Living well with Dementia: Implementation case studies

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Why applied research and implementation?

NIHR Applied Research Collaborations (ARCs) support applied health and care research that responds to, and meets, the needs of local populations and local health and care systems

Adoption of findings that:
- are recognised by end users
- Improve quality and safety
- Reduce unwarranted variation
- Cost effective and sustainable

Challenges- more than effectiveness and dissemination

One of the most consistent findings from clinical and health services research is the failure to translate research into practice and policy
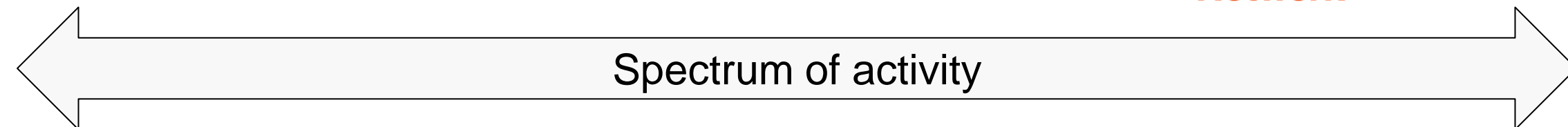
Grimshaw et al (2012)

Health systems fail to optimally use evidence with resulting inefficiencies and reduced quality and quantity of life.

Strauss et al (2011)

Implementation success is a function of the effectiveness of the intervention being implemented AND a range of implementation factors

Proctor et al, 2016
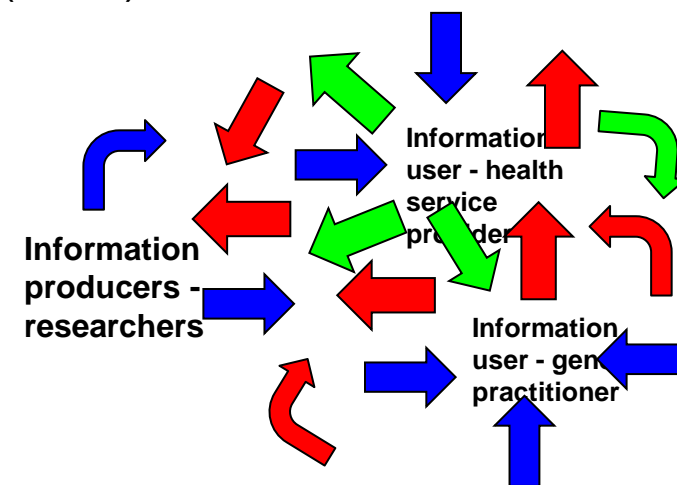
Spectrum of activity

Release of findings

Diffusion, **passive** activities and supportive policies to **make research findings available and accessible** to the general public and other audiences (EViR 2020)

Dissemination

An **active** approach to spreading of research findings to the **target audience** via determined channels using **planned strategies** (EViR 2020)

