Taking an outcomes focussed approach to improving care for older people with dementia and other needs

socialfinance.org.uk

Contents

Cover photo: Gareth Iwan Jones

Glossary of terms

The glossary below references some of the terms and language used throughout this Learning Report. Some of these terms are not standardised or uniform – they are still being redefined and iterated based on ongoing sector dialogue between academics, experts by experience, service providers, funders and commissioners. We have rationalised our definitions where possible, informed by key stakeholders from this programme, to provide context for the report.

Cultural competence	A set of aligned and transparent skills, attitudes and principles that acknowledge, respect and work together as a system towards optimal interactions between individuals and the various cultural and ethnic groups within a community.[1]
Dementia plus	Social Finance defines this as an approach which includes people living with dementia (diagnosed or undiagnosed) but does not solely focus on the clinical diagnosis and impact. A multi-morbidity approach is needed to include other similar long term conditions which can affect a person in comparable ways to someone living with dementia.
Integrated Care Board (ICB)	A statutory body that is responsible for planning and funding most NHS services in an area in England. ICBs replaced clinical commissioning groups (CCGs) in the NHS in England from 1 July 2022. We mostly refer to ICBs in this paper, however, health trusts (which typically run hospitals) also play a significant role in running health systems across an integrated care system.
Multi-morbidities	Refers to two or more long-term health conditions.

Older people with other needs	This is the term we have agreed upon to describe someone aged 65 or older who has more than one “need”. In this context, we define “needs” as including, but not limited to, medication support; financial support; assistance to access traditional services (due to mobility, language, or hearing issues); and health conditions. Please note, Social Finance often uses the term “other” needs having moved away from the term “complex” needs. This followed valuable input from our Expert Reference Group, which highlighted that: • Often it is the multiplicity of a person’s needs, rather than their complexity, that requires more holistic and personalized support. For example, an individual with dementia and a physical disability that restricts access to traditional services would fall into this category • Defining a “complex” need is challenging and has a broad range of definitions across different academics, funders and service partners. • From a person perspective, most people would not see their needs as “complex”. Describing them as “complex” may add additional barriers for people accessing services as they would not want to be labelled as “complex”.
People living with dementia	Social Finance defines this as a person living with dementia symptoms and can include those pre-diagnosis.
PCOMs (person-centered outcome measures)	PCOMs integrate objective outcome collection as part of business as usual. They have academic accreditation, typically come in a variety of forms / lengths so that there is choice for what is most suitable for different frontline services and also bridge the link between quantitative and qualitative data for outcome measurement.

Social investment	In this context, social investment is an umbrella term for funding mechanisms that seek to balance risk, financial return and social impact, based on the appetites of the partners involved. It can include capital, equity or blended investment and focuses on balancing social impact and financial return.
Transition moments	Transition moments are key points in a health journey where circumstances and current needs can change. This includes but is not limited to diagnosis, hospitalisation, move to care home and end of life.
Underserved groups	Social Finance understands underserved groups as a collective of people who have not historically received the care they require to maintain their health and wellbeing
Unpaid carer	Often a friend, family member or neighbour that provides support to a person living with dementia. This includes a broad spectrum of those who live with, nearby or far away from the person living with dementia and often have overlapping or contrasting needs to the person living with dementia
VCFSE	Abbreviation for 'Voluntary, Community, Faith, and Social Enterprise' sector, which encompasses organisations that are non-governmental, non-profit, and focused on addressing social, environmental, health and/or community needs.

Executive summary

The UK has an ageing population and with that, a growing set of challenges for the health and social care system. One in three people will develop dementia in their lifetime[2] and nearly 68% of people over 65 will have two or more long-term conditions by 2035.[3]

Older people with dementia and other needs deserve to live well. Unpaid carers bolster adult social care to the value of £162 billion per year across England and Wales,[4] and themselves, experience disproportionately poor health outcomes and deserve to live well. And yet the health and social care system is bound by funding models that do not prioritise sustained investment in preventative, community-based care that will help people to live and age well. It is critical that we work and think differently.

This report calls for systemic financial change to improve outcomes for older people with dementia and other needs, unpaid carers and the system that exists to support them. It was produced through extensive engagement with service providers across England and Wales, commissioners, funders, a Learning Community of over 50 organisations and an Expert Reference Group with clinical, commissioner and funder representation.

Key findings

- There is an urgent need to explore alternative funding mechanisms, working with statutory partners to reallocate the funds that are already available within the system and invest in community-based services that understand local need, prioritise integrated approaches to care and have deep levels of trust with their communities.
- There are significant service and system level barriers to adoption. To facilitate systemic financial change, the statutory system needs to recognise how community-based interventions alleviate system pressures. Community-based service providers need support to build a robust evidence base which is acceptable and understood by statutory providers, with the ability to access and share person-centered data that will show impact and articulate service value. Investment in that capacity and capability is key to this. Funding back-office infrastructure to improve operational efficiency, engagement efforts and data analytics capability is needed.
- A set of five 'preconditions' for investment need to exist to facilitate systemic, behavioural and structural change to improve outcomes for older people living with dementia and other needs**. Genuine partnership working with the voluntary community sector, a social determinants approach to programme design, robust data infrastructure, a clear communications strategy and commitment from commissioners to adopt sustainable funding mechanisms,** are prerequisites for a sustainable, system-wide approach to successful funding and investment.

Key insights and calls to action are summarised below, with the full report providing an opportunity for readers to dive into our programme approach, the service partners we worked with and their respective case studies, funding mechanisms and a set of short, medium and long-term recommendations.

Key recommendations

1. **Enhance funding knowledge across the commissioning community:** Sharing resources on – and examples of experiences with – different funding mechanisms and how they can be used, will ensure system stakeholders are aware of funding options available to them. This will support the wider principles of sustainability and efficiency.
2. **Improve capacity and capabilities in commissioning beyond immediate care delivery:** Operational functions are critical to strengthening service delivery, user engagement and data sharing and collection. This includes awareness- raising and service promotion to diversify referral routes; to reach and support underserved

communities; and to recruit and retain staff and volunteers. Data functions, including collection and analysis, also need to be bolstered. If the right data is captured and used effectively it can be a valuable asset; however, training and the agreement of data sharing protocols is needed to ensure this happens.

3. **Integrate unpaid carer needs into service design and delivery:** Our findings demonstrate how vital unpaid carers are to the ecosystem that supports older people living with dementia and other needs. They provide essential care which bolsters adult social care provision, often at the expense of their own financial, emotional and physical health. It is vital that the support infrastructure for unpaid carers is recognised and invested in throughout the system. This is an area which needs further testing and funding.
4. **Collaborate with the community and test within it: The programme has seeded an energetic and knowledgeable Learning Community**, the power of which can be harnessed to generate widespread and sustainable change in the funding and delivery of person-centred care. This is an opportunity to reduce duplication, consider scalability of interventions, and to test thinking on service development, its funding and evolution.
5. **A holistic approach allows for more personalised care:** Evidence shows that considering the social determinants of health and taking a person-centred approach when planning the delivery of services is essential. This encourages care providers to coordinate their approach and to deliver better health outcomes.

Calls to action

The findings underscore an urgent need for coordinated action across the health and social care sectors. We call on funders, commissioners, and service providers to:

- **Invest in flexible and personalised care models**: Prioritise funding mechanisms that support longer term investment in adaptable care solutions.
- **Promote equity in care**: Ensure that underserved populations receive the care they need by supporting culturally adaptable care initiatives.
- **Leverage existing resources**: Enhance and scale current services through strategic partnerships and integration of new technologies.
- **Support carers**: Recognise the critical role of unpaid carers and allocate resources to sustain and expand respite services.

Foreword

It's difficult for most people to understand what it means to care for a person with dementia 24 hours a day seven days a week for nearly ten years. It came as a tremendous shock to me when I realised that I was expected to care for my wife, who had Mixed Dementia, without any support other than a half hour visit with a memory nurse every three months, no training, no warning of what to expect, nothing, just get on with it.

Through our 60 years of marriage we had coped with most illnesses but this was something different and I was totally lost. I realised I had to change my way of life. I worried about doing the wrong thing, making sure that she was safe in her own home and that she maintained her normal health. All the activities that a couple shared were now my responsibility. As her dementia deteriorated through the years so did my health, I developed carer fatigue, I lost three stone in weight in 12 months, my upper body came out in a rash that took over 12 months to cure. I could no longer cope and my wife went into a care home for the last six months of her life. All of this came at a price – all support, including the care home, was self-funded.

So what now? Prevention and cure is in the distant future. What is needed now is an effective carer plan to support unpaid carers and people living with dementia from the onset. I was asking for help in explaining to me what I had to do for my wife. I want unpaid carers to be embedded in future provision of services.

Bill Cavendar
Carer for his wife, who lived with dementia for ten years

1. Context, ambition and approach

Introduction

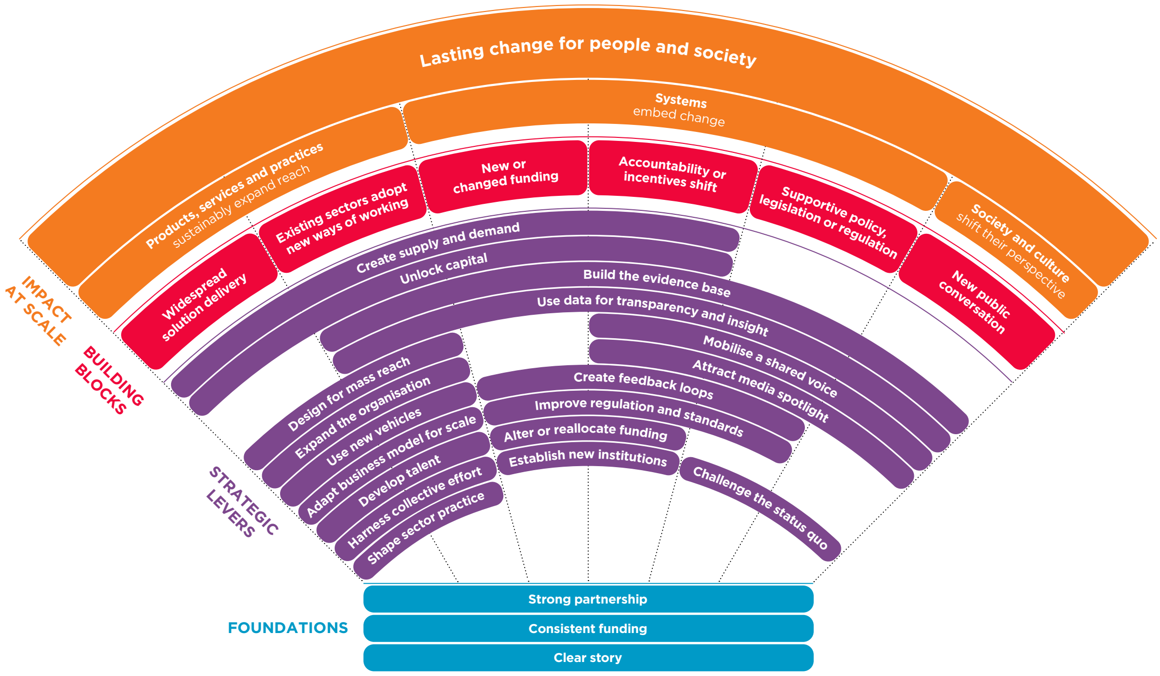
People at the front line of care know how to improve things, but don't always have the time, money and support to test their ideas robustly. Statutory bodies which pay for health and social care are often unable to commit upfront to different interventions without evidence that they will achieve certain outcomes, nor do they always have the budget available to fund the transition from the old to new ways of doing things. This 15-month 'test and learn' programme aimed to fill this gap by providing initial funding and support to test innovative services *in situ and* provide the evidence for commissioners and funders to change the way support is funded and delivered.

We partnered with teams delivering services in the community who have identified innovative delivery options and are committed to working in an outcomes-based way. This learning report shares insights and findings from the programme which was funded by The Dunhill Medical Trust and Alzheimer's Society with supplementary funding from Ellerman Foundation, Rayne Foundation and the Tudor Trust.

This report is guided by the 'Routes to Scale' framework – a tool developed by Social Finance, in partnership with national social change makers, and shaped by over 10 years' experience of driving systems change at scale. The framework maps different routes to scale and impact by exploring the foundations, building blocks, and strategic levers needed for sustained transformation and widespread systems change. The Routes to Scale framework has shaped the older people with dementia and other needs programme, keeping the team focused on what we are trying to change, what that will look like at a systems level, and what we need to do to get there.

This report will outline the programme's ambitions and present thematic learnings and insights from our extensive stakeholder network. These learnings have shaped a set of recommended 'pre-conditions' for investment designed to support funder, commissioner and social investor decision-making and guide community organisations and service providers on the infrastructure they need in place to demonstrate person-centred and system wide impact. A set of short, medium, and long-term recommendations conclude the report.

The Routes to Scale framework



A clear story – why are we doing this?

Social Finance, The Dunhill Medical Trust and Alzheimer's Society's partnership is rooted in a shared vision and commitment to understand how change can be enacted for older people with dementia and other needs; building on what works and finding solutions to what doesn't. Given the prevalence of dementia, an ageing population and the disbanding of a strategy for adult social care reform, this programme and its exploration of alternative forms of investment and funding, comes at a critical time for the sector.

Over 11 million people in England and Wales (18.6% of the total population) were aged 65 years and older at the time of the 2022 census.[5] It is expected that in 2043, the proportion of people aged 65 and over will rise to 24%.[6] Age is frequently associated with the development of multiple health conditions. In 2015, 54.0% of people aged over 65 had two or more conditions (multi-morbidity). By 2035 this is predicted to have risen to 67.8%. This is particularly acute for those in later age groups, rising to 75.9% for those aged 75–84, and 90.5% for those above the age of 85.[7]

> "Multimorbidity has emerged as one of the greatest challenges facing health services, both presently and in the coming decades".[8]
>
> **Multimorbidity – a defining challenge for health systems.**
> ***The Lancet, Public Health,* 2019**

Understanding and addressing the impact of multi-morbidities continues to be a local and national priority. People with multi-morbidities are more likely to have poorer quality of life than those in the general population.[9] The Chief Medical Officer's annual report in 2023 called on the medical profession to respond to the wave of multi-morbidity to support those affected to maintain independence and quality of life.[10]

The new 2024 Labour government has committed to a preventative approach to health care, to address and prioritise long-term health conditions and there is a robust evidence base that describes how new and revamped models of NHS care can be developed for those with multiple needs.[11]

Within this context, the partnership coalition felt that a broader focus on older people living with dementia and other needs was essential given the overlap and intersection between age and multi-morbidities, and the multiple care pathways this can generate across the system. It has been estimated there are currently more than 900,000 people living with dementia in the UK, a figure expected to rise to almost 1.4 million by 2040.[12] The condition causes non-linear deterioration in cognitive and physical health over an extended period, and people with dementia often have several additional long-term conditions. A UK based study found that, on average, people with dementia had 4.6 chronic illnesses in addition to their dementia.[13]

Providing care which addresses the full range of needs for older people living with dementia and other needs is a pressing health and social care challenge. The impact of a dementia diagnosis is not just emotional and social; it is also financial with economic implications to the health and social care system. It is estimated that the cost of dementia in the UK is expected to rise from £34.7 billion in 2019, to £94.1 billion in 2040.[14] The annual, per person cost for mild dementia is £28,700, compared to £80,500 for severe dementia and 63% of this cost is borne by people living with dementia and their families.[15]

Proposed Adult Social Care reform for 2025 planned for a cap on the amount of people expected to pay for their personal care, a more generous means-test for local authority support and an increase in the upper capital limit to £100,000, in an attempt to reduce the financial challenges of unlimited and unpredictable care costs and make access to financial support more equitable.[16,4] However, an announcement made by the new Labour government in July 2024 confirmed that reform plans will not be taken forward.

With no system or funding reform in sight, the only way to drive change is to think and fund differently – the statutory system needs to reallocate funding and work creatively and collaboratively to move money in a way that prioritises proactive, preventative care and support for people living with dementia, older people with other needs and their unpaid carers. As one ICB partner told us;

"We get money in according to assessed need and then spend based on historic allocations - we need to be able to demonstrate we can align spend to outcomes and safely move money around the system..."

Warren Heppolette, Chief Officer for Strategy & Innovation, NHS Greater Manchester Integrated Care

Broadening commissioning and funding priorities is also essential. It is sometimes easier to focus funding on front line services alone without wider consideration for the support and infrastructure required to enable these front-line services to operate effectively. An example of this is unpaid care. Across England and Wales, unpaid care is valued at £162 billion per year bolstering adult social care services and plugging underinvestment in the sector but this is not a sustainable way forward.

The financial effects of being an unpaid carer are, for many, catastrophic. A recent report conducted by The Carer's Trust found that 25% of carers are not in paid employment, forcing many in to, at best a financially precarious position and at worst, poverty. The emotional, social and health toll of being an unpaid carer is deeply concerning, with almost half reporting at least one adverse health effect because of their caring role.[17]

"I deserve a break. I've not had a night's sleep in as long as I can remember."

"Everything is so expensive. It's not fair. He paid in all his working life and now we can't get any financial help. Everything is means tested"

"I can't take a break. He is looking for me and he will forget. Even for injections, he has to come with me. Everything we do, we do together. I can't see the wood for the trees".

Unpaid carers, Live Well Dementia Hub, Stockton

Community partnerships – taking a wider determinants approach

Whilst improving quality of care for people with dementia remains a government priority, there is growing concern that existing health care infrastructure and funding is not meeting the needs of an ageing population. 50% of costs related to dementia fall under social care, despite the impact of the condition being felt across the health system more broadly (primary, secondary and community care). The system wide impact of dementia and other needs calls for a coordinated response across the health, social care and VCFSE system, not only in relation to the provision of consistent care but also the statutory actors responsible for investment, funding and commissioning services.[18]

In addition, there is an urgent need to look to the expertise of the Voluntary Community Sector (VCS) and explore what investment in high quality joined up, coordinated care can look like. Working holistically with an individual, their support network, health and VCS organisations can enable a focus on the social determinants of health, and other non-medical factors that influence health outcomes, to better support and promote independent living and the wider dimensions that affect someone's life and experience.

A key example of wider health determinants and their impact is housing.

Research confirms that 85% of people in the UK would prefer to remain in their own homes if they received a dementia diagnosis.[19] Minor adaptations can help older people remain at home and stay independent for longer.

In addition to increased autonomy, a growing body of evidence indicates that care technology aids and home adaptations can contribute to reduced hospital admissions for falls and urinary tract infections (UTIs). At the time of writing, UTIs are responsible for approximately 25% of hospitalisations in older adults, with the risk increasing for older adults with dementia, especially Alzheimer's disease, and falls are a leading cause of emergency hospital admissions.

Our partners told us that early intervention is critical if physical adaptations and aids are going to be useful.

> "It's about using technology that is already there. So, it's not the tech that's innovative. What's innovative and bold is us putting it in early rather than it going in too late. We've had examples where people have turned around to us and said, 'If only we'd had that earlier, it would have made a vast difference'. So it's not the care technology that's the issue it's the timeliness of when we can put that in and the support needed to use it."
>
> **Steve Pugh Head of Service, Access and Digital, Leicestershire County Council**

The size of the issue is significant. An ageing population, increasing dementia prevalence, the impact of multiple of conditions on care pathways, rising costs and the detrimental economic and health impact of unpaid care means that something in the system needs to change. Through dedicated staff resource, frontline service partners and the creation of a rich and diverse Learning Community of organisations, this programme set out to test what funding and operational mechanisms are needed to deepen and scale services to improve outcomes for older people living with dementia and other needs, their unpaid carers and the wider system.

Strong partnerships – a coalition of change-makers

The Dunhill Medical Trust, Alzheimer's Society, and Social Finance have worked in close partnership to develop and shape this programme. There was a desire for transformative thinking for long-term change, moving beyond how services are traditionally supported. The three organisations are uniquely placed to do this, with each holding key relationships across delivery, research, policy and investment, and a deep understanding of system challenges. The alignment of each partner's strategic vision to improve outcomes for older people living with dementia and other needs provided a compelling opportunity to work together to strengthen the knowledge base in this landscape.

Remarkable research for healthy ageing
THE DUNHILL MEDICAL TRUST

The Dunhill Medical Trust, an independently endowed charitable foundation, is the only funder in the UK dedicated to ageing-related research and improving health and social care for older people. It invests, in a range of ways for both social and financial return, in those who have great ideas for making the radical systemic changes needed to ensure that we can all age well, and in making the connections which can help them to flourish.

Alzheimer's Society
Together we are help & hope for everyone living with dementia

Alzheimer's Society is the UK's leading dementia charity focused on front line support, dementia research, innovation and campaign action. committed to supporting individuals affected by dementia. Their commitment to helping those affected by dementia ensures can continue to enhance their services and support groundbreaking research, striving to improve the lives of those impacted by dementia.

Social Finance is a non-profit organisation that helps our partners design, fund and scale solutions to complex and enduring social issues in the UK and globally. We launched the world's first Social Impact Bond in 2010 and since then our pioneering work has delivered lasting and widespread change that improves the lives of people and communities. We are FCA-regulated and help with mobilising finance, strategy, design, data, and building partnerships, in a human-centred way. We partner with local and national governments, commissioners, service providers, such as charities, as well as socially motivated investors, funders, international donors and philanthropic organisations.

Consistent funding

Just under £420,000 was committed to 15 months of testing and learning to build an evidence base on optimal funding mechanisms, and answer questions on the types of impact measures that could be used if a longer-term fund was established.

