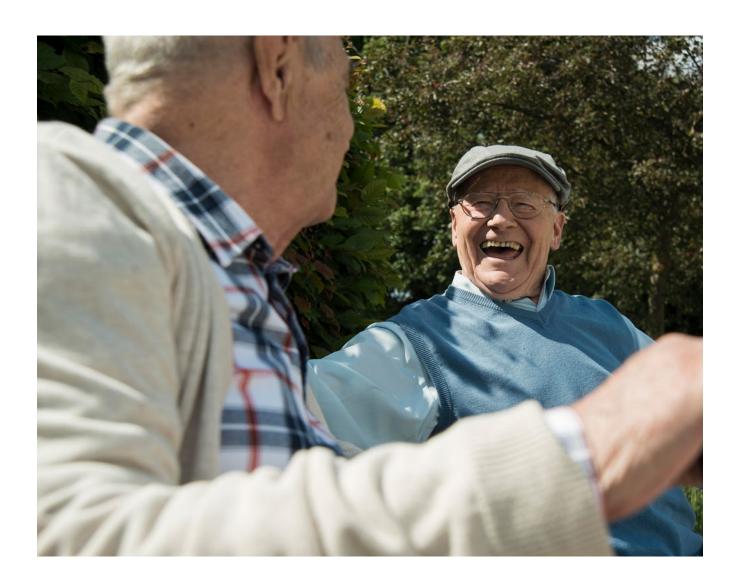
Skills, experience, and approach of activities staff also varied. We spoke with some staff who were passionate about supporting people to get the best out of life, finding creative approaches to enhance day to day life, and adopting a reablement approach which empowered people to maintain and develop their abilities.

Some services had adopted a small group living model. This was often beneficial to relationships, enabling people experiencing care and staff to get to know each other better. However, in some of these incidences, limited staff numbers were not always conducive to supporting people with activities such as going outside, as there was not sufficient staff capacity to meet all people's needs. Staff were reliant on other staff coming from another area of the service if people wanted to go outside and needed support.

"The good thing is [on one unit], with the extra staff, which means there's four, every day pretty much we used to take a resident and just go for a walk during the day. Yeah, because they could afford to do that. But it really is difficult with only two staff members in the unit."

Some services benefited from the involvement of volunteers, for example to drive the minibus, go on trips, spend social time with residents, and help with or organise activities such as arts and crafts. One service benefited from volunteers to drive older people from the community to the home to attend a regular coffee morning. However, not all homes had found it easy to engage volunteers.

"One lady comes in a couple of days a week, her husband was a resident here and passed away, and she's been a volunteer since." (HM)



# Roles and involvement of family carers and why they matter

Numerous family carers spoken with vividly described what was important to them in respect of the relationships and time spent with their loved ones, and the different roles they occupied.

### Social and emotional support

People described spending valued time with their loved ones, both when visiting the care home, and going out and about when this was possible. They recounted acting as a sounding board for worries and concerns and providing important continuity and links with life before and beyond the care home, helping to support people's sense of identity and personhood.

"Sometimes things are annoying her and we have a little blether." (F)

"I take Mum out for visits, for a cup of tea, a run in the car — we go to places she used to go, and it helps to jog her memory." (F)

"He can't hear very well but I play music, our favourite tunes and it brings back memories we shared. I'll say, do you remember they played that song in, wherever it was." (F)

### Advocacy and monitoring

Family carers described acting as intermediaries between people experiencing care and staff, to ensure their loved ones' wishes and preferences were known about and met. Great importance was attached to having the ability to visit flexibly in order to gain reassurance their relative was well looked after, particularly in the early days after moving in.

"You have to go through that coming every day to listen and get to see staff and get comfort that your wife is so well looked after, and if you don't come for 24 hours she's still fine." (F)

If they did not have confidence in the service, people often felt the need to visit more frequently to monitor the standard of care and raise any concerns.

Staff often described the importance of gathering information from families to help inform person-centred care. For instance, a member of staff described how information from one person's family about his childhood experiences during the Second World War had helped staff understand why he behaved in certain ways, making them better able to support him.

"That's the things that relatives know." (S)



Families also reported being able to provide information which was important to staff in terms of identifying situations which could trigger stress and distress, for instance sharing information about past experiences. How information was gathered was also highlighted as important. For example, one family stated they had been given forms to fill in but would have appreciated the opportunity to speak to someone about the information as well.

