Providing viable Dementia Care Services in North East London

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CARE CITY

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Executive summary

COVID-19 has changed dementia services a great deal, but they were imperfect before the pandemic, and they remain so.

The dementia pathway was and continues to be hard for patients to piece together and to follow. For some, the pandemic and new channels of communication have improved this experience. However, for many, they have found services slower to respond and more confusing. Carers are traumatised and clinicians are exhausted. These are not conducive environments to enact change.

Remote consultations are being used, and there is sufficient guidance available for clinicians to use this tool should they choose. Most days clinicians are using the telephone to do consultations and video calls have not become embedded as standard practice.

Clinicians are learning to use video calling, not learning to love it. The staff who feel remote consultation is fit for purpose are mainly those who have had to use it as they have no other option, and also see it has the most potential. Access to the technology for patients is still the largest barrier, but this is decreasing. What is seen as the most important aid to successful video consultations is support of carers. Beyond the convenience and flexibility of this technology, the biggest benefit is about collaboration - collaboration with carers, other clinicians and other professionals.

A number of clinicians felt that the argument of using video or telephone missed the point of their work, being with the patient was what they wanted. There was uncertainty about the place or value of diagnosis tools, with some saying the tools used simply provided them with a way to communicate the diagnosis they were making based on their experience. There was a lot of scepticism about online cognitive assessment tools and people felt that remote consultation was limiting their ability to do their work.

So, as vaccinations rise and COVID-19 cases hopefully fall, there will be contrasting dynamics. Adoption will likely continue, but there will be a countervailing desertion, as the service users and clinicians who struggle return to face-to-face.

We found one service that seemed to be engaging well with remote consultation and they had improved outcomes for some patients. But it's also worth noting that when you have activists on a team, people striving to make things better, things generally get better.

Another area that seems overlooked is the population of North East London. Consideration should be given to the impact of language and culture and champion improvements to that offer.

Support is needed for clinicians by both problem-solving around the use of remote consultations *and* showing how they can be used to unlock a more cohesive dementia pathway, by helping carers, clinicians and other partners work better together.

Executive Summary

Care homes have seen a set of rapid changes to their way of work primarily through the Enhanced health in care homes framework. But they face challenges with dementia care, the number of undiagnosed residents, the disconnect from primary health providers, and a lack of resources to provide the support and therapy expected of them.

Care homes are usually run by independent businesses and they value their independence. They feel resentful of the health services not working in partnership with them, but forcing programmes on them. At the current time they feel as if getting more support from primary health providers or working closer with them is equated with losing autonomy. They don't feel respected. So we reviewed ways to better communicate with care home providers and how to base their work on existing care home provider networks.

Care homes have quickly reached critical mass in their use of video consultations, just as remote consultations have become an important research tool. Remote consultations - with staff as well as patients - could help to enhance dementia care in care homes. In the process, there may be a significant opportunity to boost clinical research in care homes, particularly around dementia.

Considering all the pulls on people's resources and mental resilience, we suggest that the methodology will have a large impact on their success. There is an interesting connection between the two areas we suggest:

- Supporting clinicians to use remote consultations to improve dementia care and create a more collaborative pathway
- Supporting care homes to improve dementia care, including through stronger links to health colleagues

For clinicians and patients, the dementia pathway can be confusing. If support is given to remote consultations and a network for care homes to strengthen connections across this pathway, they could create a powerful, self-reinforcing dynamic of improvement.

Background

Who are Care City?

Care City is an innovation centre for healthy ageing and regeneration. Its mission is to create a happier, healthier older-age for East Londoners. To achieve this, Care City works as the innovation partner to East London's health and care system. It delivers research, innovation and growth of local benefit and national significance. Care City is a community interest company.

This report has been written in an accessible way for many audiences. We hope these reports stimulate discussion, but we don't think there is one solution to the vast interconnected problems within our sector and are not promising we have the solution, but we aim to have captured the concerns from all sides in a fair, but realistic way.

What is dementia?

Dementia is a term used to describe a range of cognitive and behavioural symptoms that can include memory loss, problems with reasoning and communication and change in personality, and a reduction in a person's ability to carry out daily activities, such as shopping, washing, dressing and cooking.

The most common types of dementia are:
Alzheimer's disease, vascular dementia, mixed dementia, dementia with Lewy bodies and frontotemporal dementia. Dementia is a progressive condition, which means that the symptoms will gradually get worse. This progression will vary from person to person and each will experience dementia in a different way – people may often have some of the same general symptoms, but the degree to which these affect each person will vary (Dementia Gateway, Social Care Institute for Excellence).

What is remote consultation?

A remote consultation involves the patient and clinician communicating whilst not in the same physical space, using a telephone or video link. The term virtual consultations tend to be used exclusively for video consultations. Although it is worth noting that these terms seem to be used interchangeably by various organisations and teams.

The NHS Long Term Plan made a commitment to transforming outpatient appointments, supporting providers to offer patients the choice of video consultations where appropriate. It was proposed that this would avoid up to a third of current face-to-face appointments with benefits to patients such as obviating travel time and costs and environmental benefits of reduced road travel.

Remote consultation is not new. The first telephone consultation took place 3 years after it was invented in 1879. A doctor listened to a child's cough over the phone, offered a diagnosis ("It's not the croup") and treatment ("Settle down and get some sleep"). In 1967 Massachusetts General Hospital created a tele-diagnostic clinic when it set up the Logan Medical Station. Using closed circuit television, medical personnel sitting at a console in the hospital's emergency department could evaluate patients at Boston's airport about three miles away (above).

Aims and approach

Aims

Our project funder outlined three workstream proposals aimed to improve early dementia diagnosis, optimise the implementation of innovative dementia care and facilitate research activities. Through exploring effective collaboration across North East London (NEL) within these areas the hope is to lay a strong foundation for high quality research and care for people with dementia accessing health services.

The work streams are:

1. Establishing a virtual dementia research collaborative,
2. Supporting remote consultations in dementia care,
3. Virtual multi-professional dementia care improvement community for care homes.

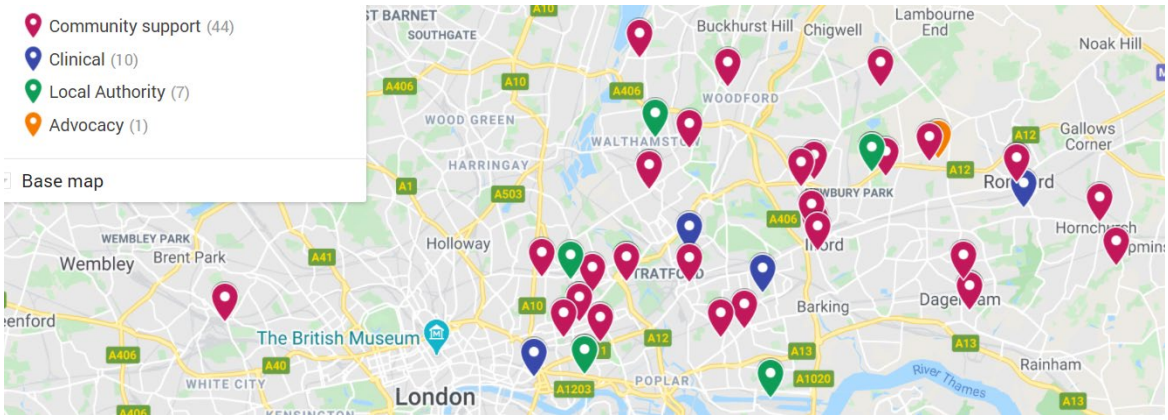
Care City has been tasked with supporting these workstreams and leading on the later two.

This work aims to:

- Support workstream 2 by ‘working with the existing stakeholder groups across North East London to make recommendations for addressing the lack of uptake in virtual and remote consultations for dementia diagnosis and treatment in NEL’
- Support workstream 3 by ‘scoping the requirements for a virtual dementia care improvement community for care homes.’

Approach

This work took place from Mid-September to December 2020 and was impacted by the ‘second-wave’ of COVID-19 which had an effect on availability engagement for the research. The project team gathered feedback from professionals across health, social care, third sector groups and the public. We mapped all the North East London dementia groups and sent a survey to each one of the third sector community support groups, we got a low response rate, so following this survey up with telephone interviews.



The feedback included individuals from:

NHS

- **NHS England and NHS Improvement:**
    - **Dementia and End of Life Care (EOLC) Clinical Networks** (London Region) providing leadership and advice to shape London's dementia services;
    - **Transforming Primary Care (Enhanced health in care homes)** which is working to improve the quality of life, healthcare and planning for people living in care homes.
- **Memory Assessment Services/Memory Clinics/Dementia Services** provided by North East London NHS Foundation Trust (NELFT), East London NHS Foundation Trust (ELFT), Central and North West London NHS Foundation Trust (CNWL) offering formal assessment, diagnosis and treatment for dementia. We sent a survey out to these groups and received 20 responses from clinicians;
- **Older people's Mental Health Team** in ELFT who provide community mental health services to people aged 65 and over with serious and/or enduring mental health problems.

Local government

- **Greater London Authority Dementia Friendly London** who are aiming to make London the first dementia friendly capital city by 2022;
- **Local Authority Dementia Commissioner**

Third Sector organisations

- **Mental Health and Mental Capacity Advocate** services who provide statutory support as outlined in the Mental Health Act 1983 and Mental Capacity Act 2005 from four separate organisations;
- **Alzheimer's Society** who provide information, practical and emotional support to help people live well with dementia;
- **Age UK** who provide information, practical and emotional support to older people;
- **Carers groups** who provide information, practical and emotional support to those who have a caring role for family;
- **Day Centres** for those living with dementia;
- **Dementia Action Alliance Leads** who represent groups of organisations for areas that want to improve with regards to support of those living with dementia;
- **Healthwatch** who gather and share views of people about their experience of health and social care;
- **Kings Fund** an independent think tank, which is involved with work relating to the health system in England;
- **Europia** a charity and community development organisation committed to supporting and empowering European nationals.

Social Care & Care Homes

- We identified 85 residential care homes within NEL and sent them a survey to find out about existing improvement initiatives and their appetite towards the future virtual

network initiatives; we also called each care home at least twice asking them to comment on our report

- **Residential Care Home Managers** across NEL who provide rooms and on-site registered care, in particular those who support those living with dementia from three separate organisations;
- **Quality and Improvement Lead** for a care provider who provided the results of a focus group set up for this project of 11 care home managers;
- **Skills for Care** - strategic body for workforce development in adult social care in England;

Public

- We conducted a focus group with five carers and two people living with dementia. The purpose of these interviews was to recognise what is working well, understand gaps in the current provision of remote consultation for those living in NEL, as well as to sense check the information from third sector organisations.

Dementia care in East London

Health services are just one part of the dementia pathway. People living with dementia and their carers have seen their entire support networks, from memory clinics to tea drop-in events change or cease all together. Residents were struggling before to understand the pathway and now it seems fragmented at best. People are being asked to do more at a time when they are uncertain of their own capacity.

The COVID experience for people living with dementia and their family and carers has been akin to a trauma. There is a lot of frustration and anger over the absence of health services and this should be considered when considering implementing new ways of working and reintroduction of services.

Recent University of Liverpool research included a survey of older adults, carers and people living with dementia at three intervals between April and July 2020. They found that, whereas some services' delivery levels are back to their pre-COVID levels (mainly domiciliary home care), day care, support groups, and social activities have been dramatically reduced and do not seem to be returning. The study concluded that the removal of these support services resulted in increased anxiety and reduced mental well-being. Many carers are overwhelmed with uncertainty about how they can manage their caring role with the lack of support and loneliness, with others reporting fatigue, and burden burnout.

Alzheimer's Society offices in NEL told us that they had been getting increased requests for support with people who are unable to get any response from local health providers during the COVID lockdown. They feel that this has greatly delayed some getting a diagnosis, and others having follow up consultations. They also pointed out that they have had a large number of requests to support people with managing video calls especially with regards to medical appointments.