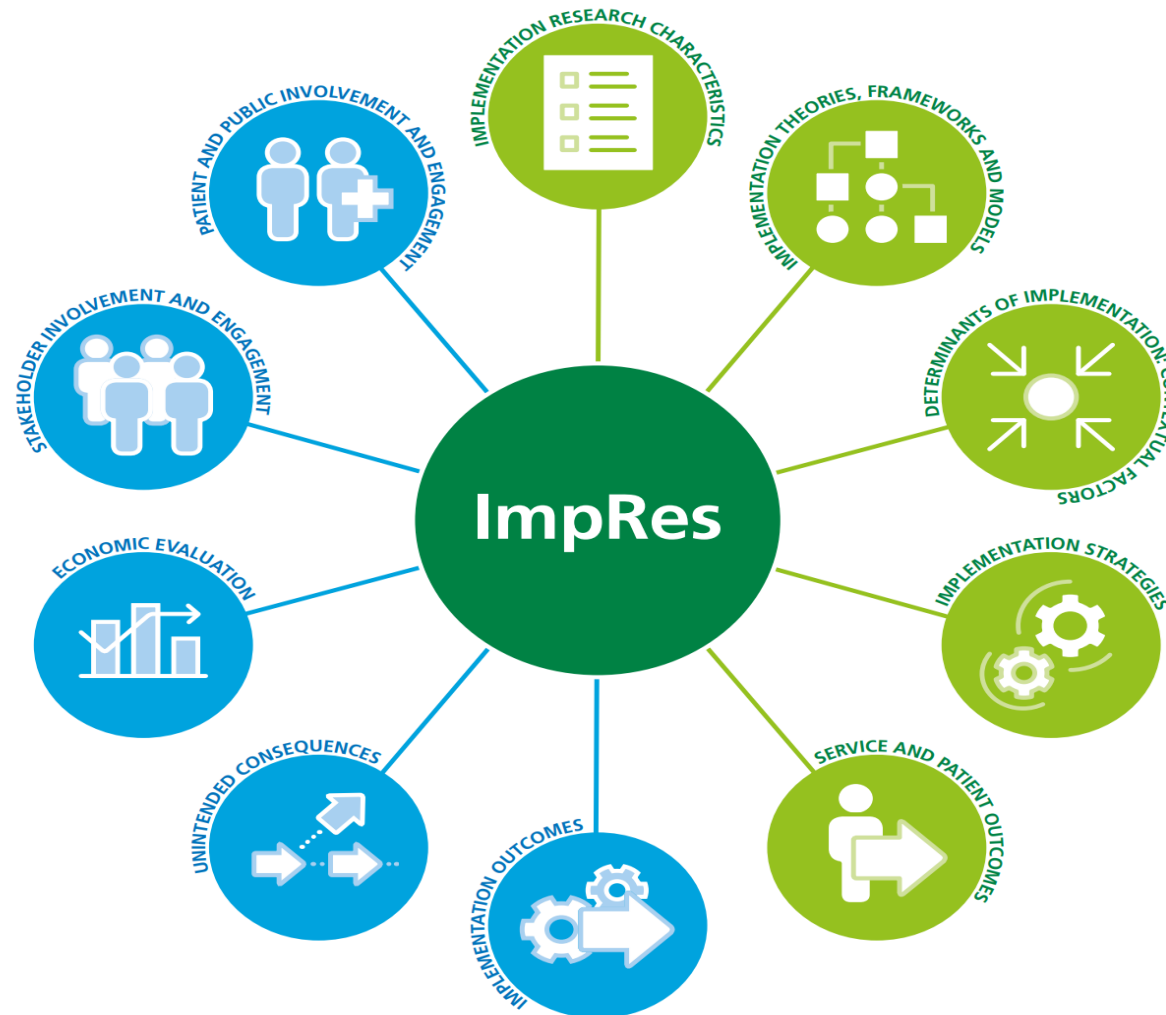## Knowledge Mobilisation

Actively **bringing stakeholders together** to **share, respond to, and act** upon research findings. (EViR)

Information user - health service provider

Information producers - researchers

Information user - general practitioner

Various implementation methodologies, tools, frameworks often focused at implementation once the research is completed.

Start early

ImpRes

- IMPLEMENTATION RESEARCH CHARACTERISTICS
- IMPLEMENTATION THEORIES, FRAMEWORKS AND MODELS
- DETERMINANTS OF IMPLEMENTATION: CONTEXTUAL FACTORS
- IMPLEMENTATION STRATEGIES
- SERVICE AND PATIENT OUTCOMES
- IMPLEMENTATION OUTCOMES
- UNINTENDED CONSEQUENCES
- ECONOMIC EVALUATION
- STAKEHOLDER INVOLVEMENT AND ENGAGEMENT
- PATIENT AND PUBLIC INVOLVEMENT AND ENGAGEMENT

Source: http://www.kingsimprovementscience.org

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Applied research and Implementation additional considerations

| Relevance | Meaningfulness | Alignment | Priority | Cost |
| Timing | Impact | Complexity | Accessibility | Capacity |