### Providing direct care

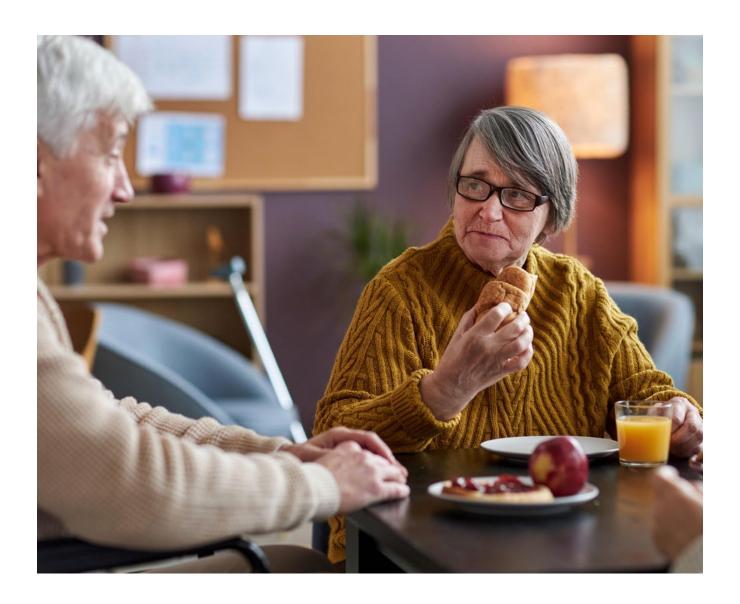
A few family carers were involved in direct care activities such as supporting with meals or personal care. While not everyone wished or was able to be involved in direct care, and for people experiencing care this was not always something they wanted, for some people the ability to do so was highly valued. Sometimes, this was associated with situations where people had experienced emotional trauma around the change in their loved one's health which had necessitated care home admission. Supporting with direct care helped provide continuity both for the person experiencing care and the family carer.

"I give him his lunch, because that's continuity, there's great love in it." (F)

"She [wife of resident] would come in four or five times a day, help him with breakfast, personal care, then go away and come back for lunch, tea, help him at bedtime. So it was more just having us there as a support." (S)

### **Enablers and barriers**

Family carers described the factors which affected their ability to be included and maintain positive, meaningful relationships with their loved ones. The following sub-themes emerged as important.



### Feeling welcome

A key theme which emerged from our conversations with people's families and friends was the importance of feeling welcomed into the care home and having a sense that their presence and involvement was wanted and valued.

"It's a very welcoming atmosphere, it's like a family really." (F)

In some services, staff welcomed people to stay for a meal. People expressed how they appreciated being invited to share a meal with their relative, and how much they enjoyed this social time together. However, some services discouraged people from visiting at mealtimes, as they felt it would be a distraction to people and may put them off their meal.

"We encourage people to come in and they can have a meal. Pop in and have your tea one night with your mum or your granny." (HM)

"[Husband of resident] said can I come in [at Christmas], and we said, we'd love you to. And they had their Christmas dinner together and the staff made them a lovely table together. It was so nice." (HM)

In some homes, family carers appreciated having been given the entry code for the door, fostering a sense of being welcome at any time.

"We don't expect family members to wait outside, they know the codes, because you'll take us as you find us. People feel welcome, they know they can come in." (HM)

"Now we've got the code for the door, before you had to buzz, so that side of it's definitely improved." (F)

Sometimes, family carers whose loved one had passed away had continued to visit the home to maintain friendships with other residents and to help out with activities. This benefited the care home as a whole, and helped to build a sense of community.

### Being included

A feeling of being included and valued as partners in care was important to many people.

"You're very much the core of their care and the staff know you. They want you to be part of it. So it's a real family feel." (F)

"Families are very important in this home. Very, very important. They like having an input. They like coming to events.... We're just one big family." (S)

Many people enjoyed and appreciated the opportunity to be involved in activities and special events, both in and outside of the care home. This often enabled them not only to spend time with their relative and be involved in their day to day lives, but also to get to know other residents, building a sense of community.

"Whatever's going on you get invited to. When things are happening families get involved." (F)

"My grandma comes down for all the things that they have. I think they did something for their anniversary. They did something for Valentine's Day. My mum's been in for Father's Day. You know, there's always something happening and just last night, my grandma and my mum were in for the silent disco. I think they probably enjoyed that more than my grandpa enjoyed it. But yeah, there's always family things happening." (F)

Some family carers had taken a more direct role in activities, such as one who ran a well-attended art class for residents. One relative was a pilot and would arrange to fly past the home in his small plane. Residents would go outside and wave white hankies, and this became a real topic of conversation for the rest of the day.