The Local Authorities dementia leads are also very concerned. They informed us they have had a large number of people complaining to them about a lack of response from dementia health services. They said they had at least 75 people contact them about waiting for a diagnosis. Dementia leads told us that health services seem to work in silo, with people reporting they have to reiterate their issues with each visit from the start, an issue that NICE was also concerned about and tried to address when they drew up the most recent national guidance in 2018. Some dementia leads also expressed concern with the lack of confirmation from health Trusts that retiring Admiral nurses will be replaced when they retire. They also wanted to express their concern over the health services facilities which they felt were moving to physically smaller spaces, with reduced assessment and waiting areas.

Care home managers told us they were also very concerned about the health provisions over the past few months of the COVID pandemic. They felt that with the exception of the Mental Health teams, there had been a significant reduction in health visits and appointments have been cancelled.

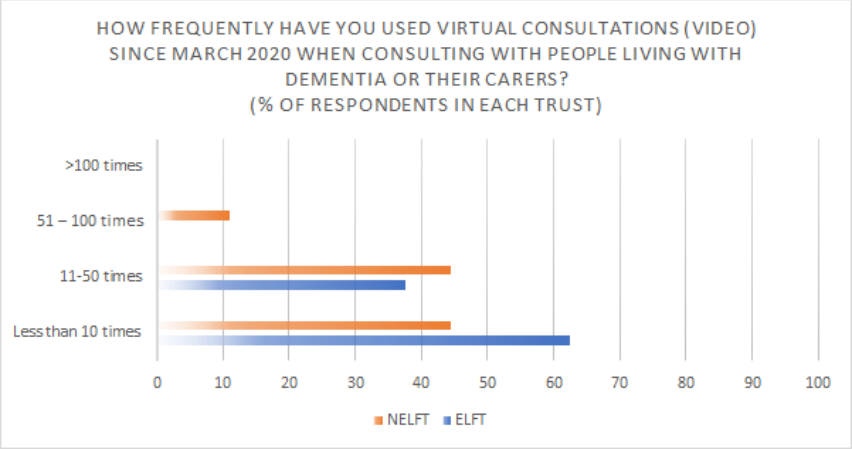
Healthwatch Havering published a report in October 2020 on the impact of COVID with those using health and care services. They reported that 41% of respondents in care homes had been able to keep in contact with family and friends using video conferencing. Less than 10% of respondents in care homes had concerns about their medical care, during the COVID pandemic with residents reporting the failure of health services to attend as the reason for this concern. Families reported that they were concerned over the failure of health staff attending to their relatives.

Remote consultations in dementia services in East London

Supporting remote consultations in dementia care is the focus of workstream 2. The COVID-19 pandemic has resulted in people using remote consultations more than ever before. Clinical staff feel that they understand and can use the technology. Telephones are being used on a daily basis for many consultations, but video is still not mainstream.

Online behaviour in the UK has hugely changed through 2020. For example, among people over-65 who already use the internet, the proportion who make a video call at least once a week rose from 22% to 61% between February and May in 2020.[1] The number of visits to the NHS website more than doubled in 2020 to 803 million. In six months (June to November 2020), 3,569,917 sessions were recorded by 111 online, a 217% increase on the same time frame in 2019. NHS Digital's Executive Director for Product Development said: "It's this technology that has enabled doctors, nurses and other health professionals to deliver care remotely where possible – freeing up time for those patients who need face-to-face care...We're fully expecting the numbers using NHS tech to continue rising in 2021, as the general public continues to play a key role in helping to ease the burden on our fantastic frontline services."[2]

These wider changes have been reflected in huge changes in the way dementia care is delivered in East London. NELFT's service map for dementia care shows clearly a 'digital first' approach at every stage, with provision then made for patients for whom this is not possible (Appendix B).



As a result, NELFT has a higher engagement with remote consultation. Overall, most NEL clinicians responding to our survey said they make daily clinical use of the telephone (71%).

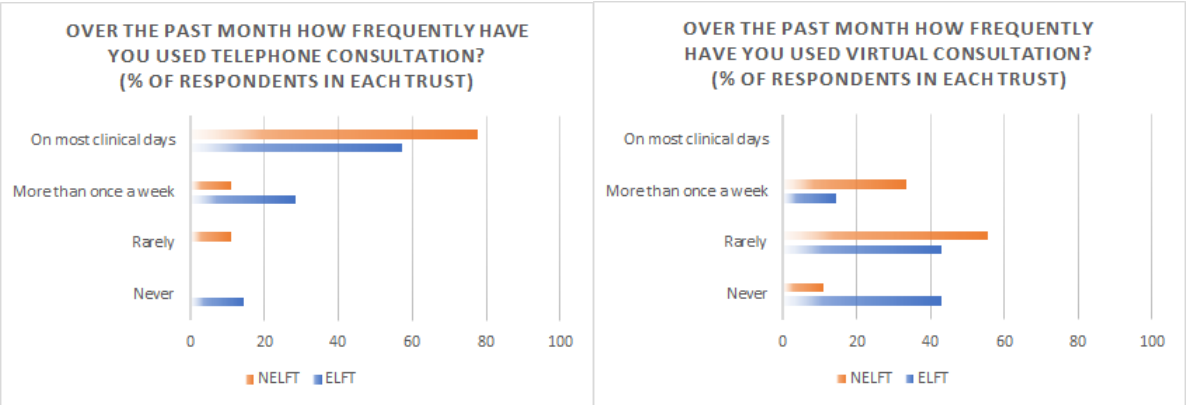
[1] OFCOM, Press Release, 'Internet use surges to record levels, 24th June, 2020 https://www.ofcom.org.uk/about-ofcom/latest/media/media-releases/2020/uk-internet-use-surges

[2] https://www.healthtechdigital.com/the-number-of-people-using-nhs-tech-in-2020-surges-due-to-coronavirus-pandemic/

These changes in clinical practice are reflected in wider changes in dementia care:

- Almost all of the care homes we spoke to are now using video conferencing for professional meetings, and video conferencing is also being used by their residents, including for healthcare appointments;
- Around 80% of third sector organisations who responded to our survey are using video conferencing with their service users;
- In carers' organisations in NEL we spoke to, they argue that carers have long had to be skilled users of the telephone, and that remote consultations build on this practice. While carers need to support those they care for to use video conferencing, this is hugely appreciated by carers and patients alike;
- In contrast, through the pandemic, just 16% of third sector organisations who responded to our survey continued face-to-face, with a third of them using text/whatsapp.

However, adoption of video consultations is certainly not universal among clinicians:



- 47% of combined respondents from both trusts say they rarely use video consultation.
- 50% of combined respondents from both trusts say they had used video consultants fewer than 10 times.
- 39% of combined respondents from both trusts say they still use face to face consultations more than once a week
- 33% of combined respondents from both trusts told us their service has a selection criteria or a triage protocol to help guide which patients should be reviewed using remote/virtual consultation.

This suggests that - unsurprisingly given the pace of change - the adoption process is far from complete. There are still significant differences across individuals and teams in how they have responded to the pandemic. In many areas, best practice and standard procedures have yet to spread comprehensively.

However, use of remote consultations has already been embedded in guidance. We found three primary sources that had provided information about remote consultation which might be considered guides for NHS staff in NEL released in 2020:

Dementia Wellbeing in the COVID-19 pandemic - A national NHS ENGLAND document which reviews how to address needs based on the 'Dementia Well pathway' page 5 providing links to further resources with regards to remote consultation.

Guidance on remote working for memory services during COVID-19 - A local NHS LONDON clinical networks step-by-step guide covering remote consultation and a review of assessment tools that could be used by clinicians remotely.

Video consulting in the NHS - A suite of resources produced by the University of Oxford aimed at explaining and setting up video consultations for both clinical staff and patients.

There are further documents, produced for other parts of the country and by other groups, but these three were referred to us by those working in NEL by more than one source.

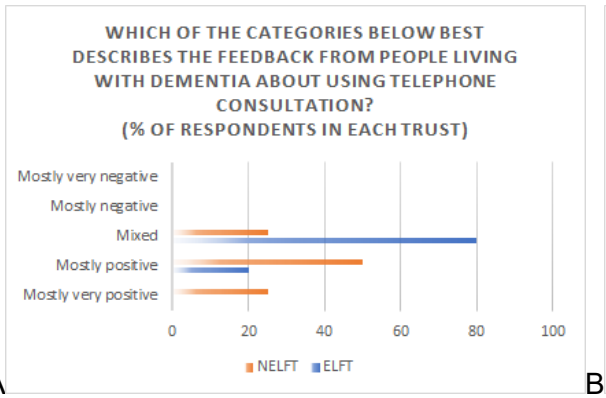
Barriers and benefits to remote consultations

A great deal of emotion attaches simply to the fact of the pandemic and the associated misery many have experienced, and this does seem to affect what people say about remote consultations. At the same time, some emotion attaches to the experience of having to change how things are done and to the faff of new technology, but these seem now of declining significance. In contrast, significant barriers to the optimal use of remote consultations remain in relation to access for patients, cultural barriers and a range of other issues.

Learning to use it, not learning to love it

Understanding experiences of remote consultations is complicated. We saw a lot of diversity in responses both from clinicians and patients. It was unclear if respondents were distinguishing their experiences of 2020 from an objective view of remote consultations.

We asked in our survey to clinicians for the feedback they had received from those **living with dementia** (charts A & B) and their **families or carers** (charts C & D). Most had no negative views of **telephone** usage (charts A & C), but there was a wider spread of views of **video consultation** (charts B & D).



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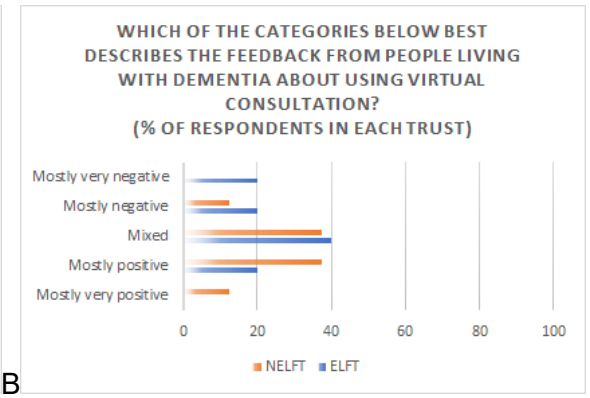

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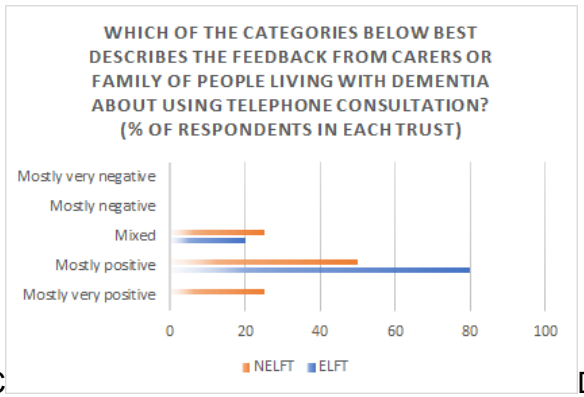

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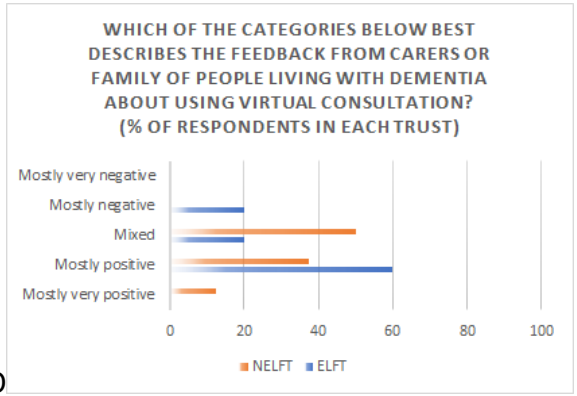


D

ELFT does more telephone consultations and seems to get more positive feedback from using the telephone than video consultation, especially from family and carers. Whereas NELFT that does more remote consultation overall has fewer negative experiences. It also seems that family and carers were more positive about the use of remote consultation. As people become more familiar with incorporating video calling into their everyday lives, both clinicians and patients, experiences seem likely to improve.

In general, clinicians and patients agree that face-to-face contact is the preferred method, and it seems to come down to the individual clinician or patient as to whether video consultations or telephone are better. How they assess their experience depends on the comparison they are making, and often this is not explicit.