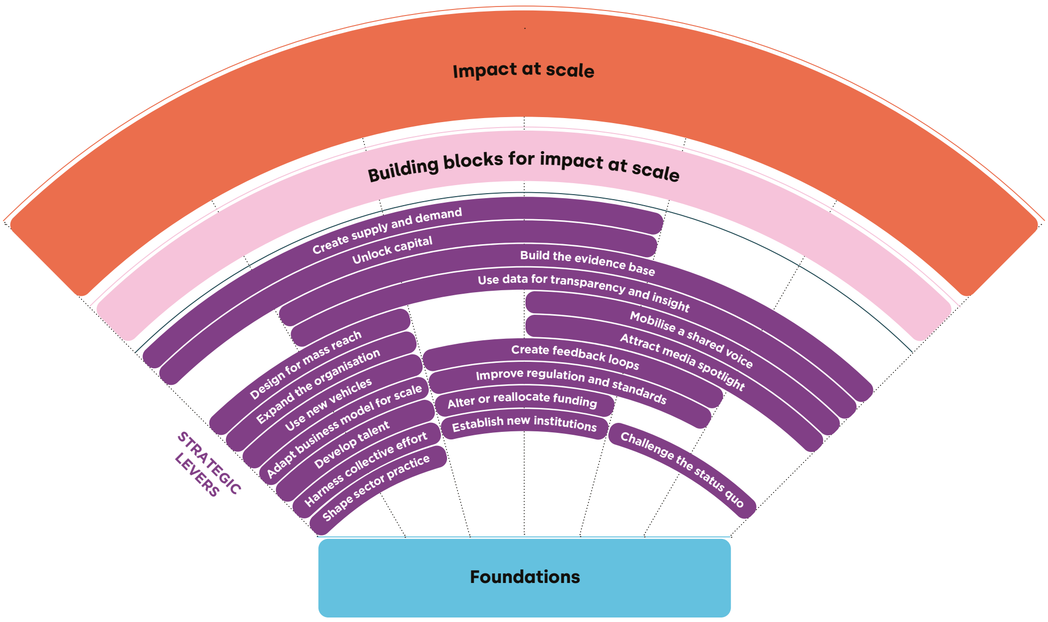
Small pots of grant funding were deployed to service partners to enable dedicated staff time on the programme and cover the costs of developing materials, engaging service users and investing in equipment to test specific interventions (such as technology supported care). Partner resources were an integral part of the programme budget as we recognise testing new ideas and interventions and gathering insight from staff and service users requires time and commitment, over and above 'business-as-usual' frontline services. Investing in our service partners to build capacity and capability was an essential component of the programme.

The longer-term vision of the programme was to understand a diverse portfolio of services to make informed, evidence-based recommendations on the types of funding mechanisms needed to either accelerate their work, deepen their impact or scale their provision. This programme has sought to understand how any 'investment' in a service can be sustainable and consistent, disrupting short termism so that interventions can grow and thrive. As noted in Social Finance's Routes to scale report.

> "The pressure of pursuing short term, piecemeal operating funding can distract from focusing on impact at scale and undermine the ability of a collective to pursue the long-term goal"
>
> **Routes to Scale report, Social Finance**

Programme approach – mapping strategic levers

A guiding principle of our programme approach was to build on what works – we did not want to invest in brand new services. We sought to understand locally embedded, existing services and the conditions needed to scale their provision for older people living with dementia and other needs.



Using our Routes to Scale framework, we mapped the **strategic levers** at play; the ‘toolkit’ of potential approaches that could be used to effect long-lasting, widespread change. We identified strategic levers already in place and working, as well as those that were missing. It’s important to note that the strategic levers sequence is never linear or fixed, and depends entirely on the issue, context and existing barriers to change.

Understanding how technical, funding, research and policy levers interplay was important in shaping the beginning of a route map for scale and change in the older people living with dementia and other needs space.

‘Shaping sector practice’ was a front runner in the strategic lever audit. In the Routes to Scale framework, this lever seeks to change how people work by sharing ideas and tools, via thought leadership, existing service examples and convening communities of practice. In addition to engagement with key system stakeholders, front line services and experts by experience, this programme was guided by insights and learning from a live, community-based Dementia service in the London Borough of Hounslow that had received social investment.

The Enhanced Dementia Care Service (EDCS) is a multi-organisation service that consists of health, social care and voluntary services who provide community-based support for people living with dementia to help prevent crisis, unwarranted hospital admissions, and enable them to live independently. This service received social investment from the Care and Wellbeing Fund, a values-aligned fund, managed by Social Finance with blended investment from Macmillan Cancer Support, Better Society Capital and the Health Foundation and supported by funding from the Life Chances Fund.

Since implementing EDCS, each year has seen between a 7.5% and 12% decrease in people with dementia presenting at A&E.[20] As a result of this success, the Hounslow Borough Based Partnership allocated additional funding to expand the service and continue to fund it to date.

> "There is not solely a financial benefit arising from this service. The value of the service affects individual people and their quality of life."

Social Worker, Enhanced Dementia Community Service (EDCS), London Borough of Hounslow

Alzheimer's Society campaign[21]

Learnings from the EDCS service and other interventions invested in via the Care and Wellbeing Fund and End of Life Care Macmillan Fund, indicate that social investment can serve as a powerful tool in building a robust evidence base for future commissioning, focusing on outcomes for people living with dementia and other needs, and cultivating a cross-system partnership to pool resources, and clinical and community-based expertise.

'Attract Media Spotlight' and 'mobilise a shared voice' also emerged as well-developed strategic levers in this space. High-profile campaigns, such as those led by the Alzheimer's Society and Dementia UK, have garnered significant attention. These campaigns have successfully highlighted the personal and societal impacts of dementia, using compelling human stories and the latest research findings to keep the issue in the public eye.

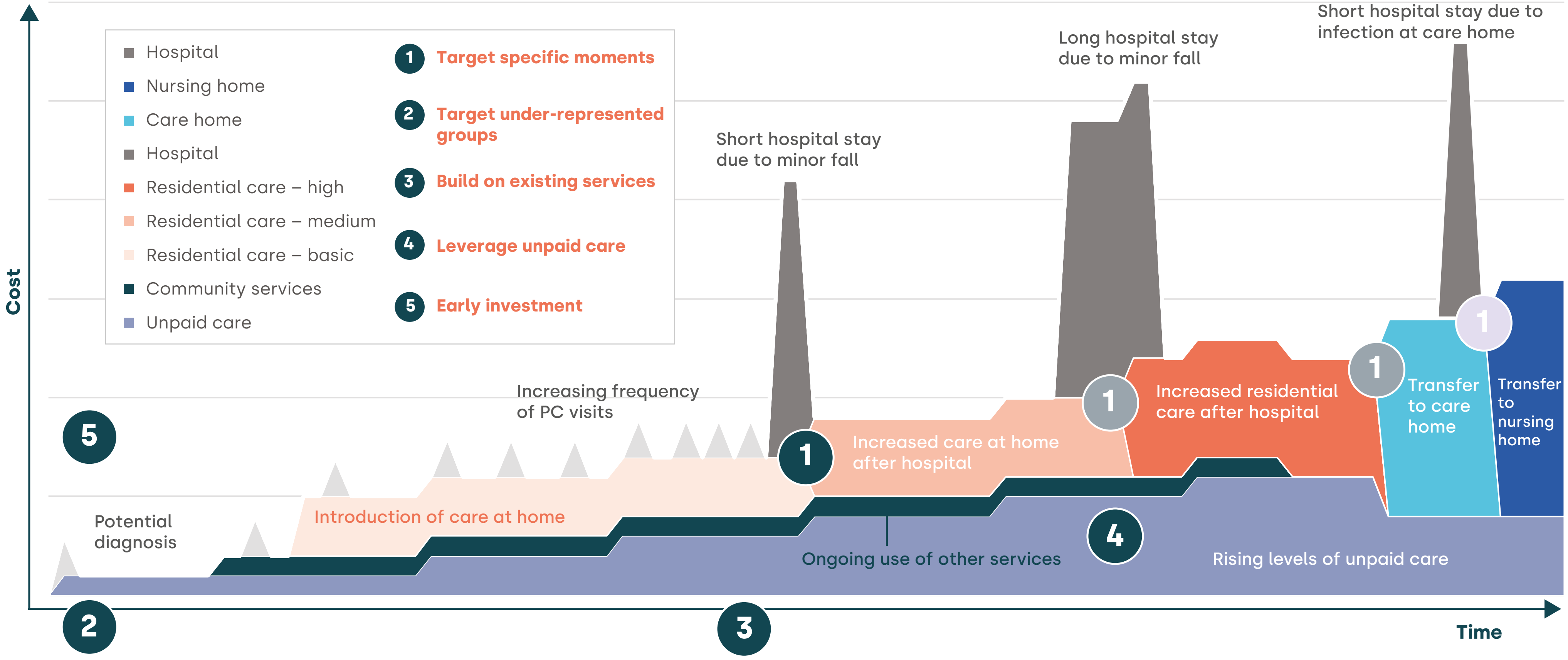
Building on the media spotlight, a **'collective voice'** advocating for better care and research has emerged through a coalition of charities, healthcare professionals, researchers, and affected families. Work of those affected by dementia continues to be amplified through events like the 'Make Your Story Heard' campaign in World Alzheimer's Month. A collective voice has been instrumental in pushing dementia further up the political agenda, however a question remains on how well the funding and policy efforts match the scale of the challenge.

These are just some of the strategic levers being used to shape service provision and awareness raising on this issue area. However, engagement with service providers, funders and commissioners confirms that levers pertaining to investment and scale, are not being pulled in this space, specifically, **'unlocking capital'**, '**using new vehicles'**, and **'adapting business models for scale'.**

These system wide gaps inspired the test and learn approach to the programme and shaped the development of a set of value-creation hypotheses to guide our engagement with service providers and the sector more broadly.

2. Project hypotheses

Shaped by conversations with service providers, unpaid carers and individuals affected by dementia, the diagram below shows an illustrative care pathway highlighting key 'transition moments' along the journey that frequently impact the trajectory of a person living with dementia and their unpaid carers, as well as the system that exists to support them.



Drawing on this pathway and our strategic lever mapping, we developed **five value-creation hypotheses** with potential to generate system efficiencies and either improve or scale outcomes for older people living with dementia and other needs. They are as follows:

1. Specifically focusing on 'transition moments' (e.g. hospital discharge), at which a person's physical and cognitive health declines and costs increase, might deliver value by reducing or delaying deterioration and associated costs.
2. Specifically targeting underserved groups in a tailored way might offer an increase in the quality of care being provided in a more cost-effective way than via "one-size fits all".
3. Building on existing services might allow efficient use of existing infrastructure and knowledge as well as quick ramp up to effect outcomes with limited risk.
4. Providing access to personalised respite services for unpaid "family and friends" carers might facilitate the delivery of more consistent, cost effective, higher quality care over the long-term.
5. Deploying technology earlier in the dementia care pathway may provide incremental benefits e.g. soon after diagnosis with functionality utilised increasing in line with condition.

We matched hypotheses to five live services across the UK to test their applicability. Whilst specific partners were aligned to each, the five hypotheses frequently overlapped and intersected, as is appropriate when services are delivering multiple interventions with a range of outcomes.

Hypotheses were designed to frame and guide our work with service partners to test different aspects of the dementia and older people with other needs journey. They were not intended to test the efficacy of a particular service or prove that one service works 'better' than another.

Frequent engagement with service partners enabled us to understand existing service models, and co-design the new intervention or pathway we planned to test, mapping roles and responsibilities and iterative outcomes. The selected services are shown in Table 1 below, alongside the primary hypothesis that we tested with each.

Table 1: Table to show the different service partners, their role, the role of the Dementia Programme in their work, and which hypotheses they primarily test.

Partner	Description of service and/or intervention	Description of Dementia programme role (beyond funding)	Associated hypothesis (-es)
The Rainbow Foundation	Rainbow Foundation is an active aging charity, operating across Wrexham. The intervention measured the steps and wellbeing of clients accessing the established day opportunity services across the three centres in Wrexham. Both measures were collected again for clients who experienced a 'transition moment' during the testing period to set a target to return to baseline where possible, in addition to the final data collection at programme end.	Define key terms such as 'transition moment' for learning across the people living with dementia and older people living with multiple needs space. Support in analysis of pedometer and wellbeing data.	1) Specifically focusing on 'transition moments'
TANGMERE SageHouse by Dementia SUPPORT	Dementia Support developed new pre-diagnosis support groups across West Sussex, hosted by its unique Wayfinding Service. The intervention was in two parts. Reactive sessions to provide support to the population local to Tangmere in response to the temporary suspension of diagnosis services in early 2024. Proactive sessions to provide support in Crawley – a population which has significantly lower diagnosis rates and more diverse communities in comparison to the population served by Sage House.	Support systematic thinking around underserved groups. Test and learn suitable routes to engagement for under-served groups to inform future service design.	2) Specifically targeting underserved groups
Genie™	GENIE is an online database of support services/activities tailored to participants' interests and needs and a network mapping tool to measures their social support over time. GENIE is not currently used in the UK as a tool for people living with dementia or older people with multiple needs, but its positive impact and potential as a tool are described through extensive research.	Intended goal to support the introduction of GENIE to care processes for people living with dementia and older people with multiple needs.	3) Building on existing services
shared lives plus	Shared Lives schemes are a flexible social care model, where someone who needs care is matched with a paid carer and spends time at the paid carer's home or in the community, depending on their needs. The programme tested and scaled the short-term respite model in existing Shared Lives schemes across the UK to provide more support for people living with dementia. The focus was on the outcomes it could provide to unpaid carers as a respite service.	Data synthesis and analysis support, particularly from qualitative lens. Enhanced user engagement across unpaid carers, people living with dementia, Shared Lives scheme staff and paid carers.	4) Providing access to personalised respite services for unpaid "family and friends" carers
Leicestershire County Council	Leicestershire County Council's Early Care Technology intervention programme for people with a recent dementia diagnosis who display mild clinical symptoms. It offers a personalised in-home care technology package based around needs and circumstances, which may include smart technology, electronic devices, gadgets etc. The aim was to understand if the deployment of care technology earlier in the pathway, when individuals have capacity to learn and use existing skills to operate technology, might prolong independent living and reduce ongoing care costs.	Learning partner provision, particularly in regard to outcomes measurement and framework development.	5) Deploying care technology earlier in the dementia care pathway
Marie Curie	Marie Curie Dementia Care and Respite Service in South Wales provides support for people living with the late stages of dementia estimated to be in their last year of life, by providing respite care, clinical assessment, and signposting. This intervention reviewed existing service data captured by the service. The aim was to identify the key components of assessment and respite care which have a positive impact on enabling people living with dementia and their unpaid carers to remain at home.	Test and learn about existing data capture for unpaid carers. Make recommendations for future pragmatic data capture focusing on quantifiable outcomes. Build evidence and share learning in around the intersection of dementia and end of life care support, with special interest on respite care role.	3) Building on existing services 4) Providing access to personalised respite services for unpaid "family and friends" carers

3. Key findings

Finding 1

Harnessing data can be transformative in care delivery but must be underpinned by a robust data methodology – what needs to be collected, why, when and how

Service partner engagement and feedback from our Learning Community and Expert Reference Group confirmed a clear ambition to collect and use good quality data. However, a lack of clarity persists on how best to collect reliable, accurate and consistent data, and how to analyse this at an aggregate level, especially when a service does not have the capacity, skills or infrastructure in place to do this. This issue affected Marie Curie Dementia Care and Respite Service and Leicestershire County Council, despite both services being at different stages of development.

Marie Curie Dementia Care and Respite Service's impact has been demonstrated through qualitative data and case studies collected by Yma, a not-for-profit social enterprise in Wales. These have been powerful and effective in demonstrating the human impact of the service on people living with dementia and their unpaid carers. However, this service experienced challenges capturing in-depth clinical data, and setting baseline data from which progress could be assessed. This affected the service's ability to generate quantitative data that articulates value to and impact on the statutory system, as noted in the Marie-Curie case study.

For a service like Marie-Curie which supports people living with dementia and their unpaid carers, agreement on data requirements to demonstrate the positive effect of respite care should be prioritised. This may involve collecting baseline data on unpaid carer stress, via the Zarit Burden scale for example, and identifying variables that can affect stress.[22] Services could also explore the development of a database centralising informal respite initiatives, and map access to and the cost of respite options in a locality to build the case for unmet need. Combined, this could underpin a powerful investment case for more effective respite care services that are closely aligned to local and individual needs.

"No one is questioning the qualitative feedback we're getting back in terms of the impact of the service, but in the current climate where financial system pressures are huge means it's not enough for commissioners to commission this service on the basis of feedback of families and carers alone. Through this partnership, we're really hoping we can look at clinical notes and the interactions we've had with people living with dementia to say actually, if we hadn't provided support, a GP would have been called out, or an emergency admission to hospital or care home admission would have been necessary, for example."

Rachel Jones, Associate Director –
Wales / Cyfarwyddwr Cyswllt – Cymru Marie Curie

Leicestershire County Council, working in partnership with PA Consulting, were better able to consider the logistics of data collection, and co-design baseline measures and anticipated outcomes with a range of partners, as they were at the beginning of service design when we initiated our work with them. Agreement on **how** data was going to be collected and in what format was not discussed, however. As a result, aggregate analysis of service data proved challenging as the raw data was collated in multi-page, PDF case files with repetitive identifying data, making extraction and pseudonymised analysis difficult.

Data and underserved groups also emerged as a key learning. We found that services do not often collect or analyse data relating to 'under-served groups'.[23] A multitude of factors influence this, including uncertainty in the appropriate language to use when collecting data or what methods to use to segment and examine it. Inequalities in health and access to healthcare according to ethnic group have been reported.[24]

This is of particular concern within the context of Dementia as Black and South Asian people are more likely to be diagnosed at a younger age and die earlier from dementia than White people, Dementia incidence is over 20% higher among Black adults compared to the UK average.[25] If data on underserved groups, such as ethnicity data, is not collected or analysed, there will be limited understanding of underserved groups' access and outcomes via services, which can perpetuate inequity.

Investing in training on cultural competency approaches for staff and building skills on data collection, analysis and tracking outcomes would support services to tailor provision for local communities, understand gaps in engagement and target outreach efforts to meet local need. This is particularly relevant when measuring the quality of access versus the quality of care. If a service seeks to expand its reach into underserved groups, it is critical that a system is in place to track how their outcomes differ, if at all, to those who are not from underserved groups.

An overarching reflection is that data collected by health and social care services, and some grant funders, is typically activity driven which makes analysis for outcomes-focussed services challenging. Whilst this type of 'outputs' data might be helpful from an operational perspective, it is difficult to articulate the value add of a service focused on improving outcomes, as data is frequently collected in non-standardised formats and compromised by personal and identifying information that renders it unviable for analysis. Furthermore, the administrative burden and complexity of completing data sharing agreements is a barrier to securing access to key data points, especially those that fall within the protected characteristics categories.

Opportunities for improvement include embedding wellbeing data and other PCOMS (person-centered outcome measures) into the service referral process as business-as-usual, to ensure high quality baseline data is collected. The Rainbow Foundation case study illustrates this well. Investment in staff training and back-office business support functions, that enable capacity and capability in data management, will also be key. Knowing how to:

- Ensure data is available and useful, and allow sufficient time for information governance processes
- Generate accurate baseline data
- Use validated tools and user engagement strategies to measure quantitative and qualitative impact
- Collect data in usable formats that enable cleaning and extraction
- Synthesis, analyse and present data

...will allow services to demonstrate impact, track outcomes, understand inequity and generate quantitative and qualitative data that make a compelling case for investment and funding.

Finding 2

Bolstering service capacity and capability is reliant on examining the wider system and leveraging assets

Our findings show a pressing need for capacity and capability building within services. This represents a broader system challenge particularly relevant to community-based organisations, who play a central but frequently overlooked role in the provision of care, support and health promoting activities for communities. This is not a revolutionary finding but necessitates reiteration given the new Labour government's focus on shifting care into the community and Integrated Care Board's (ICB) mandated role to work in partnership with community and VCFSE organisations to meet the health needs of local communities.

Our programme partners exemplify the potential for creative solutions in addressing these wider system challenges, moving beyond traditional recruitment drives to increase service capability and capacity.

Learnings from The Rainbow Foundation, which tested hypothesis 3 (**focusing on 'transition' moments**), demonstrated the need for organisational flexibility in the delivery of community-based care, especially when existing capacity is limited. Instead of recruiting a role which increases costs, Rainbow Foundation introduced a 'personalised care plan' delivered by existing staff, to increase the flexibility of their day centre service and improve outcomes for people living with dementia, older people with other needs and their unpaid carers. This tool generates a more holistic understanding of their service user needs and bolsters the capability of existing staff by upskilling them on another engagement and support mechanism.

Similarly, to bolster existing capacity and capability and build service sustainability, Marie-Curie developed a dual pronged service which utilised both paid, clinical staff and unpaid volunteers. Volunteers were inducted, trained, and upskilled to provide low to moderate support for people living with dementia, adding a flexible dimension to the offer and bolstering service capacity.

Implementing technology emerged as a potential driver of capability and capacity building, augmenting and complementing face to face services. However, learnings revealed issues with implementation and the perception of technology as a potential burden and hindrance.

Whilst the intention at The Rainbow Foundation was to integrate technology within existing infrastructure, it was apparent that the capacity and capability of the wider system had not been fully leveraged, and so the impact of the pedometers on an individual's wider health interactions could not be fully realised or understood. We were unsuccessful in the deployment of the Genie network mapping tool as prospective service providers did not have the bandwidth to engage with training staff or volunteers or rolling the tool out in their setting, despite the availability of financial resource from our programme grant.

The challenges experienced by The Rainbow Foundation and Genie reflect the importance of introducing a product into a context that is already well defined, with a clear understanding of the cultural, resource and economic shift required to implement it. Above all, it demonstrates the importance of mapping existing knowledge, infrastructure and knowledge to optimise the coordinated integration of a new service or tool.

Future testing and learning in this area could examine the impact of investing in system-wide offers related to technology support. The Leicestershire County Council and PA Consulting case study illustrates this. Deploying care technology would benefit from a coordinated approach, building on existing technology offers and resources provided by the council, to enable integrated, joined up delivery.

Training staff using care technology is also essential for effective implementation. Training programmes should cover device operation, troubleshooting, and integrating technology into personalised care plans.[27] Training costs can be integrated into existing professional development budgets, emphasising hands-on experience and continuous learning. This supports the principle of joining up and building on existing services and infrastructure and may be one way of sustainably implementing technology into health and social care services.