Some relatives had formed mutual support groups facilitated by the care home, and really valued the opportunity this gave them to share experiences and gain support from others in a similar situation.

### Being able to visit flexibly

Many people expressed how important it was to have the opportunity to look around different care homes in person, prior to making a decision on which one might be suitable for their relative, and to be able to freely visit to help their relative settle in once the move had taken place. Some feared their relative would feel abandoned or forgotten about were they not able to do this.

People whose relatives had moved in during the pandemic expressed how difficult it had been to move their relative into a care home which they had not seen, and which they were unable to visit.

"Because of the rules at the time I just had to take her to the door of this place I'd never seen, hadn't met any of this, you know, unfamiliar staff and I just had to hand my mother in." (F)

Other family carers, and in particular spouses, had continued to visit daily and this was an important part of their daily routine. A relative whose husband had recently moved into the home described how important it was to be able to visit daily, help him with his lunch, and listen to their favourite music together.

"It's a thread of his life that's maintained." (F)

Flexibility to visit at any time was important to many people. Those who had experienced restrictions previously expressed how much they valued now being able to visit without the need to plan ahead and make appointments.

"I like the fact that you can come anytime, whether it be morning, afternoon without any objection from any. You please yourself when you want to come. We're free to be together every day." (F)

"I've got young children so the flexibility means I can just pop in and I'm not going to an appointment that I've got to plan days in advance." (F)

Being able to spend visits in different areas of the home during activities, entertainment and so on, was appreciated by some families whose relative experienced difficulty in communicating verbally. For some people in this situation, spending time alone with their relative in



their room or a designated visiting room, as was the case when visits were restricted, could be a more difficult experience.

"Having a visit in the room was... really, really difficult when there's so little communication." (F)

They appreciated having the choice to spend the visit in areas where there was more going on around them, and where there were other people around to interact with. This was also described in some services as helping to facilitate connection and mutual support between family carers.

"Because for some of the families, it's a very hard visit if mum's nae speaking, or if mum's got severe dementia. So it was more sociable for them to sit with mum in the lounge and they could speak to other families that had the same issues and difficulties. And then you would see them forming friendships." (HM)

### Relationships with staff

Things family carers said they valued in staff included warmth, open and transparent communication, and a feeling that staff knew their relative well and cared about them. These factors helped to build a sense of trust that their loved one was well cared for, and any concerns they had could be raised and would be addressed.

"They always seem genuinely glad to see you and to show that they enjoy my husband being here, they show they care about him, they're always offering cups of tea, sometimes bring me soup when they bring his soup, they are very welcoming and thoughtful in every way. They are so reassuring. They totally understand." (F)

Family carers also appreciated when staff took time to get to know them and showed interest in their wellbeing.

"Staff greet you with a smile and they greet you by name. And they ask how you are and they know all the family. You never feel like you've been a nuisance." (F)

Staff also expressed the importance of building positive one-to-one relationships with family carers as a high priority, and dealing promptly with any concerns or issues as they arose.

"We invest time in getting to know them. People can feel like they trust us, we know them well and we know their relative really well." (S)

### Communication

Open, transparent communication from the care home staff was described as a high priority by many family carers.

"I prefer them not to, you know, cover it up. I would say if my mum's been shouting and hitting people, let me know." (F)

"They phone if there's anything wrong, they explain everything." (F)

Some staff also expressed the importance of reassuring families they could contact the home at any time, understanding and empathising with the anxieties which could be experienced by family carers.

"I always say to them, call anytime, it doesn't matter what time of the day. Even middle of the night. If you are worried, don't lie awake. We're always awake, you know." (S)

Some family carers described situations where communication had not been at the level they would like, illustrating the importance of being able to raise concerns openly.

"I mean in the first couple of weeks there wasn't a lot of communication. And I explained, I was my mum's sole carer at home. I need to be involved in everything, you know. And it did improve." (F)

### Trust

The ability to have confidence and trust in the service was a key factor for family carers, closely linked to other factors such as communication and relationship with staff.

"You've got that confidence, you've got that sort of peace of mind. When I leave here I know they're looking after Dad. It gives us the ability to sleep." (F)

The ability to raise concerns and have them addressed without fearing any adverse consequences was very important to family carers, and helped to build a sense of trust. Some told us of responsive leadership and management and that when they had raised a concern, it had been dealt with promptly. The manager in one home had encouraged people to contact them saying if they didn't know about it, they couldn't fix it.