NIHR | Applied Research Collaboration Kent, Surrey and Sussex

Kent Surrey Sussex Academic Health Science Network

ARC KSS Implementation strategy

Use people's (users of services and front line staff) stories to develop research questions that address locally recognised needs and will improve implementation of our research findings because they are meaningful to, and embedded in the needs of our population

Actively engage with system leaders and budget holders early to align priorities and need, engaging leaders in the work we produce

Understand relevant research, studies, projects, innovative practice, existing models of care and their evidence base - what works, and what good looks like locally, nationally, and internationally
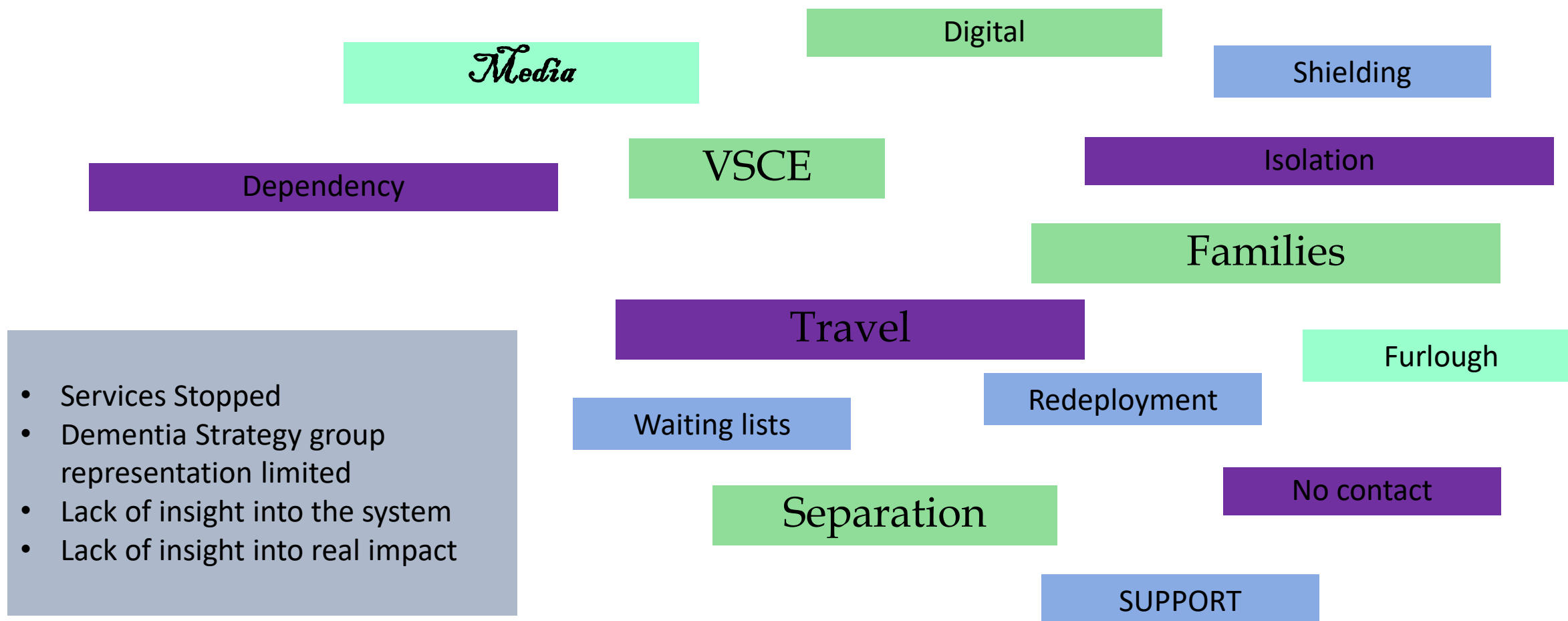
Feedback and disseminate our findings to provide challenge and inform ARC research activities locally and nationally