We interviewed some who lived in the community with dementia in NEL and their carers. About half have told us that they prefer face-to-face consultations, as it makes communication easier. When this wasn't an option there was a split between those who preferred telephone communication as it was a technology they were familiar with and had been used throughout their lives; and a preference towards video consultations as this allowed better lip reading and clearer non-verbal communication.

Perhaps the key point is that the adoption of remote consultations has been driven more by necessity, rather than by their benefits:

- Third sector organisations told us that their use of video was driven by the pandemic. When asked, four out of six community groups described the feelings of their service users towards video as 'neutral'.

- Of those organisations who had received feedback from the person living with dementia, most said feedback was too mixed to say if people had a positive or negative feeling towards using the technology;

- Redbridge Carers service told us that their work to support those living with dementia and their carers had been hit by a 94% drop in attendance when they introduced remote workshops to replace face-to-face workshops. But as more are becoming used to video conferencing, attendance is now about 30-35% of the pre-pandemic level.

This example from Redbridge of the learning process associated with remote consultations was seen elsewhere. Some patients and carers groups also talked about noticing the convenience of virtual consultations - avoiding the need to travel, it being easier to be joined by family members. At the same time, some clinicians talked about the ability to see patients at home and at ease, and to understand the context of their home life.

One mental capacity advocacy provider noted that some people living with dementia are enjoying using remote consultations and virtually meeting up with family or friends, saying 'it has expanded their world.' The report 'Valuing voices: Protecting rights through the pandemic and beyond' published by Voiceability in October 2020 highlighted how 'Digital services can be effective and can offer greater flexibility and accessibility of services for some people.'

Other advocacy services also report they found a large proportion of people living with dementia disengaged quickly during video conversations. They stated advocates prefer face-to-face as it allows them to see non-verbal cues and more body language. When challenged however they agreed that video calls might mean that advocates would simply have to look for a different set of non-verbal cues.

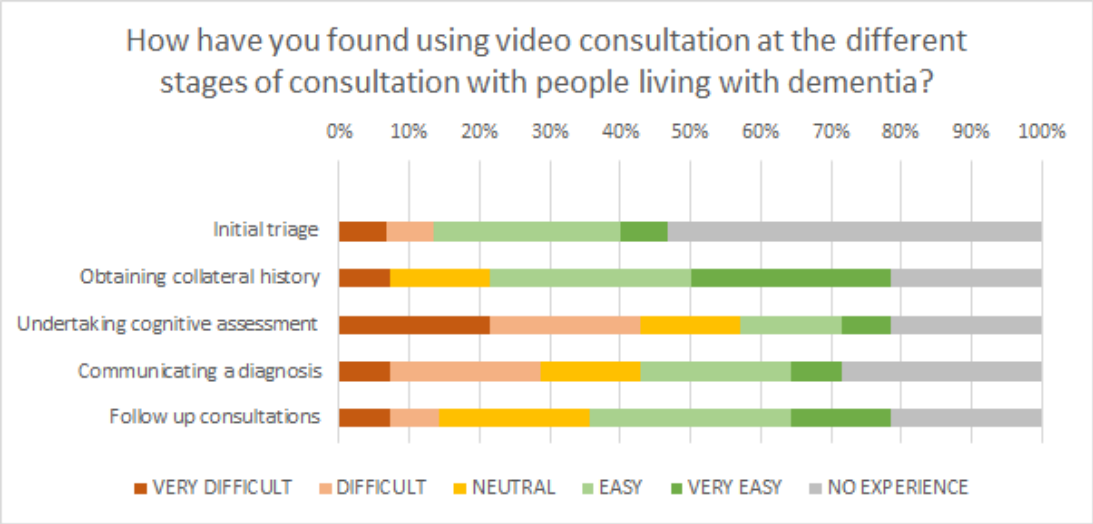
Some organisations, such as the Asian carers drop-in service in Redbridge, told us they really wanted to emphasise that face-to-face communication was vitally important. Other providers like Havering Carers hub say they have been successfully using Zoom and Apple Facetime for some time.

Some commentators have talked about the 'perfectionism' attached to conversations regarding digital innovations[3]. Over time, users learn that they are not perfect, but they note that face-to-face consultations are not perfect either, and have different costs and benefits. There was a sense that patients and clinicians in North East London are starting to learn this too.

Most, but certainly not all, find video consultations easy

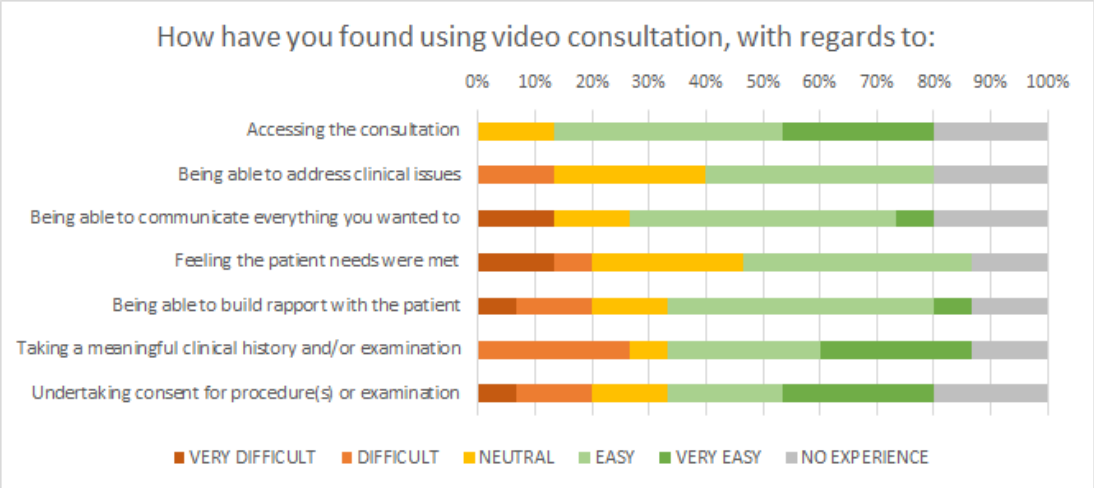
Considering the clinical pathway and tasks involved, the experience overall seems to be positive, but it's clearly not a landslide. With the most significant difficulties being experienced when undertaking cognitive assessments. Clinicians seem to feel that video consultations are easiest when obtaining a clinical history or with follow up consultations.

We expected to hear much more from clinicians about the difficulty of using remote consultations. However, we heard much less about this than we expected. When considering remote consultations we got 20 respondents to our NEL survey.



[3] An uncomfortable trust: Digital isn't perfect, but neither is face-to-face https://www.kingsfund.org.uk/blog/2020/09/digital-care-not-perfect-neither-is-face-face

Interestingly, when considering each step of the consultation process clinicians views are more positive. Perhaps noting that people have more of a concern conceptually of video consultations or that video consultation suits certain parts of the pathway more than others.



When asked to comment on their ratings, there were many positive comments such as 'It allows for better flexibility when meeting patients/carers availability.' The more negative comments included such absolutist comments, such as '...It is also impossible to control the testing environment when assessing remotely, which affects the validity of the assessment information.' Another stated 'The medium rarely works well…'

We also asked care homes about their experiences with patients living with dementia who had general health issues. Many were concerned how GPs were using remote consultation to attempt diagnosis with very little data. As standard most care homes do not have observational tools, or staff trained in how to use them.

Access for patients

The most commonly reported barrier to the use of remote consultations is access to technology for patients, but this is an issue that is quickly diminishing.

- 73% stated that the most common barrier was the lack of access to the technology;
- Clinicians told us that the barriers for remote consultation involved not knowing how to support patients with technical issues and patients having communication issues that are exacerbated by the use of technology.
- Some noted how many older people were the target of telephone scams or pushy sales calls and had been frequently warned of taking calls by family or care home managers, and so when they are called by their service, the patients would just hang up, assuming it was a scam.

While technology access is the most significant barrier, there was generally agreement that this affected a minority of patients, and that the proportion was declining fast. However, for some clinicians, the risk of this disruption - understandably - affects their perceptions and their technology choices.

Care home managers and others noted that almost all care staff are able to facilitate a video call for patients in this setting. All care home managers we spoke to agreed that they had enough devices to facilitate video calls. Although it was noted that some staff feel this is not part of their role and will use a call as an opportunity to focus on other tasks.

With this in mind however the report 'Valuing voices: Protecting rights through the pandemic and beyond' stated 'Internet access is not universal, internet enabled devices are not always available, and a person may need additional support to use digital communication tools. This has been further compounded by having to rely on busy care staff to act as mediators for communication which is not always effective.' Care managers explained that until recently WIFI provision was inconsistent throughout their services. Although it has been high on the list of expectations among residents, until recently it was not viewed as a necessity provision for landlords. This has meant that although this has not impacted professionals meetings, at times residents have had to move to another room or floor or have even not been able to attend virtual meetings due to the lack of WIFI within the buildings.

Advocates and care managers also reported that care staff are concerned about privacy and so find it hard to find private locations within the building where they can have MDT conversations. Advocates have been told by the people they are advocating for that remote consultation often makes it hard to tell if any one else is listening to the conversation, or if it is being recorded, which can increase anxiety.

Another issue advocates pointed out is that when remote consultation is used to replace a face-to-face call it reduces the overall amount of time spent with the person. Whereas face-to-face meetings mean being able to see the engagement between clients and their local support network, either family or professionals, and their living environment. Time is also spent in reflection on the person, moving from location to location, however when using remote consultation staff can move from call to call quickly without time for reflection.

Carer support

Clinicians, carers and third sector organisations also agreed that support from family, friends and carers to help people with video technology was enormously important. More needs to be done to support these ones with this new role.

- Most clinicians told us that the success of remote consultations relied on the availability of family members who can help some use the technology;
- Independent Mental Capacity Advocacy providers have noticed that the majority of people living with dementia will need at least some support with connecting and making video conferencing and there is a significant population who don't have that support;
- Carers and third sector organisations noted that this support could come from many places - family, social care, organisations like themselves - but agreed that it could often make a critical difference.

The even greater significance of carers to these consultations opens up a wider set of issues about the role of carers. Carers services in North East London told us they feel that the NICE guidance should be amended to say that carers should have a separate discussion with clinical staff as the carer can have feelings of guilt or betrayal speaking about the realities of the impact of the condition during consultations with the person sitting there. Also, when consultations with patients and carers take place at the same time and carers have to disclose something that the person living with dementia disagrees with, it can have an impact on their interpersonal relationship.

Carers services also say that they feel disconnected from GPs and the dementia pathway. They tell us that although the NICE guidance states that carers should be involved with the care coordination and offered support, one service said they have ‘had not one referral from clinicians’, either post-diagnosis or with follow up support, with other services agreeing.

Carer centres offer financial support, support with applications for benefits, run emotional & wellbeing programmes, provide training on how to adapt and manage the caring role, and a whole host of other interventions. Carers services would like health services to not just consider putting up a poster in the corridor about care services, which are easily overlooked by anxious first time patients (additionally many don’t realise they are a carer and entitle to the support of the Care Act 2014), but also want these services to ask consent from patients and their carers to make referrals.

Culture and Values

Having a new avenue of working doesn't mean that staff will stop their previous way. Clinicians and patients spoke very strongly, as if face-to-face consultations were under threat by remote consultation. There was a view from some clinicians that being asked to use remote consultation was the same as being asked to make a best guess at diagnosis, as they had no validated tools to use. Others felt that it was simply adding a new tool to their toolbox.

With clinicians as well as with patients, we saw very significant differences in attitudes to remote consultations across individuals. They were far from being explained by institution or service. As a result, we have paid more attention to the culture and values of clinicians, as these seem to be driving some of the responses to the technology.

There were a set of broader cultural and attitudinal barriers that seemed to be slowing or complicating the adoption of remote consultations within dementia care. These attitudes pre-date remote consultations in many ways - and are hard to capture precisely - but they seem to be important nonetheless.

A relational view of health provision

A significant proportion of the clinicians surveyed or interviewed seemed to believe that the promotion of remote consultations somehow missed the point about the work they do, and about the character of face-to-face interaction. For those clinicians, being with the patient - and the patient being with them - is a transformative part of the work they do.