> "They didn't notice at first but as soon as I brought it up it was immediately, immediately addressed. Whatever it is, immediately addressed, no problem." (F)



### Lack of information

Some services described being provided with inadequate information about people's family circumstances by service commissioners prior to the person moving into the service. For instance, staff in a learning disability service were advised that a person had no local family, when this later proved not to be the case. Subsequently, the person was able to make positive connections with their family after a chance meeting.

A few family carers, particularly those with relatives who had moved into the care home during the pandemic, were unclear about what they could and could not do in terms of visiting and going out and about. When asked if it would be helpful to have information about the different ways people could be connected, one family said that it would be really helpful. This could include information about going out and about in the community, as the family were unaware they could take their relative out for a run in the car.

### **Engaging families**

While some services felt that visiting had returned to pre-pandemic levels, others had found it more difficult to re-engage families and friends. Some felt that people were more hesitant to visit than had been the case in the past, prior to the pandemic.

"Half the town used to be here in the afternoons, it was good to see, but it's been hard getting that back." (S)

Some home managers described mixed success in engaging families in, for instance, relatives' meetings and consultations.

"We tried for years to have relatives' meetings. Oh, years, and I used to have them up on the board and the dates and where it was. All different ideas. Nobody came, not one person." (HM)



### Rebuilding relationships

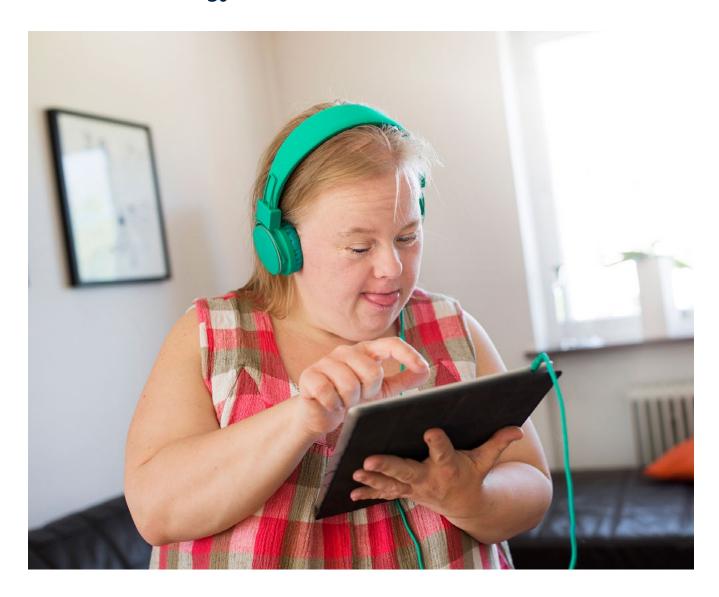
A new theme that emerged for people experiencing care who had been affected by mental health issues or were receiving support due to the effects of life-controlling issues, such as living with an addiction to drugs or alcohol, was how important it was to have contact with the people important to them, as this gave them opportunity to rebuild relationships. People described how the support they received during their recovery not only helped them as individuals, but helped to destigmatise their situation. As family carers, and often their children, visited the care home, barriers were broken down as the perceived view of living with addiction was changed, and the visits also helped the family. Staff were able to spend time with family members and help them to better understand how living with addiction and their recovery affects people. By involving the family, this supported recovery and aided the family in understanding the situation.

"Addiction isolates you and addiction is a progressive illness, people need a progressive recovery too and without meaningful connection, you are not going to get anywhere" (HM).

Family relationships can be complex and may also be a trigger to someone's emotional wellbeing or the lack of it. A visit could have the potential to make a situation worse and staff highlighted the importance of understanding people's individual situations and how the different relationships work.

"[Families] get our emotions as well as positive emotion. So I think that's the number one reason why people ultimately use drugs is they want to stop feeling. They are given an option [to visit], and that can be a trigger for them. It can be a difficult balancing act to make sure that the visit is going to be beneficial for them and the family member... family relationships can be really complicated, especially when you mix an addiction. There's been a lot of harm done...and a lot of resentment there. And usually the relationships can be pretty much near the end." (S)

# Role of technology



## Communication technology

Digital technology had been particularly valuable for keeping people in touch during the pandemic, and many people appreciated being able to see their loved ones via video calls. Staff described how they had supported people to communicate in this way, for instance, by using headsets when appropriate to enable people to hear better, and supporting people to have privacy when talking to their families and friends. However, some people were not able to understand or did not seem to benefit from video calls, and other methods of communication were better for them.

"It could trigger stress and distress in some people, and we had to be very mindful of that." (HM)

"Some people didn't understand, they thought it was a photograph or a video. Some thought it must mean there was something wrong, it caused them more anxiety. And for some it was a godsend." (HM)

Some people expressed the opinion that technology had been seen as a panacea which would alleviate the problems of separation.