Ensure research themes consider needs, opportunities, barriers and enablers, at the earliest stages of research design

Improve health and social care outcomes to the public through implementing and integrating research activity, outcomes, and new models of care that:

• are recognised by end users as needs and priorities and co-produced with them

• improve quality and safety

• are evidence based

• reduce unwarranted variation

• are cost effective and sustainable

Immediate impact of COVID 19 on people living with Dementia and services

Digital

Media

Shielding

VSCE

Isolation

Dependency

Families

Travel

Furlough

- Services Stopped
- Dementia Strategy group representation limited
- Lack of insight into the system
- Lack of insight into real impact

Redeployment

Waiting lists

No contact

Separation

SUPPORT

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ARC KSS COVID funding

ARC KSS Funding available for COVID 19 related studies- impact within 6 months

Agile system response to research governance

2 dementia studies awarded funding:

- QOL in PLWD and their carers

- Remote memory assessment

Quality of life during COVID-19 for people with dementia and carers

Dr Stephanie Daley and Dr Ben Hicks

Time for Dementia and DETERMIND studies

Importance of QoL during COVID-19

- The abrupt closure and reduction of many health and community support services is of concern for people with dementia and their family carers.
- Shielding, self-isolation, and social distancing regulations has led to further loss of support from family and friends for people with dementia and their carers (Alzheimer's Society, 2020a)
- Significant concern about the abrupt cessation of services, and worry about future provision (Giebel et al, 2020, 3 Nations Dementia Working Group, 2020)
- Concern about increasing caring tasks (Tide and Law 4 Dementia Carers) and decreasing cognition in the person with dementia (Alzheimer's Society, 2020b)
- Living with a diagnosis of dementia, or caring for somebody with dementia is impactful upon all of the factors known to affect QoL
- Lack of evidence about the impact of COVID-19 on QOL

Overall aim

TIME FOR DEMENTIA

To understand the quality of life and care implications of the COVID-19 pandemic on people living with dementia and their family carers

- Nested in the Time for Dementia (TFD) study
- Longitudinal mixed-methods
- Lived Experience Advisory Group LEAP- set up as an integral component of the study: involved in study design & family carer facing documentation, topic guide/s, interim and final findings and dissemination activities
- Carried out remotely by telephone
- Family carers provide self and proxy reports
- Family carers encompass all informal carers (e.g. family and friends) of a person with dementia.

Overall aim

DETERMIND
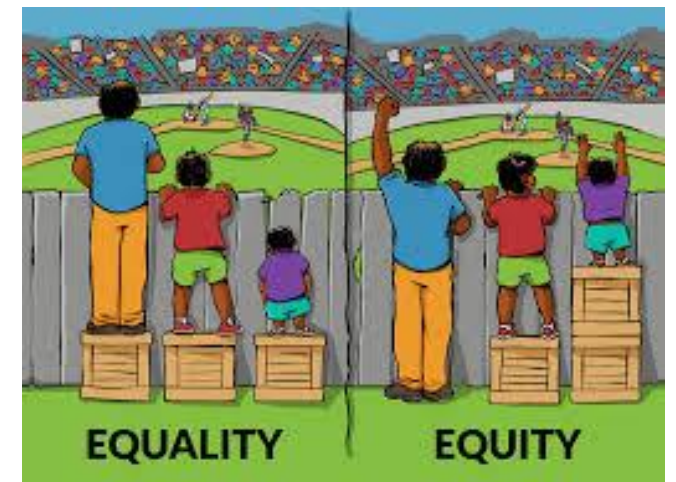**To investigate inequalities and inequities in care and outcomes for people with dementia and their carers**

Threats to QoL through a shrinking world

Reduction in use of services:
- Closure of dementia services and community groups or unwillingness to attend them
- Lack of face-to-face health visits- difficulties in sustaining well-being