These learnings are consistent with the recommendations of The Technology for our Ageing Population: Panel for Innovation,[26] a project designed to improve the way technology is used in housing and care settings, which found that technology needs to be **seamless** (accessible technology that works together), **supported** (via accessible training for service users and providers), **safe** and **affordable.**

Strategic levers that need to be pulled to scale capacity and capability include **harnessing a collective effort,** by leveraging wider parts of the system, and **building the evidence base** on ways that capacity and capability can be improved for and with community and VCFSE organisations, with a view to sharing these learnings and best practice across the sector.

Finding 3

Establishing integrated models of care that take a holistic approach will be a powerful tool in better supporting the needs of older people

Programme learnings indicate that integrated models of care are a powerful asset in improving outcomes for people living with dementia, older people with other needs and their unpaid carers. Integrated care mitigates fragmentation by providing services that join up pre-diagnostic, diagnostic and post-diagnostic support. Insights indicate that integrated care models are best suited for those with long-term medical needs, aligning closely with older people with other needs and people living with dementia.[28]

The Sage House model exemplifies this. Sage House Tangmere, delivered by the charity Dementia Support, offers personalised one-to-one support and advice for people living with dementia and their unpaid carers across the whole of the dementia journey, from pre-diagnosis to end of life. Diagnosis takes place on site at

Sage House and wayfinding support is offered to help individuals, and their unpaid carers navigate the impact of a diagnosis. Dementia friendly activities, day centre provision and respite options are all offered from a ‘one-stop’ offer at Sage House.

Sage House tested two hypotheses; **building on existing services** and **specifically targeting underserved groups,** with the understanding that integrated approaches to care are effective as they help link existing services, but they must be available and accessible to all.

Dementia Support and Social Finance worked together to prioritise engagement with underserved groups from the start of both service design, and the beginning of an individual’s dementia’s journey. Guided by learnings from the Wayfinder model in Tangmere, Sage House developed pre-diagnosis sessions for people living in Crawley, a locality with the lowest dementia diagnosis rate in the West Sussex region at 53.1%; 7.4% below the regional average of 60.5% and 13.6% below the national average of 66.7%.[2] and a contrasting demographic with 27% of the population identifying as non-white in comparison to Chichester where it is 8%.[4]

Dementia Support recognised their approach to accessing communities in need of support in Crawley must be different from the approach in Chichester, and yet uptake and engagement was still a challenge. A significant issue was ensuring sessions reached beyond the usual demographic. Learnings confirm that building trust within the local population and underserved groups was critical. Effectively reaching out to underserved groups requires extra resource (both time and effort), and awareness raising efforts need to be targeted, specifically aimed at individuals’ pre-diagnosis, on a waiting list, or considering a diagnosis.

> "The caring role can be very exhausting for someone supporting a loved one with dementia. There's a huge lack of day support available. We know that. And that means that people are ending up in the wrong kind of situations. Carers are getting burnt out. So, we know there's a demand. Trust is important and the Shared Lives model is person centred, you choose that opportunity, and it's in the community, so it can be very local, very reassuring, and a very stable way of supporting someone."
>
> **Ewan King, CEO, Shared Lives Plus**

Integrated models of care must also be designed to consider the support needs of the unpaid carer and wider support network of an individual living with dementia or older person with other needs. Learnings from Shared Lives Plus, a social care model that matches trained Shared Lives carers to a person in need of care to enable respite for the unpaid carer, highlighted that a significant amount of trust and good communication pathways need to be built as early as possible. This will translate to stronger relationships and increased confidence in the care offered to them and their loved ones.

To accelerate the impact of integrated models of care and scale this type of support in an accessible and inclusive way, multiple engagement strategies are needed, including involvement of underserved communities in the design and implementation of integrated services. This can be accelerated through genuine partnership working with the voluntary, community, faith or social enterprise (VCFSE) whose understanding of the wider determinants and their disproportionate impact on the health and wellbeing of underserved communities, will be of distinct value.

The opportunities for change intersect with several of the strategic levers and building blocks for change, including **shaping sector practice, expanding the organisation**, and **challenging the status quo.**

Finding 4

Focusing services on outcomes can secure stabilised and joint funding and commissioning streams from health and social care

Programme partners, and those from our wider Learning Community of over 50 community-based organisations, are concerned with how to access sustainable funding and commissioning to continue service delivery. Their existence and sustainability are linked to decisions on funding and commissioning; positive evidence for each can support the re-commissioning of existing services and development and implementation of new interventions.

Limited funding threatens the survival of services which are, in many cases, lifelines for people living with dementia, older people with other needs and their unpaid carers. The need for improved outcomes for people living with dementia and older people with other needs already outstrips demand and that gap is only forecast to increase. In 2021, the estimated cost of dementia care in the UK was £25 billion and this is expected to almost double to £47 billion by 2050.[18] Predictions show that those facing inequalities are most likely to be worst hit by this widening gap. Under this pressure, the only option is to think differently.

Social Finance has engaged 15 ICB and Trust Directors of Finance from across the UK over the last 15 months to understand where they think support needs to be directed. Each one sees value in the NHS shifting resource from short term fixes to long term, proactive and preventative services, and view the VCFSE sector as a key partner and ally in realising this ambition. Reallocating investment upstream and into the community demands a shift from traditional commissioning with a focus on activity and outputs, to person-centred and system wide outcomes that improve care for the community and alleviate system pressures. As explained by one of our partner ICBs:

> "… the NHS is a system under strain and because of this it defaults to fixing short-term problems, despite its objective to support the delivery of social and economic value. The NHS has a mandate to apply resources to healthcare objectives but there are limited tools and few enablers to achieve this through grant funding and existing bureaucracy…"
>
> **Matthew Gaunt, CFO Lincolnshire ICB**

People living with dementia, older people with other needs and unpaid carers fall between statutory services gaps because their needs do not neatly fit into a single funding workstream. Dementia, and the associated health conditions and challenges it brings, makes this condition complex as it straddles not only physical and mental health funding pots, but multiple care pathways across adult social care and health. As such, joined up commissioning and funding, in addition to co-designed, system-wide outcomes framework should be developed.

Leicestershire County Council and PA Consulting initiated their early care technology intervention with seed funding from the ICB, and service delivery by the local authority. This built a valuable statutory sector partnership from the outset. Social Finance worked with both partners to understand priority areas for older peoples' health and wellbeing and co-developed an outcomes framework which considered person-centred and system wide outcomes. This coordinated approach will result in a set of outcomes that demonstrate impact across health and social care once intervention data has been analysed, building the evidence base for a potentially co-commissioned service in the future.

> Outcome frameworks may make it easier to demonstrate to funders and commissioners what they would be paying for, and why they should be paying for it – co-designing outcomes that matter to people and communities and aligning them with system priorities.

In a report that consistently speaks to the importance of outcomes, and their crucial role within outcomes based contracting and social investment, defining what we mean by 'outcomes' is important. Through our engagement with community-based organisations, the statutory sector and funders, we understand outcomes as the changes that occur for people, communities and a system because of an intervention, service, new funding approach, workforce development etc. Outcomes can be person-centred, and system-wide, for example **increased awareness of services and support, decreased feelings of loneliness, increased connection with local the community, increased wellbeing and resilience, decreased unplanned interactions with emergency care, reduction in bed days**, and a variety of methods can be used to collect and demonstrate outcomes.

This test and learn programme took a pragmatic approach to identifying and collecting outcomes for older people with other needs, people living with dementia, their unpaid carers, and the wider system. We introduced methods including the Zarit Burden Scale, EQ-5D-5L, surveys and conducted user engagement with service providers, unpaid carers and people living with dementia for rich, qualitative insights. Given our focus on alternative funding mechanisms, we had a specific interest in outcomes that a system would pay for i.e. those that alleviate system pressures and divert the need away from health and social care support.

It must be recognised that an outcome measure is complex – outcomes and their benefit to a system take time to be realised and can be challenging to prove via direct attribution; as such, some will be proxy measures used to indicate progress and impact. The programme highlighted several learnings on how best to navigate the iterative process from identifying outcomes to sharing outcomes for each partnership, and the types of system-wide outcomes frameworks that can be built, both of which are available to view in Appendix 1 of this report.

4. Funding to build long-term change

Funding mechanisms

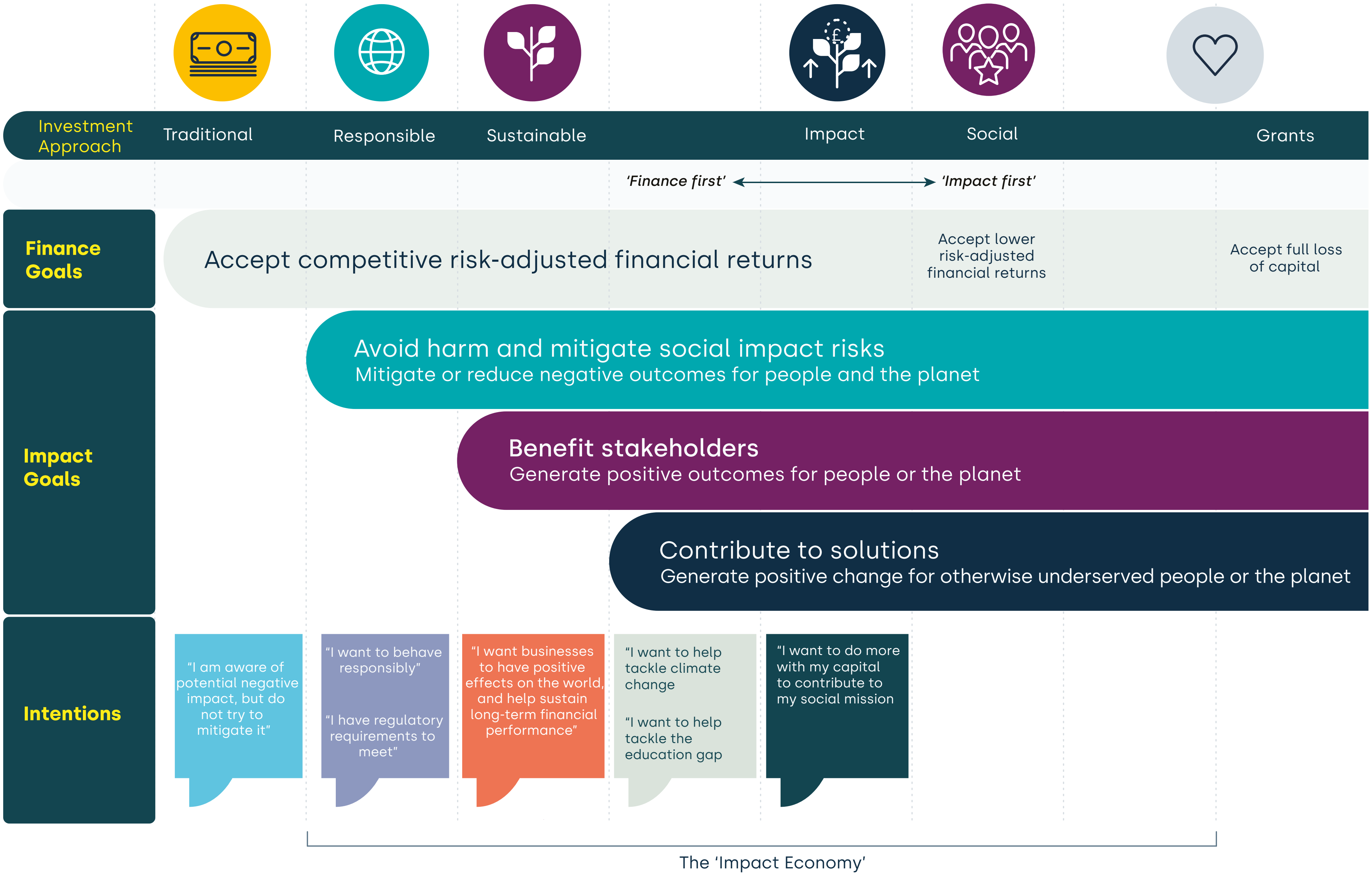
Funding decisions are shaped by the aims of a service, its issue area, maturity, and wider policy and advocacy levers that need to be pulled to effect change. A range of funding mechanisms are described below, including commonly held definitions and their role within health and social care.

"Social investment sits on a spectrum; on one end, there is grant giving, where there is no expectation of any financial return, and at the other end of the scale, you have impact-conscious venture capital, where the risk and expectation are high.

What I love about social investment is that it is a really flexible tool, where there is no one size fits all, and there's not actual hard or fast rules. What is really important is that you need the right partners around the table, and having clarity on the risks and outcomes. What is the better good that you want to deliver?"

Katy Saunders, Director of Health and Social Care – Social Finance

THE SPECTRUM OF CAPITAL



Investment Approach

Traditional

Responsible

Sustainable

Impact

Social

Grants

'Finance first' ← → *'Impact first'*

Finance Goals

Accept competitive risk-adjusted financial returns

Accept lower risk-adjusted financial returns

Accept full loss of capital

Impact Goals

Avoid harm and mitigate social impact risks
Mitigate or reduce negative outcomes for people and the planet

Benefit stakeholders
Generate positive outcomes for people or the planet

Contribute to solutions
Generate positive change for otherwise underserved people or the planet

Intentions

"I am aware of potential negative impact, but do not try to mitigate it"

"I want to behave responsibly"

"I have regulatory requirements to meet"

"I want businesses to have positive effects on the world, and help sustain long-term financial performance"

"I want to help tackle climate change

"I want to help tackle the education gap

"I want to do more with my capital to contribute to my social mission

The 'Impact Economy'

Source: Bridges Fund Management and Impact Management Project.

Social investment is an umbrella term for funding mechanisms that seek to balance risk, financial return and social impact, based on the appetite of the partners involved, and can include social outcomes partnerships (SOP), concessionary capital / investment and blended finance. **Grant funding** is often deployed for a specific purpose/project and does not expect repayment of capital or financial returns, thus sits outside of the social investment umbrella term. It can, however, be used catalytically, in tandem with one or more of the social investment mechanisms to assist in the funding of change and we highlight some examples of that here.

1. Grant funding

What is it?

- Grants do not usually require repayment.
- Often used to fund specific initiatives that may not be commercially viable but have significant societal impact or benefit.
- Typically limited in terms of duration and/or to specific goals/milestones, after which funding ceases.
- Can sometimes be restricted for use on a particular project and, depending on the funder's policy, may not contribute to overheads making it difficult for the recipient to sustain the service in the long term. Usually deployed by governments, charities or charitable foundations.
- Reporting requirements are often attached to grants. These can be highly variable in their detail and range from confirming the broad area where the funds were expended through to very detailed resource and delivery tracking.

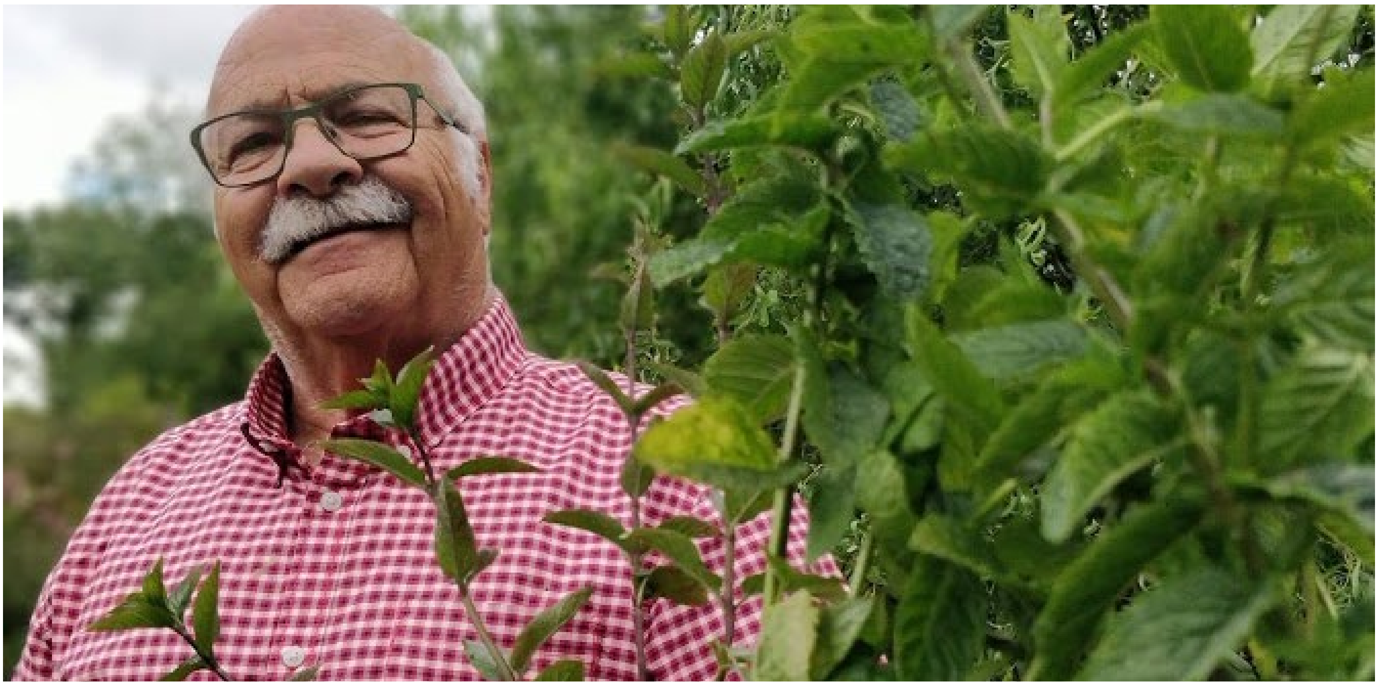
How might they be used, based on this programme?

- Grant funding can be used to support infrastructure in a targeted way. Grants could pay for a data analyst role, health economic analysis or training to upskill teams on data collection and analysis. This will build organizational resilience and support with investment readiness. Given their limited duration and frequently restricted remit, grants can generate uncertainty for an organisation, and lead to reactive service set up, which can have staff and data collection implications. See the Marie-Curie case study for more detail. For this reason, the use of grant funding requires careful consideration and is most likely to deliver greatest impact when used to pay for or invest in assets that will enable a degree of sustainability via capacity and capability building.

- Grant funding is suitable during the pilot and development period of service change, as it might not be immediately possible to monetise outcomes or locate an appropriate proxy outcome linked to infrastructure or building partnerships. The grant period can provide dedicated resource and time to develop and identify outcomes and/or proxy outcomes that a system would pay for, and more specifically, establish the notional financial value a system might pay for outcomes that alleviate pressures to acute/secondary and/or primary care. Spending time on this type of activity can lay the foundations for alternative models of funding like blended finance and social outcome partnerships which demand rigour, and an outcome focussed approach to make the investment work.

Link to policy:

- Implement grant funding for the enhancement of back-office functions, such as data analytics and marketing/awareness raising, within service-oriented programs. These would recognise the importance of capacity-building grants that focus on improving the operational efficiency and outreach capability of service providers.
- Encourage grant funding policies that support collaboration with grassroots and community-based organisations. Policies could promote longer term funding of circa three to five years to sustainably establish and nurture partnerships that are crucial for expanding the reach and impact of services, particularly in underserved communities.



2. Social Investment:

(i) Social outcomes partnerships

What are they?

- Social outcomes partnerships (SOPs) create partnerships between the public, private and voluntary sectors to help solve social problems through a clear focus on outcomes and real-world impact
- SOPs are outcome-based contracts that use funding from social investors to cover upfront capital required for a provider to set up and deliver a service. The service is set out to achieve measurable outcomes established by the commissioning authority (the outcome payer) and the investor is repaid **only if these outcomes are achieved.**
- This outcomes-based model shifts the financial risk of social interventions from the public service provider to social investors (who might be charitable foundations, service delivery charities or mainstream impact investors), incentivising effective solutions to societal challenges, and creating space and capacity for statutory systems and community-based organisations to focus on flexible delivery models that deliver the best possible outcomes for people.
- The precise terms of social outcomes partnerships will vary in line with the mission and financial objectives and appetite for risk of the investors. Some may require a financial return on their investment, some may not. Some may require outcomes achieved beyond those needed to repay the actual investment to be shared, some may not.

How might they be used, based on this programme?

- Services most suitable for social outcomes partnership models funding need systems in place to capture measurable outcomes that can be monetised or quantified financially, whilst also addressing areas of public health need.
- Social outcomes partnerships have proven valuable for new and reconfigured services, as reflected by the work of the Care and Wellbeing Fund and Macmillan End of Life Care Fund, in supporting the implementation and delivery of end-of-life care services. For example, it has been used to embed specialist care palliative care within an emergency department to help identify end of life patients and influence their management.[29] In the long-term, this enables patients in their last year of life receive treatment and care at home, whilst alleviating system pressures via reduced bed days.
- Social outcomes partnerships would be beneficial for interventions introducing something new into a person's care pathway. This could for example include the implementation of new technology or devices, such as Leicestershire County Council's work to deploy care technology earlier in the dementia journey. The potential for using technology to promote independence at home, divert need away from acute care and support carer wellbeing could work in the context of a social outcomes partnership if an outcomes payer recognises and is willing to pay for the system and person-led benefits that the use of technology generates.
- A range of social outcome measures could be used to drive repayments in the above examples exist but are contingent on capturing data to set an agreed baseline. Examples of outcomes that can be used in this way include a reduction in emergency care visits and reduced escalation or maintenance of at-home care costs in comparison to baselines.

Link to policy:

- Social outcomes partnerships, unlike third party loan financing, are specifically permitted under HM Treasury rules and requirements in England. This is related to the outcomes-dependent nature of any potential repayment, and the financial risk borne by the investors.
- Building on this, we recommend the formulation of policies that integrate social outcomes partnerships into healthcare innovation strategies, which builds on the precedent of using social outcome partnerships to improve End of Life Care and related outcomes. These policies could provide a library of social outcomes and valuation methodologies to facilitate the alignment with tangible benefits, including those with particular strategic significance given the nature of the challenges being endured.