"They probably thought with technology now, facetiming, that would negate any problems and keep people in touch with each other. But without bearing in mind that the majority of people in here are an older generation and those with dementia wouldn't be able to relate. It would actually confuse them. It's fine up to a point but it's not the same as physicality, as someone being there." (F)

Some staff described facilitating calls which were often perceived as more for the benefit of the caller than the person experiencing care, so that they could see their loved one and gain reassurance.

"Not everybody was aware to look at the screen and understand that's your relative. But a lot of what we, even though some of the residents didn't realise, we still did it because we knew that the relatives would know, so they could see their mum or their partner or whoever." (S)

After restrictions ended, the use of digital technology continued to be a very positive experience for some people, which enriched their daily lives and helped them keep in touch with loved ones. A number of people told us of using Skype and video calls as a means of staying connected with people important to them, whether they lived near or far.

"I can see the grandchildren and the animals [in the USA], it's amazing. I never could have done this in the past." (R)

For adults living in care homes who had children living elsewhere, the use of technology meant they could keep up with their lives, still feeling a part of what was going on, or could be involved in aspects of their lives growing up, such as watching them do their homework.

"Sometimes I haven't got much to say to him. But you can see it and you can see me and see what's going on back home and I can show him around here on my phone." (R)

Staff reported that availability of devices had improved, but several described having used their own devices earlier in the pandemic to help keep people in touch with their families.

"The government gave us some iPads, but to be honest, at the beginning we used our own, you know, phones and things like that." (S)

Some also reported that there were challenges with, for instance, Wi-Fi access throughout the building.

Staff had often had to become more familiar with and confident in using technology to help support residents.

"It forced a lot of the staff who weren't so confident about using devices to have confidence to be able to do things that they had never ever done before." (HM)

Some residents too had become more proficient in using technology.

"I had it [iPad] for years and years. I couldn't work it. My friend couldn't work it, either. But we're learning." (R)

### Other technology

Technology had been used in other ways during the pandemic, and much of this had continued to some degree after restrictions were lifted. For instance, livestreaming of church services benefited some people who were unable or did not want to go to church in person. Links with, for example, entertainers or exercise classes were also something that many people enjoyed.

Some services used technology very creatively to arrange activities, such as virtual trips to different countries, which provided new experiences for people and encouraged interaction between them.

"This girl [activities organiser] has lots of ideas. She does these [virtual] trips, it's amazing." (R)

Social media was used effectively by some services to keep families informed and involved, keeping them in touch not only with their own relative but with the life of the home as a whole. This was especially beneficial to people who were not often able to visit in person.

"They have a Facebook page now. And I found that reassuring because I could see Mum, they would take photographs of them when they were doing activities or musical entertainment or whatever. Lovely to see the smiling faces. And even some of the other residents that I've got to know there, seeing them engaging with things, you know, it's just lovely to see." (F)

In some services, families were also able to keep in touch with activities their relative had been involved in via an app, enabling them to be more informed and included. Others had Smart TVs in bedrooms and people had access to their own music lists. Some residents had Kindles or accounts for TV streaming

services. These were also enabled in some lounges. Some devices had voice recognition functions to support people with restrictions in their dexterity. Some services also had interactive boards, which are large touchscreen devices that are often easier to interact with than handheld devices. Staff needed to provide different levels of support with passwords and setting up devices. They spoke about how they tailored the support given according to people's individual needs due to living with a cognitive impairment.

"I can see the grandchildren and the animals [in the USA], it's amazing. I never could have done this in the past." (R)

### Conclusion

The visits aided a deeper understanding of what is important to people in terms of connection. We saw examples of very good and thoughtful practice by care home staff which enriched people's lives, supporting them to make and sustain important connections. We also heard about the barriers and challenges that exist. This included factors such as staff levels, staff deployment and access to resources both within and out with the home. The most common theme expressed was that people would like more opportunities to be able to go outside.

Themes were generally very consistent, with numerous people expressing similar thoughts and experiences. Those who had experienced care home restrictions during the pandemic vividly described the impact this had had on health, wellbeing and relationships. Many people expressed the hope that lessons had been learned regarding the importance of meaningful visits always being supported in the future, even if restrictions were needed.

The findings from the visits, as outlined in this report, have been used to inform our guidance and training resources. Current information and resources, including a series of solution-focused webinars, can be found here. The considerations raised in this report, including barriers and challenges to supporting meaningful connection and strategies to overcome these, will also form part of a forthcoming guidance document.

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