Reduced social interaction and meaningful activities:
- Cut-off from family/friends and work/volunteering opportunities
- Shielding and fear of contracting virus or family passing it on
- Limited access to cars and fear around public transport
- Pertinent for people in care homes

Reduced access to community:
Feelings of confinement particularly in smaller houses
- Unwillingness to engage with community for fear of virus
- Dementia unfriendly practices
- Exacerbate health problems- self-fulfilling cycle

'Active social agents'- actions to mitigate threats

Embraced new mechanisms for social interaction and engagement with services:
- Learned to use social networking platforms to engage with family and groups
- Accessed healthcare services online/phone calls
- Got to know neighbors better through garden chats

Employ multiple emotional coping strategies:
- Stoic acceptance of situation
- Positive re-framing of situation
- Keeping a busy routine and "escaping" through activities
- Carry on regardless and ignore rules/restrictions!

KEEP CALM AND FIGHT BACK

Renegotiate access to the community:
- For some not an issue as rarely engaged with community
- Chose times and days when they would engage so as to avoid people
- Made use of local community volunteer groups
- Easier in rural areas

Engaged in new meaningful activities:
- Learned new hobbies and activities
- Helped and supported family
- Helped others living with dementia

7 Main Themes

1 Decreased Social Interaction

2 Variable Support

3 Deteriorating cognitive and physical health

4 Decreased carer wellbeing

5 Difficulties understanding COVID 19

6 Limited impact for some

7 Trust and relationship with care homes

'*very very isolating really, both for me and mum really erm, coz she misses, she obviously misses seeing everyone*' **c12**

'(peer support group) *have never reopened. It was on Zoom but X (person with dementia) couldn't partake in Zoom, he found that really difficult….* c10

she's sitting down a lot more, not getting out and about and moving so, so she's got more aches and pains' **c7**

I've been very weepy when we were in lockdown, I've not been coping nearly as well as normal because it's been so hard because of having no time for me, and no break. I think I'm just exhausted, exhausted and no time to myself' **c10**

He doesn't, he doesn't, he's got no anxiety so he doesn't worry about people not being around the house coz he doesn't remember' **C11**

'*because I trusted them with my husband, I trusted that they told us they were dementia friendly and they weren't, they lied and trusted them to look after my husband and I'm really angry*' **c15**

and therefore she doesn't quite understand all of it. And uh just keeps repeating and repeating that you know 'Why can't we?" **c 4**

Key themes- guidance for practitioners
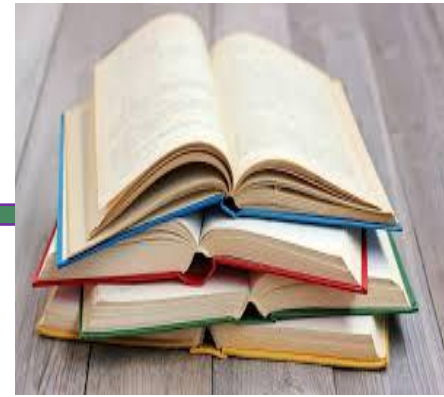
1. **Impact on quality of life:**
   - **Varied**
   - **Dependent on social location of participants**
   - **Not a one size fits all approach- identify those most at risk and work with them to develop strategies**
2. **Support and connection with others:**
   - **Felt by all people but particularly co-resident carers**
   - **Recognise the importance of community and family networks and support them to provide connection**
   - **Provide support for people with dementia and carers to engage with social networking platforms if desired**
3. **Hospitals and care homes:**
   - **Difficulties with communications in formal health and care services**
   - **Support communication and the development of trust between carers and formal services**
4. **Understanding restrictions:**
   - **Difficulties for people with dementia to follow guidance. Pressure on carers to support**
   - **Accessible dementia-friendly guidelines and practices within communities**
5. **Keeping active and engaged in environment:**
   - **Positive coping technique for both people with dementia and carers**
   - **Support people to identify activities that can adjust during the pandemic**
   - **Support people to engage with new hobbies that can provide a sense of meaning**