This is not a new tension in health innovation - many moves to team-based approaches (for example, in primary care or midwifery) or peer-based approaches similarly disrupt the face-to-face relationship with a single clinician, with costs as well as benefits.

An uncertainty about the place or value of diagnosis

Remote consultations seemed to be most popular with people who felt they were driven by necessity, not simply attracted by their benefits. They had to connect with patients to assess, support and treat, and remote consultations were the best option they had.

However, some clinicians did not seem to think like this, particularly in relation to initial assessment and diagnosis:

- For some clinicians, diagnosis was such an involved process, and needed to be so precise, that the fallback option of a remote consultation simply was not good enough to be of value.
- For some clinicians, because of there being no cure and because the therapeutic options available to patients were relatively weak, they did not feel such a drive to reach a diagnosis.

While in a sense these are contrasting views, they both seem strongly medical constructions of dementia. There is a great deal that can be done for a patient's well-being and independence, and some of this relies on a diagnosis.

Third sector organisations and carers' organisations were much more straight-forwardly of the view that diagnoses were important (as a gateway to support) and that a 'good enough' assessment was better than no assessment. The question of whether they are right is a nuanced clinical one, but this difference of view seems to shape different approaches to remote consultations.

Care home managers told us that video communications success has been dependent on the severity of the dementia. It is felt that most with moderate to severe dementia disengaged if they can't see the person physically. But many managers wanted to make it clear that this disengagement would happen just as frequently with the same residents during face-to-face engagement.

A scepticism about online assessment

Some clinicians objected to using cognitive assessment tools that they felt were not validated for remote use, and we heard a lot of times staff say that 'none of the tools are validated for remote use.' However, we have found that authors of most frequent tools in use in NEL do claim to be validated and provide researched papers that evidence their use in remote circumstances. This seems to be an area that merits further discussion by clinicians.

Reports from countries with isolated populations such as America, Canada and Australia have done research and have concluded that preliminary standardized assessment tools can be reliably administered and scored via remote consultation. Remote assessment was shown to be acceptable to patients and caregivers, although they noted that informed consent, informant history, and attention to privacy and autonomy was paramount. So conceptually remote consultation to diagnose dementia is possible.

Some clinicians felt that whatever the guidance had stated, they would have probably retained the cognitive assessment tools they previously used. This was because they felt the staff were adept at using their existing tool, and that new tools would require training. But also that the commonly used cognitive assessment tools had a similar degree of accuracy. So they felt that unless a new tool represented a significant improvement in accuracy or patient or clinical experience then there would not be a need to change. It was also felt that the purpose of assessment tools were there to learn more about a patient,
be able to communicate the findings to others, clinical staff and patients. This would not replace the clinicians experience, which would be able to diagnose most subtypes.

Other clinicians noted that the remote consultation guidance outlined a number of alternative cognitive assessment tools, but the cost to obtain the copyright was too expensive for them.

Clinical limitations

There are clearly also more profound limits to the range of patients for which remote consultations are possible. Clinicians, carers groups and third sector organisations agreed

that for people with additional communication difficulties or with more severe dementia, remote consultations can be simply too difficult to make sense of.

Carers also mentioned that for some people living with more advanced dementia, video communications can be more confusing than a telephone. This is felt that due to the nature of dementia people are more likely to retain the skills of telephone communication which has been common practice for decades, whereas video communications are a relatively new experience for much of the population until the COVID pandemic. Several carers have said the person they care for with dementia have thought video consultations were ‘odd tv shows’ and not respond, just as they wouldn’t respond to other tv programmes they might watch.

Effects of remote consultations for people with dementia

One service in East London is successfully using virtual consultations, and has studied their effects:

- 70% of patients had remote consultation (48% video, 22% telephone) with 30% face-to-face for the initial assessment.
- 75% of initial video consultations led to diagnosis, compared to 36% over the phone and 60% face-to-face.
- Video consultation also required the least number of further investigations (12.5%, compared with 36% telephone and 20% face-to-face)
- Video consultation also had the least number of re-assessments (0%, compared with 9% telephone and 7% face-to-face).

In this study patients highlighted the following benefits of using remote consultation:

- Patient feeling more comfortable within their own home,
- Patient (and any carer who would normally have to accompany them) was able to avoid often unpleasant and stressful travel,
- Patients (and any carer who would normally have to accompany them) were able to avoid exposure to COVID-19 and other communicable viruses while travelling and at the hospital.

There is certainly a greater awareness, driven by so much more use of remote consultations, of some imperfections of face-to-face appointments. Other clinicians who spoke with us were interested in video consultations as a way to reach previously unserved parts of their patient cohort, especially those who faced difficulties traveling to health services.

Clinicians also saw the benefits for multidisciplinary meetings that traditionally had low attendance, where more representatives could be in attendance to give a stronger patient voice.

Clinicians and third sector organisations talked about the benefit of enabling families to join consultations remotely. One service reported relatives from other countries being in attendance where previously this would not have been considered. Care home managers agreed saying that when MDTs took place they had much higher attendance using remote technology than previously.

The impact of language and culture

As well as being joined by other clinicians, other key partners can join remote consultations also. For example, 53% of clinicians we surveyed stated that they had used video consultation with a translation service. For the translation services, this has improved flexibility and increased capacity, which is important for patient access.

Lithuanian is the second most commonly spoken language in Barking and Dagenham. In Tower Hamlets (18%) and Newham (7%), Bengali was the second most common language, while in Redbridge (4%), Urdu topped the list as the most popular foreign language.

The Europia charity completed a project in Oct 2020 called 'Starting a Conversation About Dementia' that looked from the angle of Polish and Lithuanian communities in the UK. The project found that dementia and mental health in general is still a very taboo subject for those Lithuanian communities. The term for mental health in Lithuania is mental illness and that carries a lot of stigma.

People in the Lithuanian communities told the project that health information made available by local trusts uses direct translation rather than meaning-based translation. This results in confusion, and idiomatic language is often incomprehensible. In order for the translation of materials to be medically accurate translators seem to prefer professional or archaic terminology that is not easily understood by the common person. Additionally, since the medical model in the UK is different to Lithuania, people tend to use health services at the point of crisis, increasing pressure on acute services, rather than engage at an earlier stage.

Since approximately 2010 the Lithuanian community has grown in NEL, those who came to work were often between 20- 40 years of age. Not only is that community growing older, but their parents who are traditionally expected to be looked after by their children are also getting older and having health needs, prompting them to move to the NEL area for care. Therefore the Europia project expects that over the next 10 years the health needs of the community will greatly increase. There will also be a large increase of those with a caring role. But as well as a need for health services to consider this impact, an education piece was also recommended as there is still a perception within the community that dementia is an expected part of old age, and so few seek medical interventions.

Our reflection is that clinicians worried much more about remote consultations invalidating assessment than they did language. However, the literature about such assessments - which is encouraging about their remote use - emphasises that for ESOL patients, assessments have to be handled with care, and different tools used.

James Watson, a researcher at the School of Environmental Studies, reviewed the Inequalities in dementia care pathways in June 2020 and recommended that there needed to be more culturally appropriate dementia services that incorporated a more holistic view of health.

Care homes and dementia care in North East London

A virtual multi-professional dementia care improvement community for care homes was the aim for workstream 3. Care homes are also feeling the pressure of the COVID-19 pandemic and are struggling with the vaccine roll out. They want to feel like independent partners, with their own specialisms, but tell us they often feel 'spoken down to' and put upon. There is also a skills shortage within the sector, so there needs to be not just better links to primary care, but also improved skills to enact change or improvements. When thinking about setting up a network it is very important to think about how the network is formed as much as getting it established.

Dementia care is core business in care homes - 70% of residents[4] in care homes in England have some form of dementia. However, while this means that care home managers are highly-motivated around dementia care, this does not mean that there is not room for improvement.

Rapid changes

A great deal of change has happened in care homes over a short period of time. In relation to dementia care and its future, perhaps three sets of changes are most significant.

First, the pandemic shone a light on the weak digital infrastructure of care homes. Led by NHSX nationally, there was rapid work to:

- Help care homes begin to use NHSMail, so that they could communicate securely with clinicians about residents
- Ensure care homes had strong broadband access
- Ensure that care homes had the hardware and know-how (primarily, laptops and tablet computers) to use this infrastructure, both for clinical advice and to keep residents connected to friends and family

These changes have certainly been significant in the infrastructure of care homes in East London. At the same time, efforts to implement much of the substance of Enhanced Health in Care Homes were brought forward. On 1st May, a letter from NHS England[5] demanded a very rapid set of changes in terms of clinical support for care homes, including:

- Named GPs
- Weekly ward rounds
- MDTs
- Enhanced care plans for residents

[4] NHS England and NHS Improvement (2020) The Framework for Enhanced Health in Care Homes - Version 2 https://www.england.nhs.uk/wp-content/uploads/2020/03/the-framework-for-enhanced-health-in-care-homes-v2-0.pdf

[5] Letter from NHS England, 'COVID-19 response: Primary care and community health support care home residents' https://www.england.nhs.uk/coronavirus/wp-content/uploads/sites/52/2020/03/COVID-19-response-primary-care-and-community-health-support-care-home-residents.pdf

In East London, progress against this letter is patchy, but advancing everywhere. The Transformation teams told us they have no mechanism for either seeing adoption rates of the framework or gathering feedback from clinicians or care homes about its progress. They feel it's the CCGs role to ensure this takes place. Named GPs and weekly ward rounds are largely in place to an extent. MDTs and the level of care plans see less comprehensive coverage. In Tower Hamlets, for example, virtual MDT's have been rolled out across the borough, whereas other boroughs are further behind. However, across East London this is a rapid direction of travel for the system.

Three challenges in dementia care in care homes

The Framework for Enhanced Health in Care Homes highlights a range of areas where dementia care in care homes can be improved. These can be thought of across three areas:

- Screening and identification
- Specialist clinical interventions
- Ongoing support and therapy

Our research suggests that there is room for improvement in all three of these areas.

On **screening and identification**, it is estimated that 31% of care home residents have undiagnosed dementia[6]. However, even within care homes, screening and identification is not systematic. Proven tools are used within East London, but they are not used everywhere.

On **specialist clinical interventions**, access to healthcare for care home residents has been challenging for some time. Although it is from seven years ago, it is worth quoting at length from research looking at this issue:

'Healthcare of care home residents is difficult because their needs are complex and unpredictable. Neither GPs nor care home staff have enough time to meet these needs and many lack the prerequisite skills and training. Anticipatory care is generally held to be preferable to reactive care. Attempts to structure care to make it more anticipatory are dependent on effective relationships between GPs and care home staff and their ability to establish common goals. Roles and responsibilities for many aspects of healthcare are not made explicit and this risks poor outcomes for residents'[7]

Care home managers told us that they feel clinicians seem to see dementia as a social problem and not a medical issue, and without a cure that there was little need to prioritise responses to requests for health care. Care managers seemed to be in agreement that they had very few memory assessments conducted by services compared to pre-COVID times

[6] Lithgow, Jackson, & Browne, (2012) Estimating the prevalence of dementia https://pubmed.ncbi.nlm.nih.gov/22081511/

[7] Robbins, I., Gordon, A., Dyas, J., Logan, P. and Gladman, J. (2013) Explaining the Barriers to and Tensions in delivering effective healthcare in UK care homes: A qualitative study https://bmjopen.bmj.com/content/bmjopen/3/7/e003178.full.pdf

and that over all they had a large reduction in response from all health services with the exception of the Mental health teams who seemed very responsive. Statutory advocacy services have also been very responsive.

These challenges have certainly been an issue for care homes within East London. For example, Health1000 was an initiative in Havering - evaluated by Nuffield Trust two years ago - to provide proactive primary care to four nursing homes in Havering who previously had difficult accessing GP services[8]. While the initiative faced operational challenges (overspending and under-recruiting as a result), it saw emergency bed days fell by 53%. This is typical of care homes nationally - healthcare for residents in reactive rather than proactive.

Similarly nationally, although Enhanced Health in Care Homes was seen as the most successful of the Vanguards, its success must be understood in this light. The health of care home residents was significantly improved, but the starting point was one of highly-constrained access to primary care.