(ii) Concessionary capital / investment

What is it?

- The allocation of capital to projects, companies, or funds with the intention of generating measurable social and/or environmental benefits, alongside financial returns.
- Unlike traditional investments, which focus purely on maximising financial gain, social investing seeks to achieve positive social impact alongside a financial return for the investor.

How might it be used, based on this programme?

- Concessionary capital funding may serve as a helpful tool in the early stages of designing and launching services that lead to long-term, social benefit, rather than those which have reached a level of maturity which can support market-level rates of financial return.
- This form of investment could, for example, be beneficial for services targeting unpaid carers. Although it is harder to define hard financial indicators upon which repayments

can be triggered for this cohort, the social impact is clearer: it is widely agreed that supporting the wellbeing of unpaid carers will have a positive, long-term impact on their caring capacity and health which will in turn materially benefit adult social care, the health system and the economy by recognising their place within the workforce. This was shown by initial investments into Shared Lives arrangements across the UK prior to them achieving financial return on their services.

- The initial investment was repaid on concessionary terms once the service was meeting a level of matches that enabled it to operate as a sustainable service. Once a Shared Lives service has secured enough matches for people living with dementia for example, either privately funded or via commissioning, the initial investment could be repaid on concessionary terms as a proportion of matches made. In other situations, the conversion could be linked to the point at which a certain number of commissioned contracts are secured.

Link to policy:

- Develop policies that encourage concessionary capital / investment as a key funding mechanism for programmes with long-term societal benefits that are difficult to measure through specific indicators. These policies could incentivize investment in services that take a more holistic view of a care and health provisions pathway, encouraging more work on better recognising areas of broader social impact.

(iii) Blended finance

What is it?

- Blended finance mobilises investment by reducing perceived risks and enhancing the viability of socially minded projects, often via a combination of repayable and non-repayable finance.
- By leveraging public or charitable funds to absorb initial risks or enhance returns, blended finance attracts investment into sectors that might otherwise be deemed too risky or will deliver less-than market-level financial returns so won’t attract private capital. Public funds are provided on more favourable terms (e.g. concessionary interest rates) and capital investors decide whether they are seeking market-rate returns and/or no return on their initial investment, depending on their mission and risk appetite.
- Risk mitigation tools, such as guarantees, are used to further reduce the financial risk for private investors.

How might they be used, based on this programme?

- Blended finance is an attractive option when seeking to develop a programme that intersects with multiple parts of the health and social care ecosystem. It can combine repayable and non-repayable finance options; investment might include a non-repayable development grant to pay for the cost of partnership development, a data dashboard to improve data collection and outcomes, change management and investment preparation, in addition to repayable, upfront cash to cover service costs during the initial period of operation.
- Repayable outcomes are not usually made until at least 18 months into service delivery which creates space and time to ensure the service model is correct, capture baseline data, refine outcomes if needed – essentially adapt and flex so that the service can work optimally to deliver the agreed upon outcomes.
- The Care and Wellbeing Fund is a proof-of-concept fund using blended finance to test whether social investment funding mechanisms could be used to improve health outcomes and be a tool for sustainable innovation. It comprised £12 million pounds of repayable investment in community-based services and social enterprises within the UK and £1 million pounds of non-repayable, development grant funding to help the Fund team develop and prime investment opportunities to create social impact.
- The private investment can be repaid on a variety of pre-agreed outcomes or be based on cost-savings for other parts of the health and social care system.

Link to policy:

- Develop policies that promote the use of blended finance to support projects that intersect multiple areas of the health and care ecosystem. These policies could encourage public and charitable funding to be used for initial risk absorption and relationship building with community organisations, fostering consortium-based approaches. By facilitating collaboration across different stakeholders, these policies would enable more comprehensive and integrated care solutions.
- Implement policies that strategically use public or charitable funds to reduce the perceived risks of socially impactful projects, making them more attractive to private investors. These policies could include provisions for offering favourable terms, such as concessionary interest rates or guarantees, during the ramp-up period of service implementation.

> "We need to explore other avenues. At the NHS Confederation, we are working with partners to explore the scope for models of social investment in which upfront money generates a return through reducing demand. Ultimately, every ICS should aim to have a portfolio of social investment projects."
>
> **Matthew Taylor, CEO, NHS Confederation**

Suitability of an outcomes-based approach

Outcomes-based approaches have proven effective, as exemplified by services delivered and supported through the Care and Wellbeing Fund and Macmillan Fund for end-of-life care (amongst many others). From these funds, over £12 million worth of investments have been made in social outcomes partnerships for end-of-life care, dementia and loneliness. This work has been managed by Social Finance, with funding provided by Big Society Capital, Macmillan Cancer Support and the Commissioning Better Outcomes Fund.

> "Instead of rigid specifications that focus on inputs and activity, social outcomes partnerships empower frontline experts… to tailor delivery to individual and local circumstances."
>
> **Adam Swersky, CEO, Social Finance**

Based on our understanding of outcomes and deep experience of outcomes-based approaches, Social Finance created a 'suitability checklist', that can be used as a resource in exploring the feasibility of introducing an outcomes-based approach.

Suitability Checklist for Social Investment Funding Mechanisms

Key definitions

What is an Outcomes Based Contract (OBC) Assessment:

A suitability assessment for an outcomes-based contract examines the high-level conditions of a programme or concept against a first set of “deal breaker” criteria – that is, criteria that we know must be met for an OBC to be valuable and suitable.

The key question that we are seeking to answer in this stage is: “Why use an OBC? Will moving towards a contract that uses a real/proxy tariff increase the impact that can be created in this issue area? And if so, what impact should the OBC aim to achieve?”

What it is not?

It is not an in-depth study into the details of the programme.

Suitability Assessment

After assessing all 4 modules of the suitability framework, if:

All boxes in 1, 2 & 3 are ticked ⇒ an outcomes-based approach is appropriate

All boxes in 1, 2, 3 & 4 are ticked ⇒ an impact bond is appropriate

1. **There is a clear outcome or set of outcomes that all key stakeholders agree upon for the population of interest. This implies that:**
   - ☐ We can clearly articulate problem and population affected by it
   - ☐ The outcome(s) sought for those people can be clearly defined
   - ☐ If there is more than one outcome funder, or various interests among parties within the outcome funder, the outcomes they seek for the population of interest are compatible
   - ☐ The market providers agree on the need to achieve that outcome (and not others)
2. **There is an appropriate degree of uncertainty around the likelihood of achieving those outcomes with the population of interest. This means that:**
   - ☐ We can identify concrete sources of risk which affect the certainty of achieving the desired outcomes with the population of interest
   - ☐ The level of uncertainty is large enough that the outcome funder is not prepared to contract the services directly given their resources, priorities and risk appetite, or they see an important opportunity to improve outcomes by contracting for them instead
   - ☐ Existing evidence on the achievement of outcomes with the population of interest is sufficient to persuade a third party to finance the provision of a service and assume the risk (upside and downside) associated with the achievement of outcomes
3. **It is possible to improve current outcomes for the population of interest through adaptive management of the service. This means that:**
   - ☐ The service can be adapted throughout its delivery: there are no regulatory constraints or other barriers to doing so
   - ☐ The size of the proposed population of interest is sufficient to allow robust learning around what works and what does not in pursuit of the desired outcomes
4. **The inclusion of a new actor is both possible and necessary to enable an OBC to operate effectively. This means that:**
   - ☐ The providers are not willing or able (under current terms) to finance the delivery of the service aimed at achieving results and in so doing take on the risk of failure
   - ☐ Outcomes payer and potential providers are willing and able to include a new actor, an investor
   - ☐ The size of a potential OBC justifies the fixed costs (structuring and management) associated with an impact bond

Applying pre-conditions for successful funding

Understanding and defining the pre-conditions needed to make new service delivery models “investable propositions” (the “investment principles”) was a key objective of this programme. We have synthesised findings from the programme, our funding partners and deep learnings from our wider social investment portfolio to propose **five key preconditions** for success which we hope will guide service-providers, commissioners, funders and social investors on the prerequisites for funding success.

Pre-conditions for funding	Rationale
Active engagement with and involvement of the local VCFSE sector, with the aim of embedding an infrastructure that supports and enables this long-term collaborative way of working with VCFSE as an equal partner in planning and delivery of services.	The VCFSE sector is vital in supporting health services to deepen their reach into local communities. This is reflected by the experiences of Sage House with their Crawley service. Despite considerable background work to guide engagement with a new target population, this was not achieved. The Crawley sessions revealed the need for extra time and effort to gain the trust of local communities, some of which have historical mistrust of statutory services. VCFSE are a powerful asset in building this trust with New Local stating that ‘they are key to any genuinely integrated care system’.[30] It is imperative that VCFSE engagement is not tokenistic or short-term. There must be a strategy in place that considers each other’s roles and remits, and funding to support this way of working. Research shows there is often a perceived lack of genuine partnership working between VCFSE and the system, whereby they are seen as an afterthought or not paid for their time.[31] It is crucial they are remunerated appropriately for training on language and cultural competency. Grants may be more appropriate, however long-term collaborations would benefit from concessionary capital / investment or blended finance mechanisms.
The application of a social determinants of health approach to programme design, to enable flexible, agile and holistic service delivery	The consideration of social determinants of health in service delivery and the need to take a holistic view of a person’s health and care is crucial. This emerged across all hypotheses-related learnings, especially those implementing technology to promote independent living and monitor ‘transition moments’. Implementing technology can yield greater impact when based on a thorough assessment of a person’s medical history and the wider determinants affecting their lives. This might include assessing an individual’s home to ensure it is set up to work with the technology or thinking about their social and community networks when considering the best way to explain new technology. Services like these often receive funding from charitable organisations or government departments in the form of grants, however there is likely scope to consider the role of social outcomes partnerships. For example, social outcomes partnership funding for a Community Navigator or Technology Offer may reduce hospital visits, which would reduce costs; the challenge would be in identifying and defining the most appropriate outcome payment metric.

A clear plan to bolster data operations and infrastructure	Bolstering data collection and sharing protocols to deliver person-centred care will be critical if the service is looking to evolve and scale. Implementing a technology-based tool into someone's care pathway will require ongoing data analysis, and so skills must be in place to get the most out of both the tool and the data. This is also important for respite services as reflected by Shared Lives Plus and Marie Curie Dementia Care and Respite Service. Services providing respite need to demonstrate meaningful impact on unpaid carer experiences and wellbeing, and the potential attribution of this to the diversion and/or delay in support required by health and social care for the person living with dementia/older person with other needs and the unpaid care themselves. Positive outcomes will be proven by the data collected, be that quantitative or qualitative, and so considerations on data fields, methods of collection, extraction and analysis must be considered at the outset of service design. One route to achieving this may be through ongoing engagement with the local authority's Business Intelligence team.
Clear communication and engagement-focussed strategisation	This principle above aligns with this, whereby overall investment into operational functioning of the system will lead to better reach of the services. An effective communications and engagement strategy is essential across the multi-disciplinary and multi-professional team – which includes the voices of those drawing on services and their carers – that will be needed to deliver person-centred services, with robust governance
Commitment from commissioners to adopting routes to a sustainable and effective system-wide approach	The need for system-wide approaches to funding and delivery across the health system is well articulated. The Royal College of Emergency Medicine stated in 2023 that a 'system-wide approach is essential to save a health and social care system in need of intensive care'. The 2023 State of Care report, published by the Care Quality Commission, found 'gridlocked' care with 'people facing longer waits to be seen in urgent and emergency care'. Winter pressures, often felt most acutely by older people with multiple needs, tend to focus on emergency departments, however this is symptomatic of a wider capacity problem across the health and care system. It is important that services are given resource to develop and build a system-wide approach to funding and delivery. Future approaches should consider how physical and mental health can be supported by drawing on expertise across the system, considering the role of housing specialists and volunteers. The most applicable type of funding mechanism for progress in this space depends on the intervention being proposed. All the above investment principles intersect with this principle, and therefore a combination approach or blended finance would be most valuable.

5. Recommendations

Short-term recommendations (6 months)

These recommendations represent an opportunity for services and system stakeholders to create the conditions for improved system working. If addressed, these will lay a strong foundation for more sustainable and robust services and provide flexibility to think creatively about how to implement or adapt interventions.

Improve system-wide data infrastructure and processes

Data collection is essential for measuring impact, tracking outcomes, making a 'case' for further investment, analysing and responding to inequity, and making informed decisions, yet findings from this programme have revealed a multitude of challenges across data processes, and collection. We recommend a system wide approach to securing person-centred data, and an urgent simplification of data-sharing protocols that are consistent across all NHS providers. We suggest exploring safe and expedited ways for suitably accredited, non-NHS providers and researchers to access data that will help build evidence bases, underpin a compelling case for change and interrogate inequality in access to and experiences of care.

Conduct ecosystem mapping

Allocating resources for ecosystem mapping will allow for gaps to be identified across service provision and will allow for detailed conversations on scope and accountabilities. Ecosystem mapping in this context will involve a thorough analysis of the current older people with other needs landscape to identify unmet needs or duplications in services. By understanding where gaps exist, services can focus their efforts on addressing these areas, directing resources to where they are most needed.

Enhance funding knowledge

Building commissioner knowledge on the most appropriate funding sources for the service or point in the innovation cycle is a critical step to enabling sustainability. By investing in building knowledge on funding options, this supports the principle of leveraging the best resources to support the long-term aims of a service or intervention.

Medium-term recommendations (12 months)

These actions reflect how services working within the older people with multiple needs and dementia landscape can significantly enhance their service delivery by implementing strategic initiatives that focus on innovation, integration, and holistic care. The following recommendations aim to prevent duplication, foster innovation, and ensure that services are aligned with broader health and social care goals. By addressing these areas, organizations can create more effective, sustainable, and person-centered care models.

Leverage the Learning Community to avoid duplication

This programme's Learning Community is a valuable asset through which services can identify best practice and enhance delivery by building on what has already been proven effective in similar contexts. Furthermore, it is an opportunity to test innovative thinking on how different resources can be leveraged, such as the role of different funding mechanisms.

Identify and implement place-based testing

Implementing place-based testing allows services to experiment with new ideas in specific locations, tailoring interventions to local needs. Vanguard services can act as test beds for innovation, providing valuable insights that can be scaled across other regions.

Embed services within a 'dementia and older people with other needs' framework

A dementia and older people with other needs framework ensures that services consider the multifaceted needs of older people, placing emphasis on the multiple conditions that will likely affect an older person at a given time. Considering coexisting conditions and social factors will lead to more comprehensive, streamlines and effective care.

Incorporate social determinants of health into service design

By considering factors such as housing, education, and economic stability, healthcare organisations can design services that address the broader context of patients' lives, and how this may impact an older person's care trajectory. Additionally, this will inform what further considerations are needed prior to introducing a new intervention into their care, such as the wraparound support needed for technology-based tools in the home.

Intentionally integrate unpaid carers into service planning

The learnings from this report illustrate the extent to which unpaid carers play a critical role in supporting older people with multiple needs. Intentional integration of unpaid carer needs into service planning and design will in the long-term reduce burden. This will allow for better health outcomes for both the unpaid carers and the people to whom they provide care.

Establish clear parameters for funding mechanisms

Having resources available that articulate which funding mechanisms may be most helpful for what type of service or intervention will be helpful for providers, commissioners and funders. Clear parameters help ensure that funding is allocated efficiently and effectively, aligning with the strategic goals of system stakeholders, and facilitating better planning, execution, and assessment of funded initiatives.

Implement and refine an outcomes framework

An outcomes framework provides a structured approach to measuring the impact of services. By refining this framework over time, and ensuring a system wide approach, services, funders and commissioners can continuously improve their data-driven decision-making processes and adapt to changing needs.

Establish a series of technology support offers

Technology will continue to play an increasingly vital role in healthcare relating to older people with multiple needs. It is essential to support both patients and healthcare providers in utilising these tools effectively. Testing and establishing a range of technology support services – such as training programmes and on-site technical support – can support technology-based interventions to be more accessible, user-friendly, and integrated into care practices.

Long-term recommendations (3 years and beyond)

To enhance long-term healthcare outcomes, especially for people living with dementia and other needs, we must focus on systemic changes that promote flexibility, capacity building and accountability. A shift towards shared responsibility ensures all stakeholders are committed to better outcomes, and systematically capturing and sharing insights will shape best practices across the sector. These recommendations pave the way for a more responsive and sustainable older people with other needs care ecosystem.

Establish robust feedback loops through the Learning Community

This programme's Learning Community can serve as an incubator for innovation, allowing stakeholders to share experiences, test new approaches, and refine strategies based on real-world feedback. By fostering this community, there is an opportunity for a dynamic learning environment where best practices are identified, shared, and scaled, leading to continuous improvement and evolution of care models.

Capture and share learnings to shape sector practices

Capturing lessons learned from the variety of interventions for older people with multiple needs and people living with dementia is crucial for sector-wide improvement, particularly as the needs of this cohort will continue to evolve. By establishing robust mechanisms for documenting and sharing these learnings, services can contribute to a collective knowledge base that shapes future practices, informs policy, and drives sector-wide change.

Shape sector practices on technology use

Evidence indicates that technology will be an increasingly integral tool used in the care pathway for older people with multiple needs and people living with dementia. There is therefore a need to push for a shift in the sector-wide practices, such as by offering more consistent guidance on implementing this technology and providing ongoing support. This means that the experiences of older people with multiple needs and their unpaid carers are more likely to be equitable and for the technology to be used to its full potential. The Technology for an Ageing Population Panel for Innovation has recommended a set of principles to be applied to services development and delivery and we recommend that these are applied to future service development.

Appendix 1:
Resources and tools

A.1 Example Outcomes Pathway

	BARRIERS	OPPORTUNITIES
1 Identifying outcomes	Data that prioritises activity measures limits identifying outcome measures Requires knowledge of outcomes possible to collect	Analyse system stressors across health and social care services to come to an agreed understanding of the poor outcomes that would be experienced if the service was not in place Ensure outcomes can be collected at multiple intervals to understand if there has been an impact. This could be a baseline agreed at the start from central data or it could be individual baselines
2 Collecting outcomes	Conflicting and multiple asks for metrics creates a data burden on frontline services Duplicate and overlapping systems leads to asking the same, potentially sensitive, questions of service users multiple times	Map the data pathway of a user to understand where data systems could be linked to streamline data collection processes Build collection pathways that automatically aggregate data to enable a service perspective on outcomes for staff to view, without significant resource spent on cleaning and extraction
3 Analysing outcomes	Limited resource and/or capabilities to analyse data Data prioritises individual data stories; limiting aggregate analysis	Sustained investment into data analysis capabilities can streamline processes in the long-term and enable peer-to-peer knowledge sharing on data analyses Exploring the role of advanced analytics platforms and tools, such as machine learning algorithms, may accelerate data analysis
4 Displaying outcomes	Limited resource to create insightful visuals due to high burden collecting, cleaning and analysing Focus on snapshots of a patient's journeys rather than change over time	Develop interactive dashboards that display real-time data on patient metrics, resource use, and key performance indicators Visualise the patient journey through the healthcare system, from initial consultation to treatment and follow-up
5 Sharing outcomes	Data siloes prevent insight beyond organisation parameters Anxiety regarding data sharing restricts strategic learning across organisations nationally	Embedding clarity within the processes of data sharing can facilitate appropriate outcomes being shared and learnt from Learning communities represent routes to sharing outcomes that have cross-cutting relevance

A.2 Example Outcomes Framework

Outcome	Measure	Key learnings on outcome measure	Recommendations
Improving outcomes for unpaid carers	Zarit Burden Scale	• There are three scoring options of the scale (22, 12 and 4 item) which enables flexibility in data collection. We recommend the 4 item scale for initial implementation to reduce data collection burden • The higher the Zarit Burden score, the greater 'burden' there is. The lower the score, the less 'burden' there is. See the Leicestershire County Council Case Study for evidence of impact and data display examples.	• Build the Zarit Burden scale into BAU services to evidence the wider impact of a service on unpaid carer wellbeing. • Point reduction in 'burden' could be used as a proxy measure for carer wellbeing. This could have a financial value attached to it and be repaid by a statutory partner who sees value in reduced carer burden on the health and social care system. • See the Reconnections loneliness social outcomes partnership for a similar example of a 'scale-based' repayment model.
Improving wellbeing for people living with dementia	Self-reported health measures	• Self-reported health measures lack rigour due to subjectivity, and in a cohort of people living with dementia and memory loss, there is a high risk of inaccuracy. • Frontline providers frequently experience discomfort asking self-reported questions as part of the feedback process which can lead to low completion rates.	• Explore collecting quantitative data on health care usage from existing datasets rather than self-reported data. • As per the **report recommendations**, working with system-wide partners to simplify data sharing protocols and secure access to person-centered data that can track health and social care interactions and utility is crucial in demonstrating outcomes and building a robust evidence base.
Improving wellbeing for people living with dementia	EQ-5D-5L	• EQ-5D-5L survey evaluates five dimensions of health: *mobility, self-care, usual activities, pain/discomfort, and anxiety/depression.* • It is staff and service user friendly and generates data on physical and emotional wellbeing. • It is easily analysed at aggregate level and establishes a clear baseline. See The Rainbow Foundation case study.	• Depending on the service/intervention, we recommend embedding this measurement tool as part of business-as-usual services • Use the survey to establish baseline data, essential for measuring impact and outcomes • Use the survey to facilitate meaningful discussions between service users and staff • Work with statutory partners to test whether improvements in EQ-5D-5L scores could be used as a repayable outcomes metric