Opportunity

- Combined findings
- Co designed
- Key findings and messages feed into:
- Dementia Strategies
- Carers Strategies
- Care home insights
- VSCE
- Social prescribing

Challenge

- Delays
- Implementation work not included in proposal
- C19 has continued, ? impact changed
- Making findings accessible

Outcome

- Implementation funding sourced from DETERMIND
- Co produced key messages
- Currently being finalised
- User friendly

Remote Memory Assessment Services (R-MAS) Research

Dr Gosia Racek

R-MAS

Patient experience of remote MAS

- Patients who had remote assessment, any diagnosis
- Telephone/video satisfaction questionnaire
- Invite at diagnostic consultation (remote)

Why Remote Memory Assessment?

- National concern about PLWD- and those awaiting diagnosis

- Dementia Diagnosis rates dropped/stopped

- Consequences for people with undiagnosed dementia, access to treatment, carer and system impact

- Staff wanted to deliver service

- Only way to provide service during first lock down

- Pragmatic system response to COVID- no evidence

What is the RMAS study ?

Aims:

- To explore patient satisfaction with the use of remote MAS, and factors associated with satisfaction and dissatisfaction with the service.

- To understand how remote MAS impact clinical outcomes related to a dementia diagnosis

- To explore clinician experience and satisfaction with delivering remote assessment in memory clinic

The study design and reviews have been supported by the LEAF group

RMAS Findings:

Patient/Carer	Clinician
Satisfied with remote MAS	Advantages incl. safety, flexibility, patient satisfaction, time
Familiarity with tech	Disadvantages incl. connection (emotional and digital), less holistic, more 'steps'
Swifter assessment	Telephone not liked
Preference and convenience- no travel	Video preferred
Clinician communication important	Limited post diagnosis support*

The findings indicate that remote assessments should not be seen as an inferior system but rather as an acceptable alternative to face to face

Implementing Remote MAS

▶ Some teams developed remote MAS and piloted locally – whereas other implemented this model across all teams/led by service managers

▶ Clinicians who had piloted remote MAS reported higher satisfaction than those without

▶ Delays to setting up a remote pathway were due to; equipment

access, software access, experience using the video platform

▶ None of those interviewed had undertaken a remote MAS prior to C19

"So, whilst it was maybe perceived as not at all possible, a few years ago, within a very short space of time, the team collectively have come together and been able to kind of devise and then roll out, you know, a remote pathway which is exceptional really." (Male, Dementia Team Lead at pilot site)

Good Practice Recommendations

- **Risk assessment**
  - Evaluating the safety of having a remote appointment and weighing up the risks of face to face contact and if it is more appropriate to see a patient face to face

- **Communication Technology Guidance**
  - Provide clear instructions and guide the patient with the camera angles or volume controls if needed, use headphones

- **Building Rapport**
  - Take steps to put the patient at ease and build report over video or phone call as you might in person through small talk at the start of calls. For example you might speak with a smile over the telephone

- **Enhance Cognitive assessment**
  - Cognitive assessment images can be shared on the screen which makes the quality clearer and images larger for patients to see on their side

- **Privacy of appointments**
  - Consider that the carer might be there for technology support and might

  not be there if the appointment was face to face

- **Choice**
  - Remote can be used at different stages

"But now we are out of it [lockdown], almost out of it, so we can offer more choices, you know, more choices that we can still do in video, video assessment if they choose to, it's still equally effective, you know." (Female, Team Leader)

Opportunity	Challenge	Outcome
• Ahead of the curve • HEIF funding • Co designed • Aligns to: • Service needs • NHS LTP • Supports DDR • Builds confidence • National/international	• Delays • Capacity • Services making decisions about models now- ? time limited opportunity	• Funding from HEIF • Coproducing toolkit • Video for patients • Tool kit currently being developed

Living well with Dementia: COVID studies

Relevant | Meaningful | Aligned | Priority | Cost

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Thank you, any questions?