There are a range of reasons for this - the times of day primary care is available, resource constraints on both care homes and GPs and the challenges associated with staff turnover in care homes of around 20%[9]. However, recent research also highlights the significance of the role of care home staff as intermediaries in this process.[10] Because healthcare is largely accessed through these staff - their lack of clinical knowledge and understanding of service thresholds and protocols - significantly affects access to clinical advice.

This suggests that the idea of skills gaps in care homes is important, and relates directly to the issue of clinical support. An increasing proportion of residents, in care and nursing homes, are coping with multiple and complex physical and mental health[11] problems.[12] Because of funding pressure, eligibility thresholds have risen and fewer people are receiving publicly funded social care.[13], and so the average resident is more complex. As a result, researchers argue that 'a skills gap appears to be developing in the number of workers with the knowledge and skills to support people with complex conditions'.[14] The effects of this can

[8] Johnson, C. Crump, H. Curry, N., Paddison, C. and Meaker, R. (2018) Transforming Healthcare in Nursing Homes: An evaluation of a dedicated primary care service https://www.nuffieldtrust.org.uk/research/transforming-health-care-in-nursing-homes-an-evaluation-of-a-dedicated-primary-care-service-in-outer-east-london

[9] British Geriatrics Society (2016) *Effective Heatlhcare for Older People Living in Care Homes* https://www.bgs.org.uk/sites/default/files/content/resources/files/2018-05-10/2016_bgs_commissioning_guidance.pdf

[10] Victor, C., Davies, S., Dickinson, A., Morbey, H., Massey, H., Gage, H., Froggatt K., Iliffe, S and Godman, C. (2018) 'It Just Happens': Care residents' experiences and expectations of accessing GP care https://www.sciencedirect.com/science/article/pii/S0167494318301651

[11] National Audit Office (2018) Adult Social Care at a Glance https://www.nao.org.uk/wp-content/uploads/2018/07/Adult-social-care-at-a-glance.pdf

[12] SCIE (2020) GP Services for Older People: A guide for care home managers https://www.scie.org.uk/publications/guides/guide52/entitlements-and-requirements/access.asp

[13] NICE (2015) Costing statement: Implementing the NICE guideline on social care of older people with social care needs and multiple long-term conditions (NG22) https://www.nice.org.uk/guidance/ng22/resources/costing-statement-pdf-554559661

[14] Jo Moriarty, Jill Manthorpe and Jess Harris (2018) Recruitment and Retention in Adult Social Care Services (https://www.kcl.ac.uk/scwru/pubs/2018/reports/recruitment-and-retention-report.pdf)

be seen in declining productivity within care homes, driving up costs. According to the ONS, general problems with recruitment and retention 'one of the potential drivers of falling productivity is increasing client needs'.[15]

This suggests that clinical support to care homes and clinical knowledge within care homes needs to be grown together.

However, not all dementia care is about deep clinical knowledge. The Framework for Enhanced Health in Care Homes also highlights the range of **ongoing support and therapy** that many staff would be capable of providing within care homes, from music therapy to reminiscence therapy. In the context of the pandemic, care homes' ability to provide the range and amount of therapy envisaged in the Framework is particularly constrained. Even before 2020, East London care homes wanted to do more of this kind of work. In part, resources, space and time constrain what is possible. Staff confidence and skills, resources and equipment and staff continuity also limit what is possible. Care homes would have strong interest in work to support them to do more in this area, both because it directly improves resident well-being and because they see it supporting staff satisfaction and retention.

Care home networks

We collected information from the managers of seven different care providers, representing nineteen care homes. They told us that they are currently focused completely on managing COVID, now with the role out of the vaccine over the next 3-6 month period and rapid testing machine, it is an extremely busy time and that they do not foresee the establishment of a new network as something they would wish to develop during this time.

All who we contacted and who responded felt that having a virtual improvement network was important and most wanted them to be held monthly. Most felt that they wanted this network to:

- Provide a clear channel for the latest information with regards to dementia care;
- help them with innovation and technology advice
- some felt that it should promote better multi-professional working

Some social care stakeholders emphasised the pattern of feeling 'talked down to' by health colleagues, and the need to avoid this. They have their own expertise, but it is felt this is often ignored. They want to feel like partners, but often feel that health programmes are done to them rather than working with them. They also feel that since they spend the majority of the patients time supporting them, rather than the brief medical appointments they face with primary care, that they should have a larger stake in being heard.
Care providers told us they feel that, especially now, other organisations are interrupting their independent private businesses. They are not part of the NHS, and as they are a mixed group often have various issues when attempts are made to bring them as one.

[15] Measuring adult social care productivity in the UK and England: (2016) https://www.ons.gov.uk/economy/economicoutputandproductivity/publicservicesproductivity/articles/measuringadultsocialcareproductivity/2018-06-01

Considering existing care home provider networks

Since the Enhanced health in Care Home framework is establishing connections with individual homes, the workstream objective would suggest that it is considering something larger. All managers agreed that there are a large number of networks already in existence with different aims and objectives. With so many networks available attendance is usually low, which means that they often become ineffective to enact change and so motivation is low.

DeAR-GP protocol, used in parts of North-East London, was used to create connections between GPs, memory clinics and care homes. It required some project management to establish the protocol and maintain the connections. It was supported by the Health Innovation Network, but that support has not continued as it is out of area for their support and the project funding ended. Since the protocol works, and people are aware of it, then it makes sense to link the protocol with a network to provide a framework, and use the similar terms of reference, to fulfil the objectives of workstream 3.

Local authority provider forums are usually the most well attended of networks, however sources say the communication is usually quite one directional. So although they might be a good way to alert a large number of care homes about workstream 3, they would not be the place to have MDT or increase partnership working. There is also one forum per local authority, rather than a pan-London network.

Register managers network is not as well attended, but still reaches about between 120 and 180 providers. This would be a good space to engage with service providers about how to co-production a new partnership between health and social care. It is coordinated by Skills for Care.

Care Providers Voice is a new network being set up by providers for providers to set up a pan-London voice rather than a local authority based response. The focus of the group will be on establishing new and best practice for care providers. This seems like a good space to share best practice.

The **CEPN** (also known as 'Training Hub') is a localised model for the planning and delivery of education and training for the health and social care workforce within the community. The model has been supported by Health Education England and it is felt that these training hubs could facilitate the co-production of a network.

The **Care home resources pack** is distributed regularly by the Healthy London Partnership as part of the Enhanced Health in Care Homes Framework to all care homes. As care providers find it very hard to external responses to engagement it was felt this would be the best way to alert them all to any new network.

One local **Dementia Action Alliance**, Havering, is made up of about 100 organisations, however, most of these are businesses and so would not be the best place to have a network connecting care homes with memory services. However, The local Dementia Action Alliances have links and newsletters to carers groups who could provide feedback about their experiences and would be willing to promote any new services, networks, or create surveys to get feedback from the public from Jan 2021 onwards.

It was advised that multi-professional meetings about dementia would have more success if they involved other aspects of the dementia well pathway, such as carers associations.

Reflecting on next steps

The adoption of remote consultations within dementia care is not a ‘done deal’. Equally, while care homes have come a long way in 2020 also, there is room for further improvement in their support for residents with dementia.

In relation to remote consultations, adoption has been rapid, but clinicians have been driven by the necessity of remote consultations more than they have been attracted by the benefits. The same is true for many patients.

So, as vaccinations rise and Covid-19 cases hopefully fall, there will be contrasting dynamics. Adoption will likely continue, but there will be a countervailing desertion, as service users and clinicians who struggle return to face-to-face.

As a result, simply encouraging the use of remote consultation technology does not look to be the right approach:

- Proselytising to clinicians about an experience they have had is not persuasive for those who are not already enthusiastic,
- The most significant barrier to growth - access for patients - is difficult for the health system to resolve,
- While it is difficult to predict, in the short-to-medium-term, the number of remote consultations in dementia care may peak.

It is natural for the conversation about remote consultations to mature, and to become more integrated with the core concerns of clinicians and patients. How do we use remote consultations in the right way? How do we use them to enhance research, service quality and patient outcomes?

The biggest clue about how to do this is in the biggest benefit of remote consultations; collaboration. As we have seen, remote consultations:

- Enable MDTs and remote specialist clinical support
- Enable other key people - from interpreters to family members to join conversations
- Very often require the support of carers to make the technology and the conversation work

Support clinicians by both:

- learning from and problem-solving around the use of remote consultations
  and
- showing how remote consultations can be used to unlock a more cohesive dementia pathway, helping carers, clinicians and other partners work better together

As we have seen, this theme of growing collaboration is mirrored in the journeys care homes in East London have been on in recent months. Much more so now than a year ago, they have:

- The digital infrastructure for collaboration
- The supporting health service architecture for collaboration

However, care homes continue to face challenges in dementia care, both around building their own staff skills, knowledge and confidence, and around brokering in clinical support from partners. As we saw, these two processes are intimately linked - they need knowledge and skill in-house to get the right support for the right patients and to make sense of expert external support.

As a result - whether they are pursued together or separately - there is a common theme to how remote consultations and excellence in dementia care in care homes might be promoted over the coming 12 months. Having established new forms of connectivity, the question is now how they can be used to deliver benefits for patients, residents and staff.

Beyond this thematic link, there is a practical connection between these two pieces of work. Care homes have quickly reached critical mass in their use of video consultations. At the same time, remote consultations have become an important research tool. Remote consultations - with staff as well as patients - could help to enhance dementia care in care homes particularly. In the process, there may be a significant opportunity for an AHSN to boost clinical research in care homes, particularly around dementia. There has been much discussion throughout 2020 of the lack of clinical research in care homes - around issues like dementia - but Covid-19 has only made solving this challenge tougher. Remote consultations could be a significant element in research to overcome this and to further enhance dementia care in care homes.

In the following section, we try to draw out specific opportunities for later phases of work. Building on our analysis, these opportunities are:

- Embedded in the wider system conversation about improving quality and outcomes for people with dementia
- Weighted towards interventions that build on the potential of new technology, particularly as it enables people to work together across the pathway in new ways

Recommendations

Based on the research reported here and wider work, Care City made a set of recommendations in relation to improving dementia services. Although initially tailored to the report funder, broader recommendations have been made for wider consideration.

A headline from the NHS staff we interviewed was that the amount of documentation around the use of remote consultations was sufficient. Most staff said they didn't want any more documentation, and that during the current COVID-19 pandemic they didn't have time to fully absorb, share or implement very much from existing documentation.

However, where they had engaged with guidance, they had found it broad but shallow. Where there are gaps, they want documentation that is detailed enough and well-evidenced enough to take action. Online cognitive assessment tools are an example - clinicians would like support that includes links to the tools, costing information. As much as possible, they want support that reduces the lead time to decision and action.

Covid-19 means that there is huge pressure on health and care systems and interventions need to be clear and targeted to succeed, and ideally to connect to existing activities.

We recommend that support to enhance services for people with dementia can be embedded within:

1. The immediate response to the second wave of Covid-19
2. The system's recovery from Covid-19
3. Research activity around dementia
4. Innovation activity related to dementia

Recommendation 1: Remember dementia and remote consultations in the response to Covid-19

As part of its response to the second wave of Covid-19, **support the roll-out of remote monitoring within care homes across.** This is about monitoring vital signs and checking for symptoms of Covid-19, but it is also about supporting the establishment of MDTs around care homes. This new piece of work is an opportunity here to strengthen both the adoption of remote consultations and partnerships with care homes:

- Under significant pressure, it would be easy to unduly narrow the focus of this work, so that the concern becomes only Covid-19. At times that may be necessary, but at times also it may be possible to ensure a systematic approach to observations and contacts helps unlock opportunities to find undiagnosed dementia, or support residents better.

- In turn, there may be opportunities within this work to better support remote consultations, or to illustrate clearly their role within rapidly changing systems and pathways.
- In turn, as care homes likely continue to build critical mass around the use of remote consultations, they may become centres of expertise from which other parts of the system - looking to optimise remote consultations for people with possible dementia - can learn.

Recommendation 2: Embed a focus on dementia and remote consultations in the recovery from Covid-19

The pressure on services and resources caused by Covid-19 and its aftermath means that mental health providers will have to think hard about their service models and approaches and staffing models.