A.3 Leicestershire County Council Outcomes Framework

🟩 Easy 🟨 Fair 🟥 Difficult

Outcome					Metrics & Measurement		
Outcome		Rationale / Aim	Relevant Technology	Metrics	Potential Measurement Approaches	Measurement difficulty	Attributability
Early Intervention-Specific	**1. Adoption and adherence**	To understand whether implementing the technology early on means there is better adoption amongs people living with Dementia and their carers	N/A – based on personalised suite of tech matched to individual's needs	Attitude towards the technology	- Technology adoption scale	🟨	🟩
					- User engagement (e.g. surveys/ interviews) to understand attitudes towards technology	🟨	🟩
				Technology usage	- Utility/usage data from technology	🟩	🟩
	2. Carer burden	To understand whether implementing the technology early on reduces carer burden/ anxiety amongst carers (e.g. around wandering), ultimately offsetting or delaying carer breakdown	Falls technology, GPS mobile devices with SOS buttons, reminders	Carer stress/anxiety	- User engagement (e.g. surveys/ interview) surveys to understand how many times the person they are caring for went wondering (as proxy for policy call-out) and to what extent having the technology reduces stress in caring for the person with Dementia	🟨	🟨
					- Berlin Inventory of Caregiver Stress—Dementia	🟥	🟨
				Carer burden	- Burden Scale for Family Caregivers	🟨	🟨
					- Modified Carer Strain Index	🟨	🟨
					- Zarit Burden Scale	🟨	🟨
	3. Primary and secondary care	To understand whether implementing technology early on reduces reduce lower-grade illness or discomfort, and therefore GP/primary care appointments and prescriptions (as a proxy for something more serious/a hospital admission down the line)	Falls technology, fridge sensors, Alexa reminders	GP/primary care attendances	- Self-reported GP attendances and prescriptions	🟩	🟥 Depends on technology and reason for GP/primary care attendance
				Secondary care	- Self-reported secondary care attendances (e.g. unplanned hospital admissions)	🟩	🟨
				Adherance to technology advice (as proxy for improved health)	- Monitoring centre outputs	🟩	🟩
					- User engagement (e.g. surveys/ interview) surveys with people with Dementia and their carers to understand whether they acted upon advice given by the technology	🟨	🟩
					- Rockwood Frailty Score	🟨	🟩

A.3 Leicestershire County Council Outcomes Framework

🟩 Easy 🟨 Fair 🟥 Difficult

Outcome					Metrics & Measurement		
	Outcome	**Rationale / Aim**	**Relevant Technology**	**Metrics**	**Potential Measurement Approaches**	**Measurement difficulty**	**Attributability**
Broader pilot outcome (aligned with Care Act)	**4. Staying safe and maximising independence**	To understand whether and how the technology allows the person with Dementia to stay safe and independent	Door sensors, hydration/ food reminders, temperature sensors, remote monitoring, bogus caller devices	Maintenance of independence	- User engagement (e.g. surveys/ interview) with people with Dementia and their carers to understand feelings of independence	🟨	🟨 Depends on usage and type of technology
					- Quality of Life measure: C-DEMQOL + DEMQOL-Proxy	🟨	🟥 Can be impacted by mood on the day of the questionnaire. Deterioration will occur regardless of intervention - difficult to isolate impact of deterioration from impact of intervention. Other external factors such as lifestyle may influence QoL.
					- Quality of Life measure: I statements	🟨	🟥 As above
					- Quality of Life measure: QOL-AD scale (1-4)	🟩	🟥 As above
					- Quality of Life measure: QALYS	🟥	🟥 As above
					- Bristol Activities of Daily Living (BADLS)	🟨	🟥 As above
	5. Choice, dignity and control	To understand whether the technology helps a person living with Dementia to feel more in control of their environment	Alexa, care pager, Enuresis sensors	Feeling of control and choice	- User engagement (e.g. surveys/ interview) with people with Dementia and their carers to understand feelings of choice, dignity and control	🟨	🟨 Depends on usage and type of technology
					- Quality of Life measure: C-DEMQOL + DEMQOL-Proxy	🟨	🟥 Can be impacted by mood on the day of the questionnaire. Deterioration will occur regardless of intervention - difficult to isolate impact of deterioration from impact of intervention. Other external factors such as lifestyle may influence QoL.
					- Quality of Life measure: I statements	🟨	🟥 As above
					- Quality of Life measure: QOL-AD scale (1-4)	🟩	🟥 As above
					- Quality of Life measure: QALYS	🟥	🟥 As above

A.3 Leicestershire County Council Outcomes Framework

🟩 Easy 🟨 Fair 🟥 Difficult

Outcome					Metrics & Measurement		
	Outcome	Rationale / Aim	Relevant Technology	Metrics	Potential Measurement Approaches	Measurement difficulty	Attributability
Broader pilot outcome (aligned with Care Act)	**6. Physical and emotional well-being**	To understand whether the technology supports a person living with Dementia to establish routines and plan appointments	Reminders, medication dispensers, self-management tools	Support for better planning	- Utility/usage data from technology	🟩	🟩
					- User engagement (e.g. surveys/ interview) with people with Dementia and their carers to understand whether/ how the technology has supported better routines and planning	🟨	🟨
				Adherance to technology advice	- Monitoring centre outputs	🟩	🟩
					- User engagement (e.g. surveys/ interview) with people with Dementia and their carers to understand whether they acted upon advice given by the technology	🟨	🟨 Depends on usage and type of technology
					- Quality of Life measure: C-DEMQOL + DEMQOL-Proxy	🟨	🟥 Can be impacted by mood on the day of the questionnaire. Deterioration will occur regardless of intervention - difficult to isolate impact of deterioration from impact of intervention. Other external factors such as lifestyle may influence QoL.
					- Quality of Life measure: I statements	🟨	🟥 As above
					- Quality of Life measure: QOL-AD scale (1-4)	🟩	🟥 As above
					- Quality of Life measure: QALYS	🟥	🟥 As above
					- Rockwood Frailty Score	🟨	🟩

A.3 Leicestershire County Council Outcomes Framework

🟩 Easy	🟨 Fair	🟥 Difficult

Outcome					Metrics & Measurement		
Outcome		Rationale / Aim	Relevant Technology	Metrics	Potential Measurement Approaches	Measurement difficulty	Attributability
Broader pilot outcome (aligned with Care Act)	**7. Social inclusion**	To understand whether the technology supports a person living with Dementia to maintain and develop relationships	GPS devices, various apps, self-management tools	Feeling of social inclusion/social support	- User engagement (e.g. surveys/ interview) with people with Dementia to understand feelings of social inclusion before/during/after using the technology	🟨	🟨 Depends on type of technology
					- UCLA loneliness scale	🟨	🟥
					- Quality of Life measure: C-DEMQOL + DEMQOL-Proxy	🟨	🟥 Can be impacted by mood on the day of the questionnaire. Deterioration will occur regardless of intervention - difficult to isolate impact of deterioration from impact of intervention. Other external factors such as lifestyle may influence QoL.
					- Quality of Life measure: I statements	🟨	🟥 As above
					- Quality of Life measure: QOL-AD scale (1-4)	🟩	🟥 As above
					- Quality of Life measure: QALYS	🟥	🟥 As above
	8. Economic well-being	To understand whether the technology supports a person living with Dementia to access any opportunities they'd like to (e.g. training, volunteering) and that they will receive help when they need it/ before reaching crisis	GPS devices, various apps, self-management tools	Access to opportunities	- Data on attendance at activities	🟩	🟩
					- Usage of apps/technology	🟩	🟩
					- User engagement (e.g. surveys/ interview) with people with Dementia to understand access to opportunities / whether needs are being met	🟨	🟨
					- Quality of Life measure: C-DEMQOL + DEMQOL-Proxy	🟨	🟥 Can be impacted by mood on the day of the questionnaire. Deterioration will occur regardless of intervention - difficult to isolate impact of deterioration from impact of intervention. Other external factors such as lifestyle may influence QoL.
					- Quality of Life measure: I statements	🟨	🟥 As above
					- Quality of Life measure: QOL-AD scale (1-4)	🟩	🟥 As above
					- Quality of Life measure: QALYS	🟥	🟥 As above
				Getting help before reaching crisis point	- Self-reported data on GP appointments/ primary care attendance/prescriptions	🟩	🟩
					- User engagement (e.g. surveys/ interview)	🟨	🟩

A.3 Leicestershire County Council Outcomes Framework

🟩 Easy 🟨 Fair 🟥 Difficult

Outcome				Metrics & Measurement		
Outcome	**Rationale / Aim**	**Relevant Technology**	**Metrics**	**Potential Measurement Approaches**	**Measurement difficulty**	**Attributability**
Broader pilot outcome (aligned with Care Act) **9. Positive behaviour management**	To understand whether the technology supports a person living with Dementia to manage emotions and behaviours	Alexa	Improved stress/ emotions management	- User engagement (e.g. surveys/ interview) with people with Dementia to understand emotions/behaviour management	🟥	🟨 Depends on usage and type of technology
				- Quality of Life measure: C-DEMQOL + DEMQOL-Proxy	🟨	🟥 Can be impacted by mood on the day of the questionnaire. Deterioration will occur regardless of intervention - difficult to isolate impact of deterioration from impact of intervention. Other external factors such as lifestyle may influence QoL.
				- Quality of Life measure: I statements	🟨	🟥 As above
				- Quality of Life measure: QOL-AD scale (1-4)	🟩	🟥 As above
				- Quality of Life measure: QALYS	🟥	🟥 As above

Appendix 2: Case studies

Dementia Support Sage House Case Study

Background

Dementia Support is a charity that has been delivering integrated dementia services from Sage House Tangmere, just outside Chichester in West Sussex, for over six years. Sage House is a community hub where local dementia support services are located together under one roof to provide the support, information, advice and activities for people living with dementia and their unpaid carers.

A recent academic evaluation showed that access to Sage House could offer measurable benefits for people living with dementia and their unpaid carers; those with access to Sage House Tangmere had better Quality of Life, Wellbeing, and Life Satisfaction compared to a control group. The study found that people living with dementia who accessed Sage House Tangmere cost the NHS and Adult Social Care £430.50 less over a three-month period compared to those without access.[1]

---

[1] Rachel King and Antonina Pereira, "The Evaluation of the Sage House Model" (University of Chichester, May 2024) Dementia Support | Sage House | Academic Evaluation.

Why did we partner?

The hypothesis we tested with Sage House focused on who is most likely to receive good care:

Hypothesis – Specifically targeting underserved groups in a tailored way might offer an increase in the quality of care being provided in a more cost-effective way than via "one-size fits all"

Whilst we have reflected on who accesses and receives good care across all the partnerships, we wanted a specific hypothesis to understand how current services can increase their reach; testing what works (and doesn't work) in the process of accessing underserved groups.

The Dementia Support Sage House pre-diagnosis sessions in Crawley and Chichester

Sage House recognised that people living with dementia and their unpaid carers would be adversely affected by the temporary closure of the West Sussex NHS Dementia Assessment Service between January and March 2024; they anticipated that at least 1,000 people in the county were likely to be affected by a delayed diagnosis.

To mitigate this, Sage House used their existing support service – the Wayfinding service – to develop specific pre-diagnosis sessions in two locations (Crawley and Chichester) in early 2024. The pre-diagnosis session aimed to provide advice, information and support for those whose diagnosis was delayed by the closure and who would typically access Sage House and the Wayfinder service post-diagnosis.

The Wayfinding service is at the core of Sage House's support offer. It is a "constant companion", offering personalised one-to-one support and advice for people living with dementia and their unpaid carers across the whole of the dementia journey, from pre-diagnosis to end of life. The aim is to help individuals live well with dementia, mitigating anxiety and stress that often follow diagnosis – both for people living with dementia and their unpaid carers.

Chichester pre-diagnosis sessions

Structure and Objectives

The pre-diagnosis sessions were designed to be inclusive, involving people living with dementia and their unpaid carers. This setup was aimed at fostering a shared understanding and collective support amongst attendees. Recognising the needs for a more flexible approach, Sage House Tangmere provided sessions outside of their mainstream schedule to accommodate those who might find weekday sessions challenging to attend.

Initial Aims and Expectations

The primary aim of these sessions was to reassure customers affected by the closure of the diagnosis services. Key objectives included:

- Ensuring individuals could access services without a formal diagnosis.
- Reducing anxiety while waiting for a diagnosis, as anxiety can exacerbate dementia symptoms.[2]
- Dispelling myths around dementia diagnosis, emphasising that lack of a diagnosis only limits access to medication but not to other forms of support.
- Providing a "golden opportunity" to discuss managing anxiety pre-diagnosis and reducing reliance on medication, which is not suitable for all people living with dementia.

What did we learn in Chichester?

Five pre-diagnosis sessions were held in Chichester – four in person and one online. They were attended by a total of 21 people – seven people either living with dementia or who were symptomatic, and 14 unpaid carers.

The in-person sessions provided significant benefits; the mixed-group format, combining people living with dementia and unpaid carers, was particularly valuable. It promoted open discussion where people living with dementia could express their experiences and feelings, often for the first time in front of their unpaid carers. This environment also enabled unpaid carers to share their emotional challenges and the impact of their caregiving roles, fostering a deeper mutual understanding.

---

[2] "Anxiety and Dementia | Alzheimer's Society," accessed August 7, 2024, https://www.alzheimers.org.uk/about-dementia/symptoms-and-diagnosis/anxiety-dementia.

Uptake on the Zoom sessions was low, potentially due to insufficient marketing. However, the small, face-to-face groups were highly effective, allowing for meaningful interactions and personalised support. Participants appreciated the opportunity to manage their anxiety through engagement in activities like exercise, social groups, and mindfulness practices. Although anxiety slightly increased after the session, both people living with dementia and their unpaid carers left the sessions feeling more optimistic about the future and with more knowledge of dementia than they had before the session.

FIGURE 1: EXPERIENCE OF THE SESSION SURVEY DATA

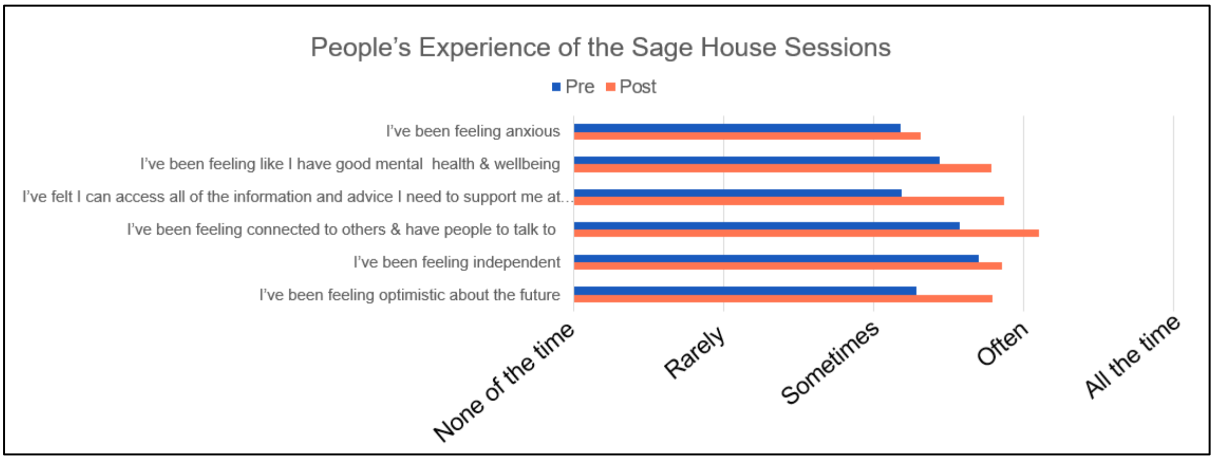
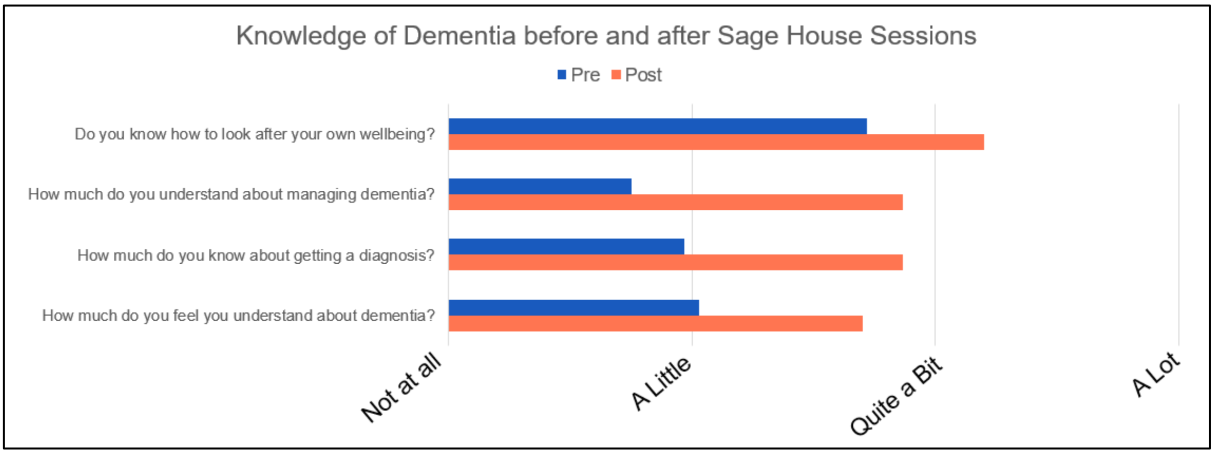


FIGURE 2: KNOWLEDGE OF DEMENTIA SURVEY DATA



Initial Recommendations

Overall, the staff felt that the sessions were a success with the importance of small group sizes (maximum 12 people) vital to ensure that each participant received adequate attention and support. If they were to do it again, they recommended enhanced marketing and awareness raising, especially for virtual sessions, to increase participation from those living farther away or with mobility issues. Additionally, holding some face-to-face sessions on weekdays could offer more flexibility.

The evaluation forms were simplified, and their purpose clearly explained up front to participants to encourage more comprehensive feedback. Targeting key employers in the area for outreach could also increase awareness and participation as well as expanding the sessions to non-dementia-specific venues to reach a broader audience.

It was recognised that wider marketing of the sessions was needed to successfully engage with communities who would not usually access Sage House Tangmere. In-depth mapping of community groups (both formal and informal) is critical to expanding a service beyond initial horizons.

All these reflections helped inform the proactive Crawley sessions.

Crawley pre-diagnosis sessions

What did we do in Crawley?

In April 2024, Sage House Tangmere expanded its pre-dementia diagnosis sessions to Crawley, leveraging insights from their successful Chichester sessions. These sessions were designed to test new support opportunities for Dementia Support and cater to a diverse demographic that differed from Chichester.

Crawley presented an ethnic demography that Sage House Tangmere sought to engage through tailored strategies and community engagement. Sage House Tangmere also engaged a variety of groups experiencing barriers to access because of disability, other health conditions, languages spoken and read, housing type, living arrangement, cultural background, and other elements that can affect someone's ability to access or receive support.

Each session, advertised to last an hour, often extended to 1.5 hours due to participant engagement and questions. Maintaining small groups, with a maximum of 12 participants, was crucial for creating an intimate and supportive environment.

Wayfinders opened each session to provide structure, address myths, and leave participants with actionable insights. Wayfinders undertook in-depth mapping of local support groups to ensure accurate and reliable signposting for participants. Participants' feedback valued having time at the end of sessions for evaluations, and additional questions were suggested to gauge interest in different venues.

What did we learn in Crawley?

Eight pre-diagnosis sessions were held in Crawley – four in person and four online. They were attended by a total of 15 people – six people either living with dementia or who were symptomatic, and nine unpaid carers.

Sage House's Wayfinders service established satellite sessions at various locations in Crawley, including Broadfield, Crawley Museum, Ifield West, and Maidenbower. Each venue had its own logistical access issues for Wayfinders and participants. Adequate equipment and clear signage were essential in identifying suitable locations for future sessions. Pop-up banners, entrance signage, water jugs, glasses, and a monitor screen for presentations were necessary to ensure smooth operation and a welcoming atmosphere.

The online sessions were unsuccessful. Face-to-face interactions were far more effective as they provided safe, physical spaces more conducive with difficult conversations and reduced administrative burdens on unpaid carers. More time and presence in Crawley were needed to build sufficient attendance and engagement.

One significant challenge was ensuring sessions reached beyond the usual demographic. Building trust within the local population and underserved groups was critical. If the dementia support needs of underserved communities are not met, it leads to negative financial, social, and health impacts.[3]

Effectively reaching out to underserved groups requires extra resource (both time and effort), especially in a new area where there was initially a territorial feel under fear of competition for resources with other service providers. The actual face to face sessions with people living with dementia and unpaid carers needed to focus on smoothing the transition, offering reassurance and support during an unsettling time.

Marketing efforts needed to be more targeted, specifically aimed at individuals who are pre-diagnosis; on a waiting list; or considering a diagnosis. The online booking form required refinement to accurately capture diagnostic stages and participant details. Reception staff needed briefings to manage specific inquiries effectively. Despite these efforts, it was evident that sessions attracted the 'usual suspects' – individuals who typically engage with these 'types' of outreach initiatives.

---

[3] Anya Ahmed, Lorna Chesterton, and Matthew J. Ford, "Towards Inclusiveness in Dementia Services for Black and Minoritised Communities in the UK," Working with Older People, January 25, 2024, https://doi.org/10.1108/WWOP-03-2023-0007 https://www.emerald.com/insight/content/doi/10.1108/WWOP-03-2023-0007/full/html .

What do we recommend for similar services?