- We propose that **a remote consultation benchmarking group** be established. This group would use a survey and operational data to track the use of remote consultations and to look at some of their impact on pathways. Do they lead to different decisions and referrals? What is their effect on waiting times? Analysis of this benchmarking - building on our initial research - would help Trusts to benchmark their use of remote consultations in dementia against the norm, as they review pathways.
- The **London Transformation and Learning Collaborative** - supported by Health Education England - is focused on Critical Care. From April 2021, this programme will focus on mental health, supporting Trusts to review staffing, skills and service models. This benchmarking work could support and be embedded within this wider work.
- Alongside this work - where feasible and as the pandemic allows - **a webinar series** for clinicians and researchers about remote consultation diagnosis, is a way to pull together and share what it is learning in this area. It should communicate the inputs and conclusions widely, and we suggest that these include.
    - **an online 'tool-share'** for clinicians to see all the tools available and how to access them as well cost. This is a gap that clinicians told us they would be a useful resource across all services.
    - A **case study and thought leadership piece** - building on this report - looking at where remote consultations have proved powerful, and what they suggest about the future of dementia services.
- **Workstream 3 - Set up a co-production steering group** made up of representatives from Skills for Care, Care Providers Voice, Care Centres, NELFT and ELFT memory clinics to develop a Virtual multi-professional dementia care improvement community for care homes. If this were to be coordinated by a third party such as Care City, which holds a unique role within the East London community, then this could help with services feeling that this is something truly co-produced and not something done to them.
    - Promoting the use of **DeAR-GP** to underpin the formation of this network and ask the Lead Dementia GP in each CCG to write to all GPs, memory clinics and care homes in East London following the template set out in the DeAR-

GP Protocol - Outcomes of the pilot included increase in diagnosis rates, upskilling the care home workforce and increased partnership collaboration.

Recommendation 3: Connect aspirations around dementia around remote consultations to research work

Research is a huge strength, and we believe that this connection can make a significant contribution to both enhancing the role of remote consultations in dementia services and strengthening support for dementia within care homes.

As the last year has shown, too little research happens in care homes, but this in part because of the barriers to research in care homes (compared to hospital-based research). These barriers have only been increased by Covid-19.

At the same time, remote consultation is a powerful research tool. Indeed, much of the practice and evidence around remote consultations was created by researchers wanting to solve problems of research, rather than clinicians wanting to solve problems of service delivery:

- To think about the ability of remote consultations to unlock greater research in care homes
- In turn, to use the growth of remote consultations and care homes research to help to enhance practice

The goal would be to create a virtuous circle between academic research and service development.

Projects that we recommend in section 11:

- A research project working with various providers of remote monitoring technology to care homes to embed screening for dementia within their tools. This will help to find the tools that can provide the most useful data to clinicians.
- A research project exploring supporting the role of the carer in the dementia wellbeing pathway. This could identify a number of ways to build the resilience of carers reducing the pressure on primary care, but also educating them to find more effective ways to navigate the pathway so that people can get the help they need when they need it.
- A research project exploring the importance of meaning-based translation, and greater integration of interpreters into remote consultation to consider the resource implications and impact of reaching people in a language they understand and the communities of NEL. It would also improve the effectiveness of remote consultation.
- A research project exploring the impact of Patient Initiated Contact models and consider the opportunity for research looking at longitudinal tracking of people with dementia. This could help with the development of the integrated care system and reduce pressure on the wider workforce.

Recommendation 4: Link dementia and remote consultations to work to develop and scale innovation

The 'Beneficial Changes Network' is an opportunity to create a key connection for the work on dementia and remote consultations - a connection to innovation.

There remains much needed innovation in this field. As the following sections show, significant innovations are on the way, but they are not here yet. We suggest two innovations particularly worth of further exploration, and possible partnership are:

- **Winterlight labs** as a dementia screening tool integrating the technology with remote consultations with the aim to increase dementia diagnosis rates and building confidence in the efficacy in remote consultation.
- **Enabling carers' centres as Hubs** from which patients could receive remote consultations. This will help to integrate the health and care services, help care centres to have stronger connections and provide a necessary resource to the community that does not rely on carers or family.

We also feel it is worth considering how the recommendations and of this report fit into the NHS England

Embedding remote consultations and care home support in pathway improvement

The NHS transformation implementation framework to improve dementia is called the Dementia Well pathway. A revised edition has been included in the 2020 document 'Dementia Wellbeing in the COVID-19 pandemic':

Preventing Well	Diagnosing Well	Treating Well	Supporting Well	Living Well	Dying Well

We will use this schematic to think through the range of opportunities for supporting:

- Remote consultations for dementia care
- Dementia care in care homes
  (we are treating Dying Well as out of scope for these workstreams)

PREVENTING WELL

Preventing Well	Diagnosing Well	Treating Well	Supporting Well	Living Well	Dying Well

Spotting signs of dementia at the earliest opportunity is hugely important to the long-term challenge of improving outcomes.

Now

The DeAR-GP protocol, used in parts of North-East London but not everywhere, is a simple case-finding tool that has been designed for use by care workers to identify people who are showing signs of dementia.

We suggest promoting the use of the DeAR-GP and use it to help establish workstream 3 networks.

One carers centre also had a unique programme to support people at the Prevent well/Living Well stage of the dementia pathway. There is a cohort who are seen by ambulance crews who are struggling with dementia and are not engaging with medical services and have no social care coordination for a variety of reasons. Ambulance crews feel that the people need support, but are unsure as to who can help and so the carers centre have provided promotional material for their services to these crews. This seems to be a well received programme that could be promoted.

Next

With people with advanced dementia it can be very difficult to act preventatively to address health issues. Some people with dementia are not able to communicate symptoms to care workers. In some care homes in East London care workers carry out a health assessment

on each resident each month, supported by observational equipment and shared with GPs. (For example, Care City worked with Feebris to roll out observations to 20 care homes across Barking & Dagenham, Havering & Redbridge to showcase the potential of this work. The service is being recommissioned for another year, but North-East London is also commissioning for a service for the whole system for next year).

We suggest that providers of remote monitoring technology to care homes work to develop protocols for doing health screenings for people living with dementia. This might begin as a research project, however, it might go on to help shape how remote technology is used across the dementia pathway.

There are a number of dementia screening tools currently in development, but not yet ready for deployment. They differ by sources of information - some rely on wearables, others smartphone data, others GP data. Those contacted stated that their programmes hope to be available for deployment within 24months. But until they are being used there is no way of telling how impactful they will be. Mindset 4 dementia is one such screening app being developed by staff at the Whittington Hospital in North East London.

We suggest that development work in this space for a focus for boosting research in care homes, in support of better dementia care.

- Astrodem is an example of an algorithm that seeks to use GP data to identify patients at high-risk of dementia. Although initial results showed limited predictive power, this is such an important area of innovation more broadly that it may be an important one to watch.

- One stand out screening tool that is being used is Winterlightlabs which uses an AI to detect changes to voice patterns to detect Alzheimer's disease, predicting MMSE for Alzheimer's disease monitoring and Subtyping primary progressive aphasia. It could bring together work to improve screening in care homes with broader development work around remote consultations and dementia

DIAGNOSING WELL

Preventing Well	Diagnosing Well	Treating Well	Supporting Well	Living Well	Dying Well

As we saw, assessing and diagnosing was a source of significant anxiety and challenge for clinicians. It is a significant change to their clinical practice and they have questions and concerns about the use of assessment tools in the context of remote consultations.

However people living with dementia have a number of mental health and community support entitlements which only become available to them upon clinical diagnosis, for example, the support of a Dementia Advisor.

Now

As we saw, whether tools have been validated for use online was a significant concern for clinicians. Staff told us that the remote consultation guidance outlined a number of alternative cognitive assessment tools, but the copyrights were often too expensive for them to be used. There is significant potential for work to share tools and practice in this space. It might also need to encompass broader engagement of the clinical-academic community, to help to set some benchmarks for good practice in this space.

Our reading of the evidence is threefold:

- What is meant by validation of these tools - even in face-to-face settings - should not be overstated. They are stable assessment tools, the results of which will tend to correlate with the clinical judgments made as part of a holistic assessment of a patient. In other words, in no settings can these tools be operated in an algorithmic or 'tick-box' way.
- With that in mind, there are a set of tools that have been validated for remote use, and we give more detail about this at Appendix A. One tool worth highlighting is Free-Cog, which is newly published and freely available. We have been in touch with Alistair Burns, its creator, about a collaboration in this space.
- There is some good evidence that - beyond any single tool - cognitive assessment tools for which there is strong face-to-face evidence (and where there are no special features of the test that clearly cannot be reproduced remotely) tend also to work remotely.

Disseminating the resource 'Video consulting in the NHS' produced by the University of Oxford may also help with concerns over privacy as it addresses this concern.

Additionally, Craig Murray from the University of Liverpool also highlighted in a recent talk the benefits of having increased multi disciplinary work between memory clinics and orthoptic departments. We have been in touch to ask how this might become established in locations where there are no previous engagements.

We suggest a webinar for clinicians and researchers about the issues of validation, sharing its conclusions widely and hosting online a 'tool-share' for clinicians working in this space. Post COVID-19 ongoing webinars on the issues of remote consultation could highlight best practice and innovation in this space.

Next

There are two further areas of interest:

- The role of carers seems to be pivotally important to the process of diagnosis, because they hold so much vital intelligence, alongside the patient. At the same time, clinicians have said that very often, carers are pivotal to making remote consultations work, by helping with technology and with the conversation.
- Translation services are hugely significant to healthcare for older people in East London, and interpreters have been very positive about the opportunities and flexibility afforded by video consultations.

In both of these cases, there seems to be huge potential for further service design work, to build possible roles for interpreters and carers into remote consultations so that they work better for everyone.

We suggest research should be done into how the role of carers could impact the dementia well pathway, specifically with regards which digital tools make the greatest impact to their support of health services. Also research the effectiveness of various remote interpretation tools, and the impact of meaning-based translation within health services.

TREATING WELL

Preventing Well	Diagnosing Well	Treating Well	Supporting Well	Living Well	Dying Well

The way the system works together to treat dementia looks set to change radically over the coming years, with much greater professional collaboration.

Now

Clinicians saw one of the benefits of remote consultations as being the way the lower barriers to bringing together different clinicians around the patient. As practice develops, it seems likely that practice in this space will need to mature, given scarce resources. It would be great to explore - given greater ease of other professionals joining consultations - the optimal use of this element of remote consultations.

Equally, it is certainly true that the vast majority of conversations we had about video technology were about clinician/patient interactions. However, as MDTs become established, it may be that clinician/clinician interactions become very significant, as different kinds of working relationships are established between secondary care, primary care and social care.

We recommend remote consultations to support multi-professional working - and the roll-out of Enhanced Health in Care Homes (EHCH). They could help to move the conversation from clinician/patient to a Trust level discussion, especially getting the trusts to monitor the uptake and embedding of EHCH.

Next

As this practice develops, in the future two further areas may be of significance.

- Given the rising awareness of the limitations of face-to-face consultations as well as remote consultations, particularly for people for whom travelling is difficult, would there be any benefit in enabling carers' centres (for example) as Hubs from which patients could receive remote consultations? Having someone who patients trust assisting them with setting up remote consultations may alleviate some of the concerns over privacy. Disseminating the resource 'Video consulting in the NHS' produced by the University of Oxford may also help with concerns over privacy.
- As multi-professional practice develops it will ultimately become quite sophisticated. There could be a need for algorithm-driven digital assistants to run some of the scheduling and referrals, to optimise efficiency and outcomes.

Embedding remote consultations and care home support in pathway improvement

We suggest the development of remote consultation hubs within care homes, and AI scheduling for multi professional practice.

SUPPORTING & LIVING WELL

Preventing Well	Diagnosing Well	Treating Well	Supporting Well	Living Well	Dying Well

The third sector community groups and public we spoke told us that they feel the pathway stops at diagnosis. They feel that there is funded support, but there is little or no connection with the GP/ memory services with little promotion or marketing. This results in few knowing about what to do once they have a diagnosis. In contrast, other support services say that patients are given too many leaflets and that more marketing money could be used for social prescriptions or improving services. We feel that there are ways to create awareness that don't rely on creating leaflets, such as protocols within GP record systems that prompt for referrals when diagnosis are being recorded, or via the previously recommended webinars.