There are two key reflections that have implications for all services that want to increase their offer to more underserved groups:

1. Importance of Community Engagement and Trust-Building

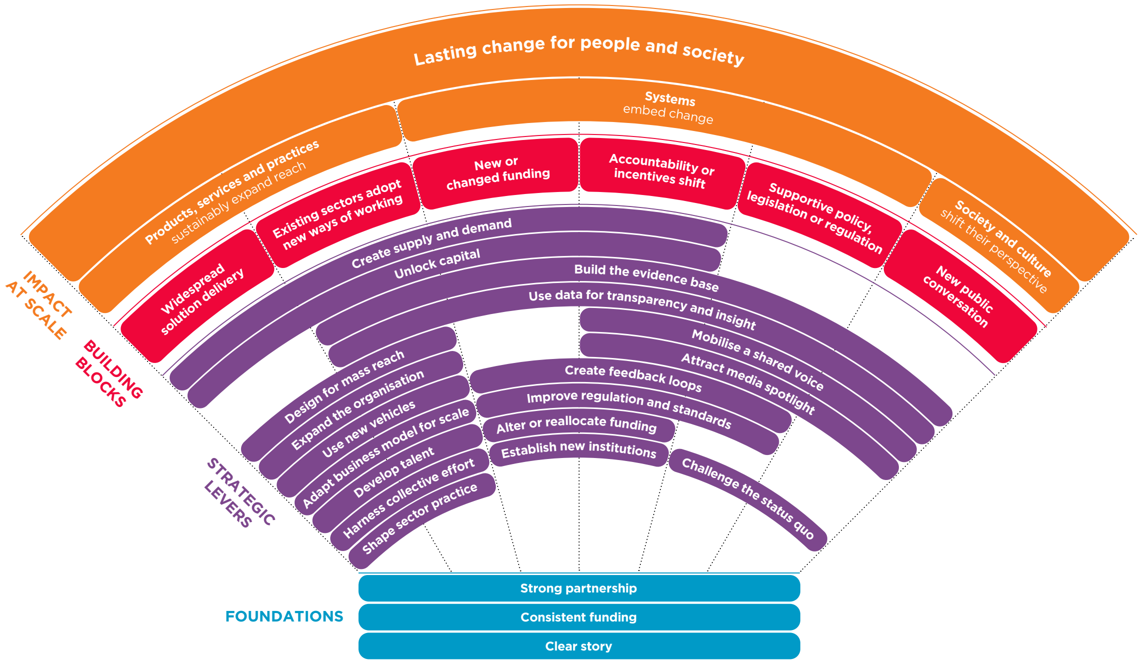
Building trust within local populations, particularly among underserved groups, is critical for the success of dementia services. The Crawley sessions revealed the need for extra time and effort to gain the trust of local communities. Targeted marketing, awareness raising and community engagement strategies are essential to reach diverse groups, including LGBTQI+ communities, religious groups, and other local organisations. Investing in initiatives that focus on long-term relationship-building and trust is vital. This may involve partnering with local leaders and community groups, as well as conducting long-term outreach in non-traditional settings to increase visibility and acceptance.

2. Addressing Logistical and Structural Barriers

Practical considerations, such as venue accessibility and session timing, are vital to ensure dementia services are accessible to underserved groups. The challenges encountered in different Crawley venues, from issues with signage to the availability of facilities, highlight the need for careful logistical planning. Additionally, offering sessions outside traditional working hours and ensuring that venues are welcoming and well-equipped can help accommodate the needs of a wider audience. Investors should support the development of infrastructure that minimises access barriers, such as transportation and flexible scheduling, to make services more inclusive and user-friendly.

Scaling the Sage House Model

Dementia Support's ambition to establish another Dementia Hub in Crawley by replicating the Sage House Model needs a clear vision to ensure it is impactful and successful. Dementia Support have developed their own toolkit to help other place-based organisations to develop their own models suited to local needs. We utilised the Routes to Scale framework with Sage House to map where they need to target their own route to scale.



Unlock Capital

The Sage House model raises circa £1.7 million pounds annually in fundraising from trusts and foundations, with very little investment from the statutory sector. An evaluation of the model carried out by Chichester University's Cognitive Ageing and Dementia Laboratory over an 18-month period, found that the Sage House Model saved £1,722 per person, each year, when compared to the standard cost of care, making it 38% cheaper. The evaluation also found that:

- People living with dementia who had access to Sage House experienced significantly greater Life Satisfaction (20% higher), Wellbeing (16%) and Quality of Life (10%) than the standard care model.

- Care partners with access to Sage House demonstrated better access to information and support which led to a significantly greater Quality of Life.

The evidence base indicates that the model works, demonstrates efficiencies and improves person-centered and system outcomes however, replication and expansion into a new locality, with specific needs ,carries some risk. As such, a blended finance approach that unlocks public or charitable capital and absorbs risk, might work for this model. This could include a non-repayable, development grant that would fund a team to establish key system-wide partnerships, conduct deep place-based mapping of existing provision and gap analysis, build trust with the VCFSE sector, and set up data systems and health and social care baseline data to track impact. Repayable social investment would be made into the services offered by Sage House, with either market-rate or concessionary repayments made on a set of pre-agreed outcomes that a statutory partner would pay for.

Mobilise a Shared Voice

For the Sage House Model to succeed in Crawley, it is essential to secure buy-in from a broad spectrum of the community. This requires increasing visibility and using appropriate marketing channels to reach those who need the services most. Building trust and ensuring community awareness are pivotal in this process. Replicating the Sage House Model in Crawley involves the delicate task of building new relationships in a different community and reaching underserved groups. There is a critical question of whether Sage House Tangmere can effectively manage two hubs simultaneously without diluting their resources and focus, or if the model needs to be introduced as a separate entity and a charity in its own right.

Design for Mass Reach

The approach involves detailed planning, personalised support, and the flexibility to adapt continually. Establishing clear foundations and learning from ongoing experiences are vital to ensuring the Sage House Model's success and sustainability in Crawley. A key strategic lever is to ensure their toolkit is designed for mass reach, allowing for suitable adaptations to suit a new geographic location and increase access for underserved groups whilst remaining loyal to the core principles of service delivery of the Sage House Model.

Harness Collective Effort

The expansion is fuelled by excitement and the promise of positive change. Strong and thoughtful leadership at Dementia Support inspires confidence in the initiative. The motivation to secure funding is crucial for scaling impact, and the organisation's pioneering spirit drives them to innovate and lead in the field of dementia care. This motivation should have spillover effects in encouraging statutory, third sector and private organisations to increase their support for people living with dementia and their unpaid carers living in Crawley.

There is an acute need to address the slow diagnosis rates for dementia in Crawley, which may lead to poor outcomes for people living with dementia. This urgency underpins the belief that establishing the Sage House Model will significantly enhance support and accessibility, encapsulated in the notion of "build the hub and they will come." Dementia Support aims to navigate the complexities of the health and social care system, setting a direction that others can follow. The new hub is expected to build strong relationships and create a healthy competitive environment that complements existing services. This will help people living with dementia and their unpaid carers live and age well.

Rainbow Foundation Case Study

The Rainbow Foundation

Background

Supporting over 3,000 people annually, The Rainbow Foundation in Wrexham is an active ageing charity dedicated to enhancing the health and wellbeing of its local communities by empowering older individuals to maintain independence where possible.[4]

The Rainbow Foundation operates three care hubs in Wales (Chirk, Marchwiel and Penley) which provides access to day opportunity (sometimes referred to as day care) services, Rainbow Meals (a meals-to-you service), social prescribing activities, peer support groups, lunch clubs and community classes and transport. They also provide a domiciliary care service providing support at home to people in South Wrexham rural communities.

Within their community wellbeing team, Community Agents offer free information, support, and advice to individuals over-50 in the local communities, taking a holistic approach to a person's health. The charity also hosts an array of social and support groups at their hubs and in other local community spaces.

---

[4] 2023/24 IMPACT Report (therainbowfoundation.org.uk)

Why did we partner?

We chose to partner with The Rainbow Foundation because they:

Had an existing service with sustained connections with individuals both before and after a ‘transition moment’.

Were eager to test a new data collection method to evidence the impact of the intervention in the programme timeframe.

The hypothesis that guided this partnership was:

> Specifically focusing on ‘transition moments’, during which a person’s physical and cognitive health tends to decline and associated costs increase, might deliver value by reducing or delaying deterioration and the related costs.

Social Finance and The Rainbow Foundation jointly categorised ‘transition moments’ into specific types: falls (whether an injury occurred), hospitalisations (both planned and unplanned), physical illnesses, bereavements, and other personal events specified by the individuals.

This approach enabled the team to capture a range of experiences that might impact an individual’s life. Social Finance also defined specific ‘transition moments’ within the dementia journey, identifying diagnosis, a sense of loss, the initiation of paid care at home, hospitalisation, entry into a care home, and end-of-life scenario as examples. These categories helped structure our joint understanding but also emphasised the diverse nature of these moments

What did we do in Wrexham?

We supported the design of a new intervention to provide support to The Rainbow Foundation’s Day opportunity clients following a ‘transition moment’. This provided an optimal opportunity to test how a “transition moment” could be proactively identified if a service has pre-existing relationships with older people with other needs.

The intervention concentrated on increasing and promoting physical activity for The Rainbow Foundation’s clients. Day opportunities clients were invited to participate in the intervention and included people living with dementia and older people with other needs. 50% of the current clients have a dementia diagnosis, and several others are noted under the memory clinic or their GP as symptomatic.

Through a sub-grant from Social Finance, The Rainbow Foundation purchased a suite of physical activity monitoring equipment to support the implementation of the intervention. Willing participants were provided with a monitoring device to wear during their time at the day opportunities centre and for an additional week to set a baseline on their average daily step count.

During the intervention's time frame, clients were encouraged to join a physical activity class offered at the day opportunities centre. The aim was to enhance their wellbeing and promote sustained levels of physical activity outside the centre.

During the monitoring period, while tracking the number of steps taken by each client, staff at The Rainbow Foundation also assessed the clients' wellbeing using two standardized surveys:

1. **EuroQol-5 Dimension-5 Level (EQ-5D-5L)**

   This survey evaluates five dimensions of health: **mobility, self-care, usual activities, pain/discomfort, and anxiety/depression**. Each dimension has five levels of severity, ranging from 'no problems' to 'extreme problems'. Clients indicated their health state by selecting the most appropriate statement for each dimension, resulting in a five-digit number that describes their overall health state.

2. **EuroQol Visual Analogue Scale (EQ VAS).**[5]

   This survey captures the clients' self-rated health on a vertical visual analogue scale, with endpoints labelled 'the best health you can imagine' and 'the worst health you can imagine.' This scale provides a quantitative measure of health outcomes based on the clients' own judgements.

From a potential pool of 71 clients, 26 participated in the intervention, representing 37% of the eligible group. Staff closely monitored each participant and determined whether a 'transition moment' had occurred. When a 'transition moment' was identified, additional support was provided to the client, and the physical activity monitoring device was reissued to them during their time at the day opportunities centre. Their steps and wellbeing were recorded again to compare with their baseline measurements.

At the end of the six-week intervention, all clients had their steps and wellbeing measured once more. This final assessment allowed the team to evaluate the impact of promoting physical activity on all day opportunity clients' wellbeing, not just those who had experienced a 'transition moment'.

---

[5] EQ-5D-5LUserguide-23-07.pdf (euroqol.org)

What did we learn in Wrexham?

The intervention provided a wealth of quantitative and qualitative learnings applicable to a range of services that want to start collecting outcomes data and utilising care technology across existing provision. It is important to caveat that we received a small sample size of data, with a number of incomplete entries and had a limited timeframe of 6-weeks for data collection. This may indicate that outcomes captured as part of this analysis are not entirely representative of the wider target cohort.

Focus on independent quantitative wellbeing results to ensure a holistic understanding of need. Of the 26 client record entries relating to wellbeing, there were 18 complete entries for the EQ-5D-5L scale and 20 complete entries for the EQ-VAS scale which informed the figures below. Figures 1 and 2 represent bar graphs depicting the change in EQ-5D-5L and EQ-VAS scores over the period of 6 weeks for each client record (ie the difference between the end total score and baseline total score)

Figure 1

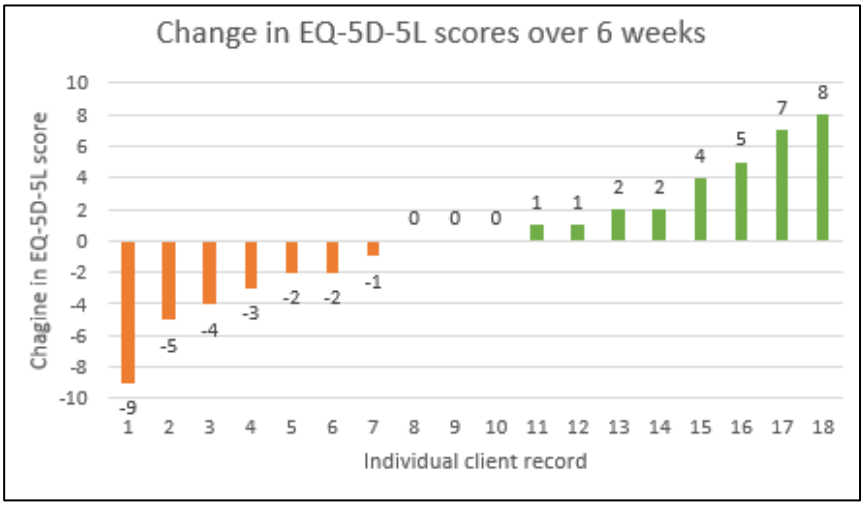
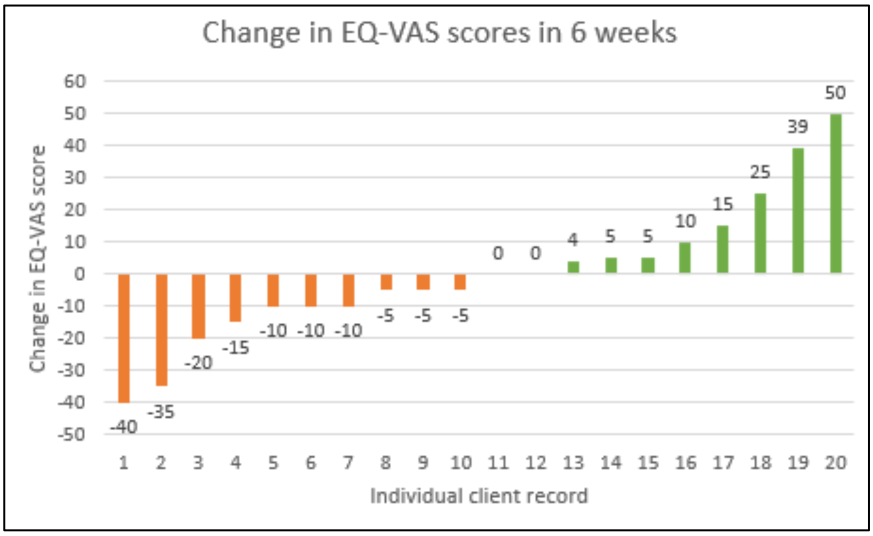


Figure 2



The overall average change in EQ-5D-5L scores across the whole cohort is a positive increase of 0.22 whereas the overall average change in EQ-VAS scores is a negative decline of 0.10. Given that the aggregate change in wellbeing score across both categories is not a whole number, these measures may provide more useful insights at the individual client level rather than an aggregate level.

Fiigures 3 and 4 represent double bar graphs comparing the baseline and end EQ-5D-5L and EQ-VAS scores for each client (corresponding to the individual client record order in Figures 1 and 2 respectively).

Figure 3

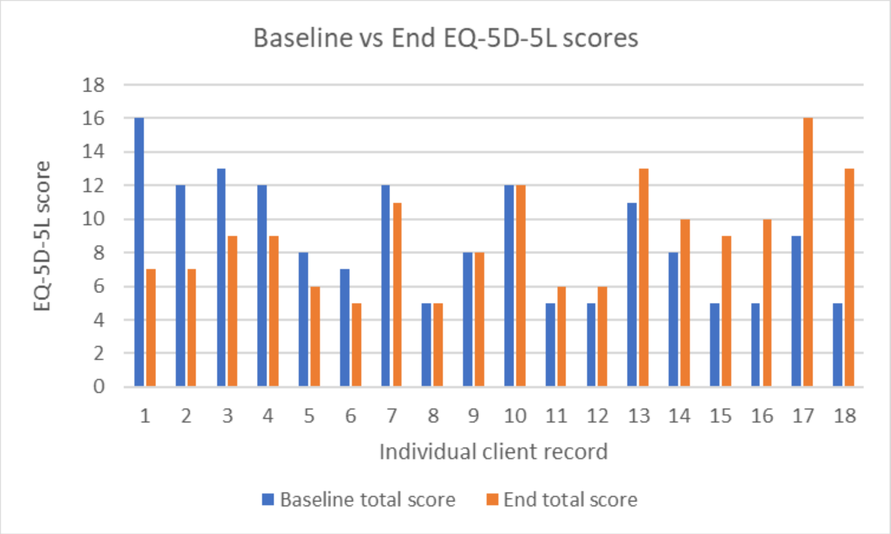
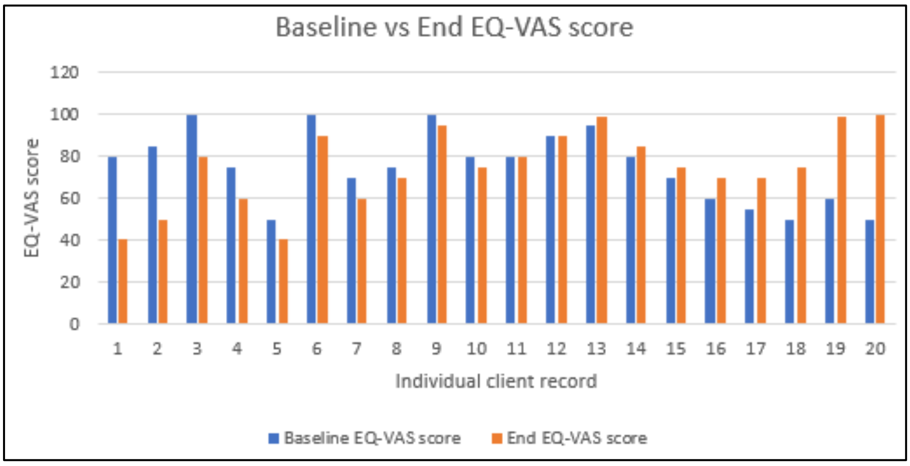


Figure 4



Figures 5 and 6 are pie-charts outlining the aggregate outcomes across the client cohort for EQ-5D-5L and EQ-VAS scores respectively.

Figure 5

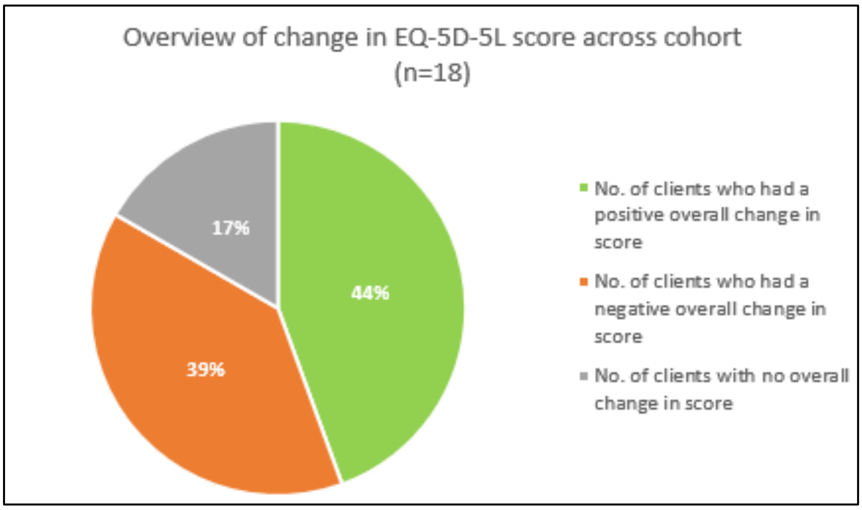
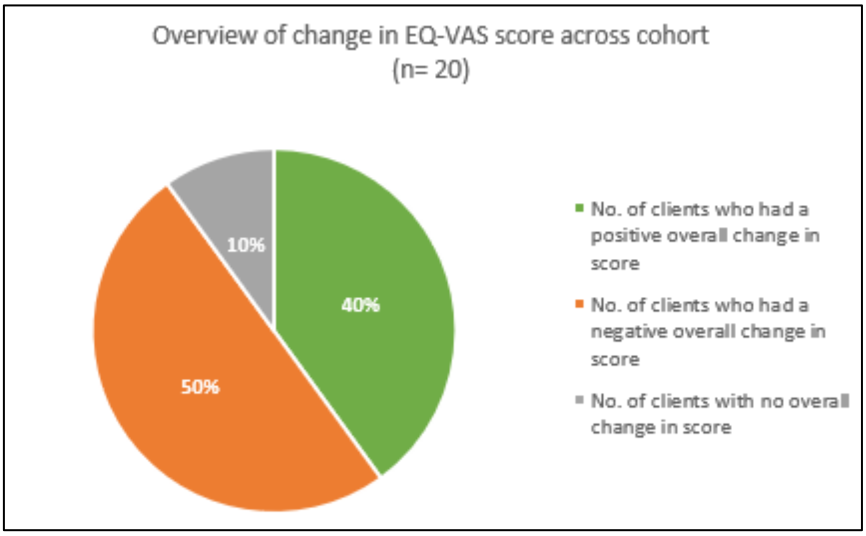


Figure 6



Four client records were flagged as experiencing a ‘transition moment’ during the six-weeks, and three of these did not record any post transition moment data which is discussed below. Two of the clients experienced a fall, and two had transition moments described as ‘other’ which led to the wider learnings to define transition moments.

What did we learn?

1. The type and severity of ‘transition moments’ vary for the client and their unpaid carer.

The Rainbow Foundation needed to support the unpaid carer as much as the client to maintain and / or prevent further escalation. See example below:

An 98-year-old woman who, after being admitted to the hospital, was keen to stay at home but her son was keen to place her in a care home. The Rainbow Foundation helped manage the anxieties and wishes of both the unpaid carer and the day opportunity client to find the most suitable outcome after the initial ‘transition moment’ into hospital.

This led to supporting the woman to remain active and avoid entering a care home and provide fair and objective reassurance to the unpaid carer to ensure that home was still appropriate for the individual.

2. A change in care routine stood out as an important transition moment; again for both clients and unpaid carers.

A couple, both living with dementia, received additional domiciliary care support which was well-received by one but not both people in the household. The project viewed the implementation of domiciliary care as a ‘transition moment’ for both clients. The community social prescribing practitioner provided support to help them consider their needs now and into the future.

The case above illustrates the complexity of managing care for multiple individuals within the same household, especially when both are experiencing cognitive decline. The need for consistent and appropriate support is crucial, as any changes in care routines can impact the household’s emotional and physical stability.

3. A ‘transition moment’ needs a broad definition to ensure that personalised support for an individual is impactful.

There was an initial assumption that ‘transition moments’ might be more medical in nature, yet the reality proved to be more nuanced and personal. The social and inter-personal dimensions of someone’s life are correlated with decline in a far more tangible way than initially anticipated.

Many of The Rainbow Foundation's clients were reluctant to share their 'transition moments', preferring to keep that information private as a mark of individual pride, worried that they if they voice their concerns, they will materialise. This reticence highlighted that these moments are frequently linked to wellbeing and personal circumstances rather than health issues alone.

4. Importance of balancing physical and mental health support in an intervention.

One of the main successes of the intervention was the integrated and holistic approach to client care, with a balanced focus on physical and mental wellbeing across data capture and support. See the example below:

> A programme client experienced several 'transition moments'. After experiencing a head injury but not seeking hospital treatment, she had several falls and suffered from dizziness which led her family to suggest she move into a care home. She initially took part in step count, but after a transition moment she was very anxious, and The Rainbow Foundation felt that re-issuing the pedometer could compound this anxiety. She was referred to social prescribers within The Rainbow Foundation, who specialised in mental health interventions, and received home visits and one-to-one sessions aimed at supporting positive behaviour change and improving mobility.

This case highlights the challenge of balancing physical and mental health support, especially when mobility issues are compounded by emotional distress. The technology itself might have created more distress for the individual rather than act as a supportive measure but the wider, integrated support offered by The Rainbow Foundation helped improve outcomes for this individual.

5. The introduction of care technology needs supportive infrastructure and training to ensure it is smoothly adopted and used

We intended this intervention to run for three months but due to complications with purchasing the correct monitoring devices and data sharing, the intervention was shortened to six weeks.

Establishing an intervention that relies on technology requires a strong knowledge infrastructure to allow for successful roll out. The Rainbow Foundation had a deep and intimate knowledge of their clients which was vital to establishing trust, but did not have the in-house expertise to understand what monitoring equipment would be suitable for their clients straight away. This had three effects:

- Accurate data could not be recorded on people's activity affecting the ability to measure the intervention's impact. Of the 25 entries where some pedometer data was collected, only 14 were suitable for analysis due to either incomplete data points at either baseline or end, or anomalies in recording the data on the devices.

Figure 7

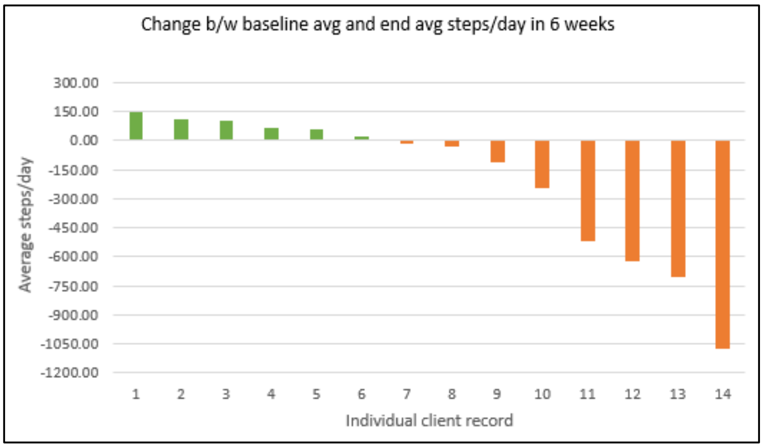


Figure 7 is a bar chart depicting overall change in average steps a day from two collection periods separated by six weeks for each individual client record.

- The small sample size of data shown directly above in the pedometer analysis (and also in the wellbeing analysis mentioned previously) has limited the quantitative learnings that can be applied to the whole service cohort.
- As new equipment was required to be purchased after the start of the intervention, the full roll out was delayed. This had an effect on the ability to collect data but did not fully negate the intentions of the intervention which was to promote physical activity.
- Equipment was not always suitable for the clients. Watches did not work for people who use walking frames, or they were taken off which led to loss of accurate data collection. The Rainbow Foundation did secure additional monitoring equipment that could be fitted around someone's neck or belt, but these had other issues. As they were removable, some clients forgot to put them back on, and in some cases, devices caused distress to unpaid carers who did not know why their loved one had wearable technology. This caused confusion for people living with dementia and their unpaid carers, which in turn led to a loss of trust in the intervention.
- Need to support unpaid carers so they are aware of support available for their loved one and the potential implications: the intervention must not indirectly affect unpaid carers' wellbeing. A crucial element of success in interventions for people living with dementia and their unpaid carers is gaining and maintaining trust. Several family carers declined the intervention either at the start or the second time that the care technology would be issued to understand the final impact as they didn't want to cause more confusion to their family member.

Photo: Gareth Iwan Jones

Whilst the delays had implications on the validity and reliability of our quantitative results as well as the conclusions we could draw from them, the intervention and findings were a success, and they are likely to have lasting positive impact for The Rainbow Foundation and their clients.

What do we recommend for similar services?

1. Incorporate care technology (where relevant) and wellbeing data collection into existing services

Rather than running a stand-alone service, we recommend introducing the pedometer and wellbeing check when people are referred into the service as part of a business-as-usual approach to initial assessment. We have encouraged The Rainbow Foundation to ensure the kit and equipment acquired during the programme is used in future projects. The team reflected that using the technology and collecting the survey data required training and information sessions across the frontline team in how to:

- Use the equipment with clients
- Introduce the technology and survey to clients and unpaid carers
- Synthesis and analyse data from both the care technology and wellbeing

Secondly, the wellbeing and care technology data can help demonstrate impact and outcomes evidencing the ongoing need for the services that The Rainbow Foundation delivers. As part of our role, Social Finance provided The Rainbow Foundation with a data sheet that automatically analyses data inputted to understand the impact of the care technology and wellbeing data on individuals' health and wellbeing. This tool was developed to help bolster data infrastructure within the organisation and reduce data burden for ongoing analysis. Both can be used to onboard new clients and provide staff with a baseline understanding of clients' physical fitness and wellbeing.

The Rainbow Foundation is planning to incorporate the EQ-5D-5L questionnaires as part of quarterly home care reviews to monitor wellbeing and ensure that there is holistic support available if there are a change in scores.

2. Prioritise collecting wellbeing data for unpaid carers

The key learnings highlighted the importance of the unpaid carer before, during and after 'transition moments' and that support offered is often difficult to attribute to one person in a household. Collecting quantitative data on the wellbeing of an older person living with dementia can be challenging due to the symptoms of cognitive decline as well as changes to mood, personality and behaviour when collecting subjective data.

The conversations and surveys are still valuable to ensure a service is personalised but, by including unpaid carers, The Rainbow Foundation can strengthen its narrative on broadening access to support when advocating to local or national commissioners.

This approach supports the assumption and growing evidence, that maintaining good wellbeing for unpaid carers can delay or avoid the need for care escalation and unplanned hospital admissions for those they care for.

3. Ensure holistic support around a 'transition moment' is both physical and mental

The Community Social Prescribing model in The Rainbow Foundation was vital to the success of the intervention with several clients. While physical activity can potentially slow cognitive decline in older adults, especially those living with dementia,[6] it may not always be appropriate to encourage increased physical activity immediately after a 'transition moment'. The Community Social Prescribing model, where practitioners visit clients in their homes and build trust to help them regain their confidence, serves as an excellent example of how to provide appropriate support at a critical time.

---

[6] Helena J. M. van Alphen, Tibor Hortobágyi, and Marieke J. G. van Heuvelen, "Barriers, Motivators, and Facilitators of Physical Activity in Dementia Patients: A Systematic Review," Archives of Gerontology and Geriatrics 66 (September 1, 2016): 109–18, https://doi.org/10.1016/j.archger.2016.05.008.

Scaling the recommendations from Rainbow Foundation

Whilst we wouldn’t recommend social investment for the pedometer intervention in isolation, learnings indicate that The Rainbow Foundation’s integrated range of services are a highly effective model of care and could be invested in as a holistic package of support that improves at home, ‘transition moment’ and day centre forms of care and support. Our recommendations below use the Routes to Scale framework to highlight areas that could support the growth of the overall model.

Building the Evidence Base

The intervention demonstrated potential for building a robust evidence base by starting to collect rich data, via the EQ-5D-5L wellbeing score. We recommend embedding this measurement tool as part of business-as-usual services to build rich, qualitative and quantitative data that demonstrates impact of the The Rainbow Foundation’s range of services to commissioners and funders.

Create Supply and Demand and Unlock Capital

This strategic lever focuses on fostering supply, demand and making the business case for the provision of quality services/products that people need. To create a demand for this service and enable scale and expansion, we would recommend grant funding to fund the team to build a compelling business case and continue the generation of robust data collection and analysis that we co-designed during the partnership.

Following this ‘development’ phase of work, The Rainbow Foundation’s holistic offer could unlock capital via a blended finance approach. This is particularly useful when seeking to develop a programme that intersects with multiple parts of the health and social care ecosystem.

Non-repayable grant funding could be used to increase and bolster data infrastructure, build system-wide outcomes frameworks with the statutory sector and conduct mapping and gap analysis if scaling into a new locality.

Repayable social investment would be made into The Rainbow Foundation services (social prescribing, home support etc), with either market-rate or concessionary repayments made on a set of pre-agreed outcomes that a statutory partner would pay for, which could in this case, could include reduced use of primary care (GP visits), reduction in avoidable A&E attendances (through falls for example) – outcomes that a system values and would pay for.

Marie Curie Dementia Care and Respite Service Case Study

Background

The Marie Curie Dementia Care and Respite Service (launched October 2022) covers the footprint of Swansea and Neath Port Talbot local authorities and was designed to provide additional care and respite support for people living with late stages of dementia and estimated to be in their last year of life. It aims to help people remain at home, and to provide support for their unpaid carers to reduce or prevent an escalation of need and crisis leading to hospital or care home admission. Funding primarily came from the West Glamorgan Regional Partnership Board (with additional funding from Marie Curie) which meant that the service needed to align with the objectives of the Welsh Government's Regional Integration Fund.

The service works as follows:

- A Marie Curie **registered nurse** undertakes a needs assessment for both care and respite and ensures that there is a plan in place. They also signpost to other services available in the area. Throughout the period of care, the nurse is there to listen to any concerns and will conduct a review every 12 weeks.
- A team of **healthcare assistants** provide short periods of personal and emotional care over an agreed timeframe. They can help with things like washing, dressing, pressure area care, oral care, preparing snacks and drinks. Care is organised in blocks of 12 weeks and is available Monday–Friday 08.00–22.00. The standard visit lasts three hours, and the unpaid carer is able to use this respite time as they wish and need. Emergency and ad hoc respite care is also available.
- Trained **companion volunteers** provide regular support to the person living with dementia at home and their unpaid carers. They offer companionship and emotional support, practical help with things like getting to appointments and household chores, the chance for unpaid carers to take a break and, if and when needed, include some bereavement support.

Although the service has several 'prongs' it is the interface between them that is unique, and the intention to achieve both clinical and social outcomes.

Why did we partner?

Understanding how the partnership between Marie Curie and Social Finance could support the programme of work and add value to the service provider, took time. The partnership was formalised in Summer 2024, which meant working to a tighter timeframe, but it offered several opportunities for learning, including an opportunity to focus on late-stage dementia. Partnering with the Marie Curie service provided an opportunity to test two of the programme's hypotheses:

Building on existing services might allow efficient use of existing infrastructure and knowledge as well as quick ramp up to effect outcomes with limited risk.

Providing access to personalised respite services for unpaid "family and friends" carers might facilitate the delivery of more consistent, cost effective, higher quality care over the long-term.

The service is up and running, but to be sustained it needs to demonstrate impact and value for money. It has collected data on activity (eg referral numbers) and experience (eg surveys regarding the quality of the service) but was finding it challenging to evidence quantifiable outcomes and impact.

There is currently a two-year independent qualitative review of the service being undertaken by Yma, a not-for-profit social enterprise in Wales. We were keen that the programme work complemented Yma's outputs and did not lead to duplication. We have had sight of their interim evaluation report and are aware of work in progress for staff and unpaid carers to self-report 'impact measures' going forward.

What did we do?

Our aim was to audit some of the existing data and extract data that could be used to demonstrate impact. If the data was not readily available, we suggested tools and data approaches that would be helpful in demonstrating outcomes so that the service could be expanded and scaled across localities.

To do this a registered nurse (RGN, RMN) within the Social Finance team, who has experience within palliative care, elderly care and mental health, visited the service at one of their sites in Llanelli. She spoke with eight members of staff, and (within agreed data protection guidelines) discussed 'cases' alongside a review of the documentation and data collection related to them.

This was supplemented by other reading and conversations with the Marie Curie senior team about the service aims (including the Learning Community webinar presentation in July 2024), its history and development, current data collected, refinements in progress, and relevant Welsh guidance regarding dementia and unpaid carers.

What did we learn?

1. Benefits of an interlinked and integrated service that was trusted in the community

There was notable passion and compassion of staff and volunteers, all keen to talk about their service, proud to be part of Marie Curie, and open to new ways of working. Marie Curie is trusted and respected by the public and professionals – many of the people, experience, skills and networks needed are already in place. They are seen as “a safe pair of hands” and unpaid carers are willing to leave their loved ones in their care.

Once supported by Marie-Curie, access to their broader range support including hospice care at home and bereavement care, is readily available. However, the public and professional perception of Marie Curie as a cancer care specific provider may be restricting referral numbers, and this is being addressed by the team.

The service is flexible and personalised, with interface and synergy between the different elements. This is combined with fast response times, supporting changing circumstances that might demand acute care or rapid support. There is considerable interest in this service from other organisations and geographies, particularly the more visible recognition and involvement of Marie Curie in dementia care provision.

2. Systemic challenges inherent in a dementia care and respite service

This service highlighted the nuances in a dementia care and respite service. Dementia is not always diagnosed and, where it is, it is not always recorded or coded in clinical systems. The ‘stage’ of dementia, or the prognosis of the patient is not often documented. This provides challenges in accessing publicly available and aggregate datasets as the number of people living with dementia with admissions to hospitals will always be under-represented due to the challenges of clinical recording.

A focus on healthcare usage of solely people with a recorded dementia diagnosis would not accurately capture the full impact of some of the initiatives due to noted data quality issues in primary and secondary care data sets. For example, many older people with other needs are diagnosed with dementia in acute settings so it would not be recorded at admission.

For those admitted and who have a diagnosis, dementia is often not the primary or even secondary recorded reason for admission or interaction so it would not be

recorded on clinical notes and therefore would not appear on aggregate analysis.[7] People living with dementia may have more than one unpaid carer – presenting challenges in how to define the 'main' carer (or the one with the biggest load) for support and outcome evaluation.

3. Challenges capturing quantifiable and objective outcomes data as part of business as usual

The service had an overarching 'aim' but there were no SMART (Specific, Measurable, Achievable, Relevant, Time-Based) objectives so it was hard to define and measure system impact and outcomes.

As is frequently the case for services regardless of health condition or issue area, proving prevention in escalation of need and crisis is challenging as it relies on evidencing the absence or avoidance of something. This often requires an agreed baseline of activity for individuals if the service was not in place, also known as the 'cost of doing nothing'.

To create a baseline, and then demonstrate a change from it, views are needed across different health and social care systems, and it is difficult to combine them.

---

[7] Emergency admissions to hospital with Dementia: A Count of Emergency Admissions to hospital with i) a Primary Diagnosis of Dementia ii) a Primary or Secondary Diagnosis of Dementia from 2018 – 2019 to 2021 – 2022. Emergency admissions to hospital with Dementia – NHS England Digital

Although the service sought to avoid crises or hospital admissions, there was no reliable documentation of 111/999 calls, falls, or hospital admissions – either before or during an episode of care from the service. Often this data is held in a different health and social care IT systems which Marie Curie could not access such as GP or hospital notes. Securing access to this type of data takes time, investment in partnership building and approved data sharing protocols to de-silo data access.

As Marie-Curie set this service up rapidly in response to pressing need and a funding opportunity, there wasn't time to establish some of these foundational data processes and opportunities for system wide partnership building. There was also some anxiety (from organisations and individuals) regarding data sharing protocols, particularly related to patients who were unable to give informed consent.

What do we recommend for similar services?

Data Collection: identify the sources and processes of data collection before a service 'goes live'

- Identify and agree baselines of interest
- Ensure data is available and useful, and allow sufficient time for information governance processes
- Engage with those members of the team (potentially junior and/or clinical staff) who need to record ongoing data: incorporate prospective data collection into 'business as usual' as opposed to retrospective research projects

Patient-Centred Outcome Measures (PCOMs): consider appropriate measures for this cohort

- Measuring outcomes can be challenging because they are often captured across different collection formats, in detailed case notes written by staff members or in surveys shared separately to service interaction with service users.
- Reviewing case notes to extract outcomes can be time consuming on top of business-as-usual service delivery for frontline or management staff and surveys shared after a service interaction often have low completion rates, exacerbated if sent to an unpaid carer who is already stretched for time. This often leaves services focusing on 'activity' as part of data collection which doesn't capture quality or outcomes.
- Patient-Centred Outcome Measures provide an opportunity to integrate objective outcome collection as part of business as usual. They have academic accreditation, typically come in a variety of forms / lengths so that there is choice for what is most suitable for different frontline services and also bridge the link between quantitative and qualitative data for outcome measurement.

Appropriate PCOMs might include end-of-life care and frailty measures, as well as dementia-specific measures eg:

- The Zarit Carer Burden scale could be used within assessments and reviews, and to show any change. Importantly it also a useful therapeutic tool to open up any difficult conversations. It is available in 22, 12 or 4 item versions.[8]
- IPOS-Dem assesses the symptoms and distress of people dying of or with dementia.[9] It is available in versions for both family carers and professionals.
- SIDECAR-D measures the direct impact of dementia on unpaid carers through 18 items and has been used by other services in Wales as an outcome measure focusing on unpaid carers.[10]

'Deep-dives': consider tracking a small number of cases as examples of a cohort, rather than the whole cohort

Develop a case study template for services to use, perhaps at trigger points. 'Case' could be a patient/service user, carer, professional, organisation, or system.

---

[8] https://wai.wisc.edu/wp-content/uploads/sites/1129/2021/11/Zarit-Caregiver-Burden-Assessment-Instruments.pdf

[9] Palliative care Outcome Scale (POS) – Integrated POS (IPOS) for Dementia and Translations (pos-pal.org)

[10] Horton MC, Oyebode J, Clare L, Megson M, Shearsmith L, Brayne C, Kind P, Hoare Z, Al Janabi H, Hewison V, Tennant A, Wright P. Measuring Quality of Life in Carers of People With Dementia: Development and Psychometric Evaluation of Scales measuring the Impact of DEmentia on CARers (SIDECAR). Gerontologist. 2021 Apr 3;61(3):e1-e11. doi: 10.1093/geront/gnz136. PMID: 31688902; PMCID: PMC8023371.https://pubmed.ncbi.nlm.nih.gov/31688902/

Scaling the Marie Curie Dementia Care and Respite Service

Unlocking Capital

This model has potential for replication across geographies but is dependent on the right infrastructure. To understand and demonstrate impact of the service, we would recommend a combination of grant funding and a social outcomes partnership approach.

Grant funding could be used to improve data collection methods and analysis, ensure standardised baseline data is set and collected, build robust system-wide partnerships to enable access to key health social are data, and build co-designed outcomes frameworks with the statutory sector to ensure alignment on the desired impact of the service.

This grant funded activity would lay the foundations for a potentially effective social outcomes partnership, which work particularly well when something new is added in to an individual's care pathway; in this case, clinical and volunteer support for the individual living with dementia and respite support their unpaid carer/s.

By collecting baseline data that tracks the individual's health care interactions across primary and secondary care (number of GP attendances, planned and unplanned attendances at A&E for example) and carer wellbeing via the Zarit Burden scale at the start, mid-point and post intervention, a comparable data set will be built that assesses the impact of the service.

If these outcomes are demonstrably alleviating statutory system pressures and improving quality of life and wellbeing for individuals and their unpaid carers, adult social care and the ICB could agree on a monetary value against these metrics and joint fund these repayable outcomes as and when they are achieved.

Shape Sector Practice and Harness Collective Effort

Expanding this service model in other localities and geographies will require extensive mapping of existing provision and gaps in support, to build the case for a multi-pronged service without creating duplication or confusion. This type of service can really scale impact by harnessing partners from across sectors but must be done with a lens of system change to ensure all partners move together.

Use Date for Transparency and Insight and Create Feedback Loops

The Marie Curie service in Wales has demonstrated qualitative impact via powerful case studies and a high-quality report by Yma. Our partnership with Marie-Curie and this case study reflects on the need to build better data practices and introduce different measurement tools to demonstrate the service's quantitative impact and benefits to the wider system by diverting need away from primary/secondary and acute care.

Shared Lives Plus Dementia Support Case Study

Background

Shared Lives Plus is the national membership charity for the Shared Living sector, supporting over 140 local Shared Lives schemes and over 6,000 carers.[11] Shared Lives Plus provides support to individual schemes and self-employed Shared Lives carers to ensure the model delivers consistent, quality care, and support efforts to help the model scale.

Shared Lives is an innovative model of care, where someone who needs care is matched with a paid carer and spends time at the paid carer's home, or out in the community. The care provided can be either long-term or short-term 'respite' care, depending on needs of the individual and carer. Shared Lives schemes predominantly support working age adults with a learning disability, enabling people to live more independently for longer through personalised community-based care.

The UK Government have explicitly recognised the value of the Shared Lives model as they "offer greater flexibility and more community-based care. Embedding innovative approaches to delivering care can ensure that care is more personalised, supports individuals to live more independently for longer, and can adjust to the needs of future populations".[12]

Why did we partner?

We worked with Shared Lives Plus to test the hypothesis below:

> Providing access to personalised respite services for unpaid 'family and friends' carers of people living with dementia might facilitate the delivery of more consistent, cost effective, higher quality care over the long-term.