Now

Around some diseases - such as cancer - the information provided to people on diagnosis has been professionalised and digitised. Smart use of simple databases allows static information about the condition and national sources of support to sit alongside dynamic content, based on post code or other characteristics. If consultations are already digital, will this be the spur to strengthen the infrastructure for social prescribing across East London for those diagnosed with dementia, to enable clinicians to share comprehensive, up-to-date information easily with patients?

NELFT has indicated that they want to shift focus more towards more of a Patient Initiated Contact model. This way patients can avoid the need for risk based mandatory check-up meetings, which patients feel are paternalistic, and move to a more pragmatic approach.

There may be merit in increasing the regularity of digital cognitive assessments to track deterioration. Care Homes would see this as part of their growing health monitoring remit if they could train their workers to complete basic assessments.

We suggest the impact of Patient Initiated Contact models be explored and consider the opportunity for research looking at longitudinal tracking of people with dementia.

Next

The biggest barrier to the growth of remote consultations at present is access for patients. This access is both about internet access and hardware, and skills and confidence. Traditionally, this is outside of the scope of health services, but it is a growing barrier to a growing number of services, and it is not insurmountable.

For example, in Barking & Dagenham and Havering, Reconnections - run by Independent Age - is a new pilot service to tackle serious loneliness. Through the pandemic, they have

been running Tech Tasters, at a unit cost of £50. Each beneficiary receives a 4G-enabled tablet for 3 months, skills training and remote support, with many then going on to acquire what they need to stay connected. Building on the triage of patients for remote consultations, is there a business case to think seriously about investing at scale in this kind of provision.[16]

[16] There is more information about Reconnections and Tech Tasters here https://www.lbbd.gov.uk/older-peoples-day

Beyond 24 months

There are three clear areas of consideration when thinking about the dementia well pathway over the next 24 months that have not yet been discussed in this report:

The **PrecivityAD** test is a highly sensitive blood test using mass spectrometry to aid in the diagnosis of Alzheimer's Disease received European CE marking in December 2020[17]. The test does not involve any radiation and is non-invasive. The analysis process is semi-automated and allows for the test's manufacturer to process samples in a routine and repeatable manner at their lab. The UK government advice[18] on CE marking Directive 98/79/EC, which the test received, will continue to be based on the requirements derived from current EU legislation and so will be to be used in the UK following the Brexit transition. As yet NICE have not commented on the test and there will be a number of factors that they will consider before they include them in the dementia guidance. However, this is expected to be highly significant for the dementia pathway.

Aducanumab is a monoclonal antibody that has been studied for the treatment of Alzheimer's disease. It was expected that this would have a huge impact on the treatment pathway of dementia. However, Phase 3 clinical trials have not shown it to be beneficial and the trials have been stopped early[19].

NICE guidance NG97 'Dementia: assessment, management and support for people living with dementia and their carers' published in 2018 was the first update to their dementia guidance fo a decade. It is expected that the next iteration of the guidance will not take as long, with an internal pre-COVID recommendation that consultation will begin in 2021. Changes are likely to be recommended that will have an impact on the dementia pathway.

[17] https://www.businesswire.com/news/home/20201208005906/en/PrecivityAD%E2%84%A2-Blood-Test%E2%80%99s-Reach-Expands-to-Europe-and-California-Following-Initial-Launch-Test-Detects-Alzheimer%E2%80%99s-Disease-Pathology

[18] https://www.gov.uk/guidance/regulating-medical-devices-from-1-january-2021#the-role-of-the-mhra

[19] https://alz-journals.onlinelibrary.wiley.com/doi/full/10.1002/alz.12213

Appendices

CARE CITY

Appendix A: Assessment tools

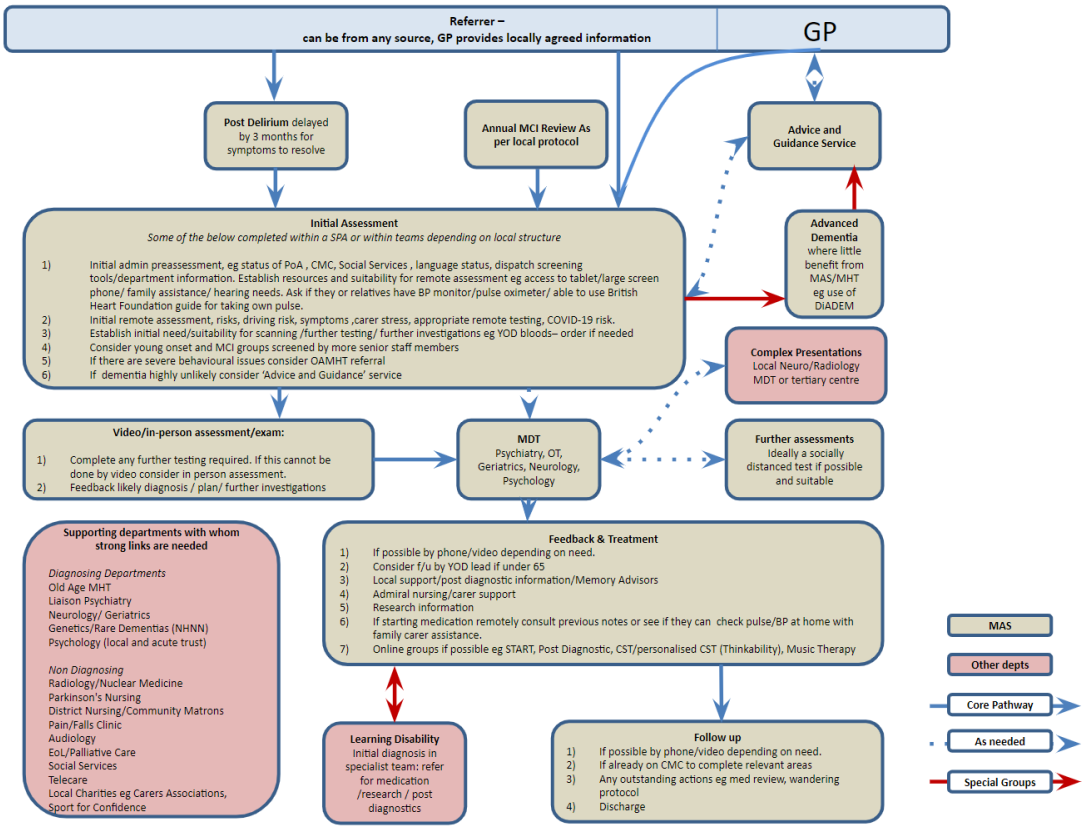
The most common tools used for assessment by clinicians were survey were (in order of popularity by respondents):

- ACE-3
- IQCODE
- Bristol Activities Daily Living Scale
- RUDAS
- MoCA/blind MoCA
- PALS (Pool Activity Level)

We looked at assessment tools that had been validated for remote use, which are of a range of types:

- Tools to assist with taking a history from someone suspected dementia,
  - Memory clinical staff interviewed stated that the commonly used IQCODE was not clinically validated for remote consultation, according to NHS dementia clinical network guidance it can be used for remote consultation.
- Cognitive testing,
  - Cognetivity is in use in some Trusts, and they did some service evaluation in NELFT. We may be able to disseminate its use further in NEL.
- Validated structured cognitive instruments for cognitive testing,
  - Free-Cog - free to use, measures both cognitive and executive functioning and is less likely to be perceived as a 'test' by patients meaning overall performance may be less impacted by patient anxiety
  - Telephone Assessed Mental State (TAMS) & Structured Telephone Interview for Dementia Assessment (STIDA) according to their authors have been validated for remote telephone use and is not included in the London Clinical networks guidance.
  - Repeatable Battery for Neuropsychological Status (RBANS) according to its author has been validated for remote video use and is not included in the London Clinical networks guidance.
  - Some memory clinical staff interviewed stated that the commonly used MoCA was not clinically validated for remote consultations, but there are remote consultations of both the 'Blind' (for telephone) and 'Video conferencing' versions which have been clinically validated. We likewise found the same was true for Addenbrooke's Cognitive Examination (ACE) 3rd edition and had been validated for both telephone and video consultation.
  - More information about Diagnosing Advanced Dementia Mandate (DiADeM) was requested by one memory service and has been included in the technology scan list.
- Tools for ESOL patients
  - Languages - tool - The RUDDAS appears to be the commonly used screening tool used when diagnosing a patient who doesn't speak English and it is delivered using an interpreter.

Appendix B: NELFT Service Map



Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
Diagnosis and evaluation of Dementia	**COGNISION**	ERP and qEEG testing	Non-invasively detect differences in the neural processing of auditory stimuli in people with neurological disorders	Part of NICE Horizon Scanning	Not able to be used remotely as it relies on hardware and wearables	https://www.cognision.com/
Dementia Screening	**Evidation**		Dementia screening tool based on wearable consumer devices	Still in research phase	N/A	https://evidation.com/research/cognitive-impairment-digital-measures-real-world-apple-devices/
	Mindset4dementia		AI dementia screening tool based on personal app information	Still in research phase	N/A	https://www.mindset4dementia.com/
	Winterlightlabs		AI Dementia screening tool based on voice analysis		Yes	https://winterlightlabs.com/clinical-research
	Astrodem		AI dementia screening tool based on GP information	Still in research phase	N/A	https://wellcomeopenresearch.org/articles/5-120/v1
	DeAR GP tool		A protocol developed for care providers to refer patients of concern	Established in some parts of NEL. The tool is used by care workers in care homes to identify residents who may be showing signs of dementia. Care workers are asked to identify signs such as confusion or memory problems which have lasted over 3 months, and if they have concerns to report these to the GP or another clinician by completing the DeAR-GP tool.	N/A	https://healthinnovationnetwork.com/resources/dear-gp-final-report/
Tools to assist with taking a history from someone suspected dementia	**Informant Questionnaire on Cognitive Decline in the Elderly (IQCODE)**		A screening tool for dementia	It has been validated for telephone consultation	Yes	https://patient.info/doctor/informant-questionnaire-on-cognitive-decline-in-the-elderly-iqcode
	Functional Activities Questionnaire (FAQ)		It measures instrumental activities of daily living	It is unclear if this has been validated for use with remote consultation	Unclear	https://www.alz.org/careplanning/downloads/functional-activities-questionnaire.pdf

Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
Cognitive testing	**CANTAB**	Paired Associates Learning (PAL) Spatial Working Memory (SWM) Match to Sample Visual Search (MTS)		Suite of tools, including their CANTAB Insight programme to do cognitive assessments, CANTAB BrainHealth for occupational assessments, CANTAB Mobile for memory assessments, CANTAB Connect eCOA system	It maybe able to be used remotely	http://researchonline.ljmu.ac.uk/id/eprint/3221/5/Does%20the%20Cambridge%20Automated%20Neuropsychological%20Test%20Battery%20CANTAB%20distinguish%20between%20cognitive%20domains%20in%20healthy%20older%20adults.docx.pdf
	Cognetivity		AI Dementia screening tool	In use in some Trusts, and did some service evaluation in NELFT	It maybe able to be used remotely	https://www.cognetivity.com/
Validated structured cognitive instruments for cognitive testing	**Neuropsychiatric Inventory (NPI-Q) for dementia**	Neuropsychiatric Inventory (NPI)	Assessment for neuropsychiatric symptoms	It is unclear if this has been validated for use with remote consultation	Unclear	https://download.lww.com/wolterskluwer_vitalstream_com/PermaLink/CONT/A/CONT_21_3_2015_02_26_KAUFER_2015-10_SDC2.pdf
	Severe Mini-Mental State Examination (SMMSE)	Mini-mental State Examination (MMSE)	Assessment for neuropsychiatric symptoms	This tool seems to be used more in clinical studies that use video conferencing.	This tool seems to be used more in clinical studies that use video conferencing. It is unclear if it validated for such use	https://eprints.qut.edu.au/49489/1/martinkhan_DIAGNOSTIC_2012_JAMDALF__mmk_12032012_complete.pdf
	Telephone Version of the Mini-Mental Status Examination (ALFI-MMSE)	Mini-mental State Examination (MMSE)	Assessment for neuropsychiatric symptoms		Yes this tool has been developed for telephone	https://www.bgs.org.uk/sites/default/files/content/attachment/2018-07-05/mini-mental_state_exam.pdf
	Telephone Assessed Mental State (TAMS)	Mini-mental State Examination (MMSE)	Assessment for neuropsychiatric symptoms	Recommended in the 'Guidance on remote working for memory services during COVID-19' report	Yes this tool has been developed for telephone	https://med.stanford.edu/content/dam/sm/svalz/documents/publications/aloth6.pdf
	Rowland Universal Dementia Assessment Scale (RUDAS)		A short cognitive screening instrument	The RUDAS has been validated for video conference use, where it was administered unchanged, and compared to face-to-face testing. Mean scores between videoconferenced and in-person administrations were very similar. Recommended in the 'Guidance on remote working for memory services during COVID-19' report	This tool can be used with VC	https://www.dementia.org.au/resources/rowland-universal-dementia-assessment-scale-rudas

Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
	Repeatable Battery for Neuropsychological Status (RBANS)		Measure cognitive decline or improvement	RBANS has been validated for telehealth use via high-definition video system with generally high correlations between videoconferencing and face-to-face scores	This tool can be used with VC	https://www.pearsonclinical.co.uk/Psychology/AdultCognitionNeuropsychologyandLanguage/AdultGeneralAbilities/rbans/RepeatableBatteryfortheAssessmentofNeuropsychologicalStatus(RBANS).aspx
	Remote Assessment of Disease And Relapse: Alzheimer's Disease (RADAR-AD)		Collaborative research that explores the potential of mobile and digital technologies to improve the assessment of Alzheimer's Disease	This still in the research phase to see if physical pieces of technology commonly (smartphones step measuring, fitbit, etc) used can help diagnosis dementia. It is unclear if they would be using an AI to alert for signs of dementia or if it is gathering data for consideration of a clinician	It would be applied remotely, to give clinicians data	https://www.radar-ad.org/
	Structured Telephone Interview for Dementia Assessment (STIDA)	Clinical Dementia Rating (CDR)	Measures cognitive and functional performance applicable to Alzheimer disease and related dementias		Yes it's designed for remote consultation	https://knightadrc.wustl.edu/cdr/cdr.htm
	Blessed Roth Dementia Scale		Measures the "degree of intellectual and personality deterioration"		It is unclear	http://www.strokecenter.org/wp-content/uploads/2011/08/blessed_dementia.pdf
	Alberta Assessment and Placement Instrument (AAPI)		Used to measure functional performance of the persons with AD	Designed for one geographical location that we don't fall into	It is unclear	https://www.cambridge.org/core/journals/canadian-journal-on-aging-la-revue-canadienne-du-vieillissement/article/validity-of-the-alberta-assessment-and-placement-instrument-aapi-for-use-in-admitting-longterm-care-clients-to-home-care/565FAF105FBB100C59076CC25C1E3F94
	Telephone Interview for Cognitive Status (TICS)		Rates global cognitive function	One clinical study found it to be as useful as MMSE. Recommended in the 'Guidance on remote working for memory services during COVID-19' report.	Yes - Telephone	https://www.annarbor.co.uk/index.php?main_page=index&cPath=416_249_478
	MoCA BLIND	Montreal Cognitive Assessment (MoCA)	Cognitive screening tool for use over the telephone	There have been 5 clinical validation studies of MOCA BLIND and MOCA Audiovisual. Recommended in the 'Guidance on remote working for memory services during COVID-19' report. Although it has been validated for mild cognitive impairment diagnosis after stroke/TIA.	Yes - Telephone	https://www.mocatest.org/

Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
	MoCa Audiovisual	Montreal Cognitive Assessment (MoCA)	Cognitive screening tool for use with virtual consultation	See above. It is less well used in services	Yes - VC	https://www.mocatest.org/
	Free Cog		A screening instrument for dementia designed to address not only cognitive but also functional abilities		This can be adapted to be used over the phone	https://pubmed.ncbi.nlm.nih.gov/31315124/
	DiADeM with GP COG	General Practitioner assessment of Cognition (GPCOG)	A screening tool for cognitive impairment	This protocol aims to support GPs to diagnose dementia for people living with advanced dementia in a care home setting. DiADeM is designed to be used only with those patients living with advanced dementia within a care home setting for whom a trip to memory services is unlikely to be feasible and/or make a difference to ongoing management.	Yes	http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/2017/DiADeM/DiADeM%20Tool%20and%20GPcog%2026062017.pdf
	Addenbrooke's Cognitive Examination (ACE) 3rd edition		A screening tool for cognitive impairment	Recommended in the 'Guidance on remote working for memory services during COVID-19' report	This can be used with telephone and video conferencing	https://www.sydney.edu.au/content/dam/corporate/documents/brain-and-mind-centre/ace-111-updates/remote-access-v2/ace-iii-remote-admin-guide-clinician-2020.pdf
	10-point cognitive screener (10-CS)		Cognitive screening	NICE Dementia guidance recommended NG97	It is unclear	https://pubmed.ncbi.nlm.nih.gov/25779210/
	DiADeM with 6CIT	6-item cognitive impairment test (6CIT)	Cognitive screening	This protocol aims to support GPs to diagnose dementia for people living with advanced dementia in a care home setting. DiADeM is designed to be used only with those patients living with advanced dementia within a care home setting for whom a trip to memory services is unlikely to be feasible and/or make a difference to ongoing management. 6CIT is NICE Dementia guidance recommended NG97	Yes	http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/2017/DiADeM/DiADeM%20Tool%20Final%2026062017.pdf
	6-item screener		Cognitive screening	NICE Dementia guidance recommended NG97	It is unclear	
	Memory Impairment Screen (MIS)		Cognitive screening	NICE Dementia guidance recommended NG97	It is unclear	https://www.alz.org/media/Documents/memory-impairment-screening-mis.pdf

Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
	DiADeM with Mini-Cog	Mini-Cog	Cognitive screening	This protocol aims to support GPs to diagnose dementia for people living with advanced dementia in a care home setting. DiADeM is designed to be used only with those patients living with advanced dementia within a care home setting for whom a trip to memory services is unlikely to be feasible and/or make a difference to ongoing management. Mini-cog is NICE Dementia guidance recommended NG97	Yes	http://www.yhscn.nhs.uk/media/PDFs/mhdn/Dementia/Dementia%20Diagnosis/2017/DiADeM/DiADeM%20Tool%20and%20Mini%20Cogv2.pdf
	Test Your Memory (TYM)		Cognitive screening	NICE Dementia guidance recommended NG97. Recommended in the 'Guidance on remote working for memory services during COVID-19' report	Can be completed via telephone	http://www.tymtest.com/
Tools to assist with distinguishing dementia from delirium or delirium with dementia	**Confusion**	Confusion Assessment Method (CAM)	Smartphone app to aid junior doctors to assess people with delirium	CAM Recommended for use in NICE Guidelines on Delirium - July 2010. NICE Dementia guidance recommended NG79	Seems to be a reference aid for clinical staff	https://bmjopenquality.bmj.com/content/4/1/u202580.w1592
	Diagnostic and Statistical Manual of Mental Disorders (DSM 5)		Mental disorders classification guide - A reference standard	The Royal Australian and New Zealand College of Psychiatrists (RANZCP) stated 'Diagnostic manuals allow clinicians, teachers and researchers to ensure consistency in diagnosis. However, the complexity of patients' presentations may not always fit neatly into diagnostic categories'	Information available remotely, but it is a guide rather than a tool	
	Short Portable Mental Status Questionnaire (SPMSQ)		Brain Impairment tool	Finish study showed it was less able to pick up delirium	No evidence of use with remote consultation	https://pubmed.ncbi.nlm.nih.gov/3571790/
	Delirium Rating Scale Revised 98 (DRS-R98)		Delirium assessment tool	Standardised tool	No evidence of use with remote consultation	
	Cognitive Test for Delirium (CTD)		Delirium assessment tool	Standardised tool	No evidence of use with remote consultation	
	Observational Scale of Level of Arousal (OSLA)		Delirium assessment tool	NICE Dementia guidance recommended	No evidence of use with remote consultation	https://researchonline.gcu.ac.uk/ws/files/40256374/Hall_R._et_al_2020_The_Observational_Scale_of_Level_of_Arousal_A_brief_tool_for_assessing_and_monitoring_level_of_arousal_in_patients_with_delirium_outside_the_ICU.pdf
Digital replacement for paper tools	**Clockreader**	clock drawing test (CDT)		Digital replacement for clock drawing test.	No evidence of use with remote consultation	https://www.todaysgeriatricmedicine.com/archive/050712p8.shtml

Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
Post diagnosis Remote patient monitoring	**Technology Integrated Health Management (TIHM) Monitoring Service for dementia**		Uses smart sensors in home to alert monitoring team	TIHM (Technology Integrated Health Management) for dementia was part of the Test Bed Programme. remote monitoring service that is increasing support for older people across Surrey during the Coronavirus outbreak. It is available to people of any age who have been diagnosed with dementia or mild cognitive impairment and people aged 65 and over who have a diagnosis of depression and/or anxiety.	Yes	https://www.sabp.nhs.uk/TIHM/about
	Smartmeters		Analysis of smart meters to detect changes in behaviour	Still in research phase	N/A	https://2020health.org/publication/smart-future-of-healthcare/
Support for carers	**DEM-DISC**	Camberwell Assessment of Needs for the Elderly (CANE)	A customized e-advice on health and social support services for informal carers and case managers of people with dementia.	A study in 2015 of 41 carers and managers showed that using DEM-DISC had a positive effect on the sense of competence and experienced (met) needs of informal carers	No evidence of use with remote consultation	https://pubmed.ncbi.nlm.nih.gov/25872457/
	Neuropsychiatric Inventory Questionnaire (NPI)	NPI consultation questionnaire	Stress assessment tool for carers of people living with dementia	Assessment for neuropsychiatric symptoms using a screening strategy. Examining and scoring only those behavioral domains with positive responses to screening questions. The similar pattern of results across two cohorts of patients support the validity of these constructs.		https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3913908/
	Telephone Tracking-Nursing Home (FITTNH)		Supporting dementia caregivers' adjustment following nursing home placement	One clinical evaluation from 2010 showed it had positive support	Yes - for Telephone	https://pubmed.ncbi.nlm.nih.gov/20842759/
	Residential Care Transition Module (RCTM)		Supporting dementia caregivers' adjustment following nursing home placement	Assess whether the RCTM yields statistically significant reductions in caregivers' primary subjective stress (e.g., burden) and negative mental health outcomes (depressive symptoms) in the 12 months following enrollment when compared to controls; trial due May 2021	No evidence	https://reporter.nih.gov/project-details/10168229
	Rally Round	N/A	Emails/texts support tasks to a group of family or friends	Online communication tool with text and email notifications	Yes	https://rallyroundme.com/
	Jointly	N/A	Emails/texts support tasks to a group of family or friends	Online communication tool with text and email notifications	Yes	https://jointlyapp.com/#about-section
Assessing and managing comorbidities	**Pain Assessment in Advanced Dementia (PAINAD)**	Observation tool	observational pain assessment tool	Pain assessment on evaluation to score patient pain level - reviewing cognitive behaviour	Yes	httppubmeds://.ncbi.nlm.nih.gov/30371557/

Area of interest	Tech Name	Based on tool	Tool Description	Comments	Remote Consultation	Link
	Non Communicative Patients Pain Instrument (NOPPAIN)	Observation tool	observational pain assessment tool	Several observational tools have been developed in order to assess pain behaviors in non-communicative patients. The aim of the present study was to verify if the Italian version of the Non- Communicative Patients Pain Assessment Instrument (NOPPAIN) could be used in a hospital setting.	Yes	https://www.ncbi.nlm.nih.gov/pmc/articles/PMC4978178/
	Painchek	Unclear	AI pain assessment tool	Unable to get clear response from developers about how it works	Unclear	https://painchek.com/uk/
Case management systems	**Collaborative cARE for people with DEMentia (CAREDEM)**		Case management tool	This Care management system was not validated in the report, and there were issues connecting the US model to UK practice, as well as connecting everyone in practice. It was recommended in the NICE guidance on dementia not to use case management systems for people living with dementia, in part becuase this models outcome is focused on the mental health definitition of recovery.	Unclear	https://pubmed.ncbi.nlm.nih.gov/25138151/

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