While adults with a learning disability are the primary recipients of Shared Lives schemes, Shared Lives Plus estimates around 3% of people receiving care through

---

[11] Shared Lives and Homeshare in England receive their biggest government funding boost yet – Shared Lives Plus

[12] Department of Health & Social Care, Adult social care system reform: 'Next steps to put People at the Heart of Care' (April 2023) Next steps to put People at the Heart of Care – GOV.UK (www.gov.uk)

the model have confirmed or suspected dementia and there is an appetite to expand the Shared Lives model to support people living with dementia and their unpaid carers. The model featured in a 2022 All-Party Parliamentary Group in 2022 and the scheme has demonstrated real success in Moray, Scotland and in Wales.[13]

Unpaid carers often face heightened stress, with 90% experiencing feelings of stress and anxiety several times a week, and 40% reporting depression.[14] Regular access to respite care can reduce these adverse effects, improving unpaid carers' overall well-being.[15]

The cost of respite care varies widely depending on the type and duration; on average, in-home respite care costs about £18–30 per hour,[16] while residential respite care can cost around £700–£1,500 per week.[17] Despite these costs, respite care can be cost-effective by delaying the need for full-time residential care, which is significantly more expensive, averaging £60,320 per year for residential care and £73,320 for nursing care.[18]

Research conducted in 2017 highlights that the costs of Shared Lives solutions are in line with, or in some cases, more affordable than some 'traditional' forms of respite.[19] As a provider and champion of personalised respite care, Shared Lives Plus was ideally placed to partner with us to test this hypothesis.

What did we do with Shared Lives Plus?

Given the breadth and diversity of the Shared Lives model, we set clear parameters for our scope of work:

- **Focusing on day respite offers for periods of less than 12 hours, not shared living arrangements**
  Shared Lives offers different models of care including longer-term living arrangements and respite care over multiple days to enable an unpaid carer to spend more than 24 hours away from the person living with dementia. We anticipated access to day respite data would be more available, and its relative

---

[13] https://sharedlivesplus.org.uk/2022/11/02/shared-lives-scheme-speaks-in-westminster-about-support-for-people-experiencing-dementia/; https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/Shared_Lives_Moray_final_2019-ilovepdf-compressed.pdf ; Short breaks for people living with dementia and their carers: exploring wellbeing outcomes and informing future practice development through a Social Return on Investment approach | Health Care Research Wales (healthandcareresearchwales.org)

[14] Livingston G, Barber J, Rapaport P et al. (2013) Clinical effectiveness of a manual based coping strategy programme (START, STrAtegies for RelaTives) in promoting the mental health of carers of family members with dementia: pragmatic randomized controlled trial. BMJ 347: f6276.

[15] https://www.york.ac.uk/inst/spru/pubs/pdf/respiteEx.pdf

[16] https://www.elder.org/paying-for-care/how-much-do-carers-cost/#:~:text=The%20price%20of%20home%20care,18%2D%C2%A330%20per%20hour

[17] https://alinahomecare.com/home-care/respite-care/cost-of-respite-care/

[18] https://www.carehome.co.uk/advice/care-home-fees-and-costs-how-much-do-you-pay

[19] https://sharedlivesplus.org.uk/wp-content/uploads/2019/04/Review_of_Shared_Lives_for_older_people_and_people_living_with_dementia_2017-1.pdf

value compared with traditional day centre opportunities, and therefore chose to focus on this form of care.

- **Focusing on arrangements where there are positive outcomes for unpaid carers, rather than solely for people living with dementia.**

  Some Shared Lives arrangements support a person living with dementia who does not have an easily identifiable unpaid carer. Shared Lives provides value in these situations, but we chose to primarily focus on unpaid carers as a frequently overlooked 'cohort' to test the primary hypothesis.

We set out to achieve two objectives to effectively test this hypothesis:

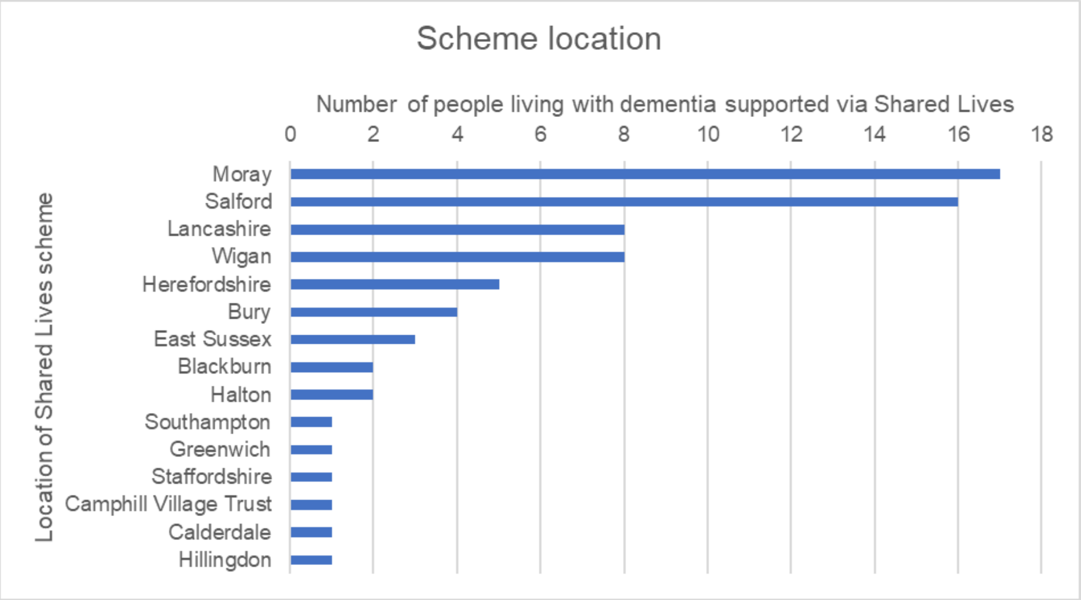
1. **Assess how the Shared Lives model currently supports unpaid carers for people living with dementia across the UK.** Social Finance analysed data provided by individual schemes detailing the quantity and type of care currently provided to people living with dementia as of late 2023.
2. **Understand the demand from Shared Lives schemes wanting to extend their offer to unpaid carers of people living with dementia.** This was conducted jointly by Social Finance and Shared Lives Plus and sought to examine the need for Shared Lives schemes to expand support for this cohort and their unpaid carers and identify barriers to roll out and access.

Based on our findings, there is a need to **design core principles** for the proposed extension of the Shared Lives model for people living with dementia to illustrate where the model is best suited to provide support for unpaid carers (including recommending a suitable outcome metric for improving unpaid carer experiences).

We undertook a mixture of primary research via interviews and workshops with unpaid carers, Shared Lives carers and officers, and, where possible, commissioners. These findings informed our work against objective 3. We engaged with Shared Lives schemes who wanted to expand their support to dementia carers in Stockton, Newham, and Wiltshire, to understand demand in their area and their progress and challenges in launching new services. We carried out in-depth user research with unpaid carers at Stockton Dementia Hub to understand key drivers and barriers in accessing respite care. We resourced Shared Lives Plus to support sites to expand their offer, by developing communications and marketing materials and guidance for new sites.

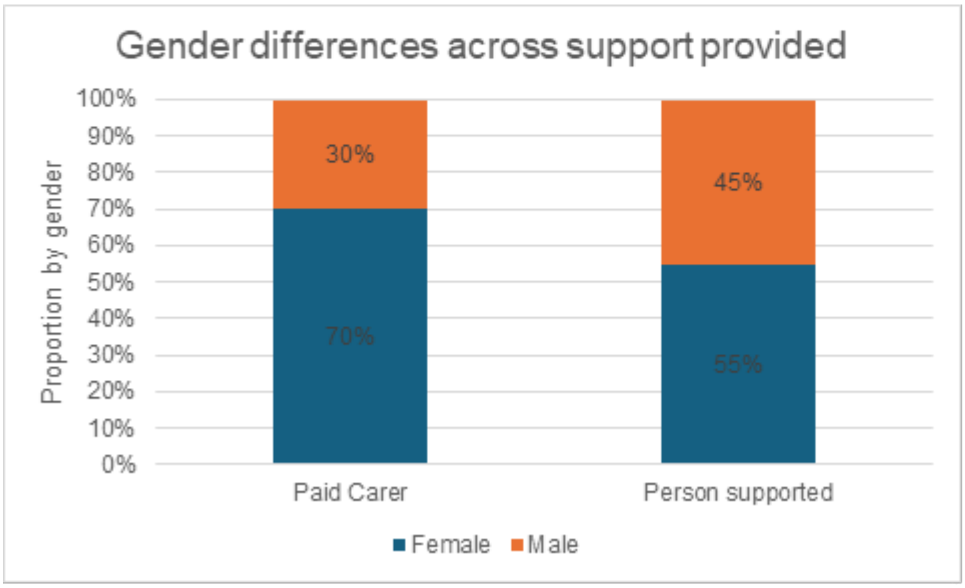
What did we learn from Shared Lives Plus?

The quantitative data on existing support for people living with dementia highlighted clear hot spots of support in Salford and Moray, areas that had focused on promoting Shared Lives for people living with dementia. Of the total 71 people living with dementia supported via a Shared Lives scheme, 46% of them are in these two areas.



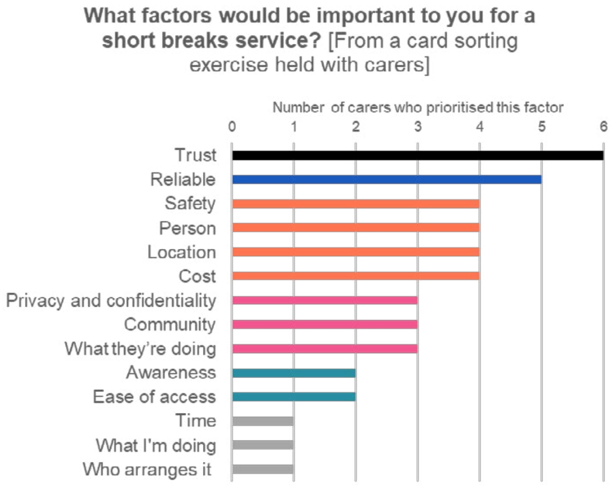
The types of support provided to the 71 people living with dementia varied from once a week for 4 to 8 hours through to regular support 2 or 3 times a week for shorter periods of 2 to 3 hours. The range of support offered demonstrates a truly personalised and flexible offer, which is a positive finding, but did make aggregate analysis challenging.

An interesting supplementary theme that emerged was gender in relation to matching. Most Shared Lives carers were female providing support to male individuals. Whilst we are not suggesting that support needs to be matched by gender, it is worth highlighting this point as it emerged in discussions with scheme providers with some indicating the most successful respite offers were peer support led. Some schemes highlighted that a targeted recruitment drive for male Shared Lives carers could be effective as it would offer more choice for individuals in need of support.



Shared Lives Plus could only collect data on the person directly provided with care (e.g. the person living with dementia) or the paid Shared Lives carer. The unpaid carer was not identifiable in this data which led Social Finance to engage with unpaid carers via user engagement (face to face and virtual) to understand their support needs which informed our learnings below.

There appears to be a clear need for personalised, trusted ‘short break’ offers. Unpaid carers expressed that **trust, reliability and safety** were the most important factors to them in high quality respite care. They wanted services to be transparent about their care offer, so that unpaid carers would feel reassured that their loved ones were receiving high quality care. They also wanted the option to stay with their loved one, before slowly stepping back at their own pace.



In addition, traditional respite offers such as day centres were perceived as unsuitable due to **limited capacity and flexibility**. Low capacity diminishes flexibility; e.g. low staffing numbers mean that Stockton’s Time Out service can only be booked on the 1st of the month and is first come first served. Options are therefore one-size-fits-all, with limited person-centered provision that meets diverse cultural, linguistic and activity-based needs, Shared Lives’ personalised offer would meet a clear need here.

However, while schemes have had some success recruiting Shared Lives carers, they have struggled to secure referrals for people living with dementia. Equally, the majority of unpaid carers had not accessed respite care, and those who had only did so when their loved one’s dementia became severe. Key challenges include:

- **Low unpaid carer take-up** – unpaid carers often feel embarrassed or guilty to ask for help with care as they feel they should be providing this themselves; many do not identify as ‘unpaid carers’ in the first place.
  - Lack of certainty about the progression of dementia means unpaid carers are less willing to ‘let go of the reins’ and arrange support, as they can’t predict their future needs, and may feel their efforts are temporary.

  - Many unpaid carers have experienced or heard second-hand reports of bad care (often due to risk aversion), which has negatively affected their trust in services.
- **Early intervention** – unpaid carers often reach out for support when they are at crisis point; by this time, they will benefit less from Shared Lives support, which is most effective for carers earlier in their loved one's illness. Additionally, social work and local authority service contacts – which Shared Lives schemes typically rely on for referrals – are rarely involved early in the caring pathway due to strict eligibility criteria.

Despite these challenges, schemes feel hopeful that a cultural shift will take place with time. They see a role for themselves in having conversations with unpaid carers to help them identify themselves as carers, pointing out their responsibilities and suggesting ways to mitigate burden and stress. This is a gradual process: one scheme noted that on average, **their service touched unpaid carers 6 times before they accepted support.**

To enable this work, schemes would like:

- **Carer-facing resources and materials** aimed at shifting self-perceptions and culture, which Shared Lives Plus is helping to create.
- **Funding and resource** to free up constrained capacity and enable a shift away from fire-fighting and troubleshooting. Invest in more innovative approaches to engagement to highlight the benefit of personalized support to people affected by dementia.

What do we recommend for similar services?

1. Utilising place-based support networks to gain the trust of unpaid carers in a personalised respite offer

It takes time and skill to identify and meet ‘unpaid carers’ and establish the necessary trust for a successful service. This foundational work must precede any service offer or delivery and may need to be approached differently for pro-active (elective) respite, and crisis (emergency) respite. Services or networks that have already established trust with unpaid carers are more likely to have success engaging them in proactive respite than an unknown new service. We recommend mapping existing support networks, including informal respite initiatives, across a locality via dementia support groups, to highlight where personalised, proactive respite might play a role in reducing carer burden.

2. Co-design engagement strategies with unpaid carers to ensure that a proactive personalised support offer uses the correct language and representation to drive engagement with and access to the service

The word ‘respite’ has different practical and emotional connotations and may deter people from using a service. Shared Lives has had real success with the term “short breaks” after listening to feedback from people living with dementia and unpaid carers. During user engagement sessions, unpaid carers consistently highlighted that they needed ‘a break’ and support however many struggled with the word ‘respite’. Most highlighted that ‘respite’ implies a failure on their part to provide support for their loved ones.

These important semantics are part of a wider cultural shift needed to frame unpaid care as something that should be shared, not solely performed by an unpaid carer with little support. Reframing how personalised “short breaks” are provided could enable unpaid carers to proactively take up support available.

3. Iterative communications and engagement with potential referral routes (statutory and non-statutory)

A personalised respite offer such as Shared Lives is innovative but that will mean it is unfamiliar, perhaps even challenging, to many prospective referrers. Health and social care staff will need clear explanation of the ‘offer’ and the way it works in practice to encourage access. Shared Lives Plus are developing resources that clearly communicate the offer for various referral partners to ensure those who need the service can access it.

Scaling Shared Lives

The Shared Lives model has real potential to diversify its offer to support older people living with dementia and other needs. This has happened organically in some regions across the last five years, and we recommend focusing on the levers below within the Routes to Scale framework to target growth and opportunities for scale in other areas across the next five years.

Create feedback loops

Learnings from this programme highlight the need for an adaptive, personalised model that people are aware of and can access with ease. The most effective way to do this is ensure the offer is linked in with existing trusted networks and embedded within system-wide referral pathways. Feedback loops via these networks and across the system, will be critical in ensuring personalised short breaks reach those who need it; at any point in their journey, and ideally before crisis point.

Develop talent

Ensuring that local networks know about the offer requires engagement and partnership building with trusted individuals at organisations and forums already part of a network of support for unpaid carers. In Stockton hub, experts by experience were well respected and were a key intermediary connecting Social Finance to unpaid carers for user engagement sessions. These intermediaries could be key advocates of the Shared Lives model and potentially become Shared Lives carers themselves. Developing existing talent via these networks are key to building Shared Lives as a trusted support partner for unpaid carer support.

Build the evidence base

Assuming unpaid carers know about the offer, and trust and shape the model, a key driver for scale is building an evidence base that demonstrates impact and efficacy. Shared Lives has a wealth of qualitative case studies that demonstrate the individual impact and outcomes different Shared Lives schemes provide. We would recommend implementing quantitative data outcome measures, such as the Zarit Burden scale, that can measure the impact of an intervention at an aggregate level into business as usual. The Zarit Burden scale has real potential in evidencing how the Shared Lives model reduces carer burden and potentially increases carer resilience. This metric, triangulated with deep dive analyses of a subset of unpaid carer case files (on health usage/utility) and ongoing qualitative insights, could build a robust and compelling business case for commissioners and funders, demonstrating person-centered and system impact.

Unlock Capital

Investing in unpaid carers is challenging – this cohort of people bolster adult social care to the value of £162 billion pounds annually across England and Wales and so incentivising investment in unpaid carers at a system level can be difficult, despite the unsustainable nature of current funding structures and lack of carer support available. However, Shared Lives schemes could benefit from a blended finance approach, including non-repayable grant funding and social investment repaid on concessionary terms, which recognises the broader social 'good' and impact of the service on individuals living with dementia, unpaid carers, adult social care and health, and the wider workforce.

Non-repayable grant funding could be used to drive place-based engagement efforts with trusted networks to increase awareness of the service, build system-wide partnerships with the statutory system via workshops and events to raise awareness of the service and join up referral routes. Grant funding could also bolster data infrastructure, support implementation and training on use of the Zarit Burden scale and support the development of person-centered and accessible marketing materials and carer-facing resources.

Once these pre-conditions for investment are in place, supported by grant funding, repayable social investment could be made into Shared Lives schemes. This has been done before with initial investments into Shared Lives arrangements across the UK prior to them achieving financial return on their services (not for people living dementia however). The initial investment was repaid on concessionary terms once the service was meeting a level of matches that enabled it to operate as a sustainable service.

In the case of social investment in to Shared Lives schemes supporting people living with dementia and other needs, social investment could be repaid on concessionary terms once a scheme has secured enough matches for people living with dementia, either privately funded or via commissioning or at the point a certain number of commissioned contracts have been secured. It could also be repaid based on a set of pre-agreed outcomes (reduction in carer burden per Zarit Burden scale for example) that a statutory system values and would be prepared to repay on.

Leicestershire County Council Early Care Technology Case Study

Background

Leicestershire County Council's (LCC) Care Technology Service offers a range of monitoring and alert equipment to help individuals maintain their independence, both at home and in the community. This service is supported by PA Consulting who offer expert advice on technology options as well as performance management in relation to business activity.[20]

Care technology encompasses various devices, including **alarm systems, medication dispensers, and GPS location trackers**, designed to support those who are particularly vulnerable due to health or social circumstances. The service is especially beneficial for individuals with dementia, as it is non-chargeable for adults who meet the eligibility criteria, including those with a dementia diagnosis. The technology operates by connecting the equipment to a monitoring centre via a mobile network or telephone system, negating the need for a home phone line. Additionally, mains-powered devices come with a battery backup to ensure continuous support during power outages.

For those living with dementia, there are care technology products that can help enhance safety and independence. These products include calendar clocks, memo minders to remind individuals to take medication or secure the door, locating devices, and door and bed alarms.

Why did we partner?

This partnership focused on determining the optimal time to introduce care technology interventions for older people living with dementia and other needs and their unpaid carers. In collaboration with LCC, we developed a hypothesis to test as follows:

> Introducing care technology earlier in the dementia care pathway may offer incremental benefits for older people living with dementia, their unpaid carers, and the health and social care systems.

There is a trend towards technological interventions playing a significant role in adult social care delivery; organisations are turning to technology to save costs

---

[20] Care technology has the potential to deliver better... | PA Consulting

whilst finding effective solutions for different target populations, including the ageing population.[21,22]

The Digital Care management market is projected to grow from £2.1billion in 2024 to £3.4 billion by 2029.[23] Research on care technology in dementia support highlights its potential to enhance care quality, support independence, and reduce unpaid carer burden.[24]

Digital and technical solutions are going to play a leading role in supporting older people with other needs and their unpaid carers. To enable this, local authorities will need the necessary infrastructure in place to deploy technology in effective and coordinated ways to ensure social impact and financial savings are aligned.

Partnering with LCC enabled us to learn from their pre-existing technology service, leveraging insights to shape what a new intervention providing care earlier in the journey would need to include and measure.

What did we do with LCC?

Social Finance was a learning partner for the LCC's Early Care Technology intervention. The pilot sought to expand LCC's existing care technology offer to a wider cohort. The programme aimed to offer care technology to people with a Mild Cognitive Impairment (MCI) or in the early stages of dementia. These people would not have been eligible for the existing care technology route as the aim was to provide support earlier in the journey. The pilot relied on a partnership with Age UK whose team referred people into the pilot.

Our involvement with LCC's Early Care Technology service focused on supporting the team in identifying the most relevant outcomes to collect and the importance of adopting a holistic system-wide approach to understand the impact of the intervention. The Early Care Technology service launched in February 2024 and has supported, as of 31st August 2024:

- 80 referrals into the pilot
- 50 people initially assessed
- 40 people had technology installed in their home.
- 35 people had follow up conversations to understand the early impact of the intervention

---

[21] New report suggests greater use of digital technology is a crucial step in reforming adult social care – County Councils Network

[22] Technology In Adult Social Care: Very Wide Potential | The King's Fund (kingsfund.org.uk)

[23] Digital care management – UK | Statista Market Forecast

[24] Brown, E. L., Ruggiano, N., Li, J., Clarke, P. J., Kay, E. S., & Hristidis, V. (2019). Caregivers' willingness to adopt new technologies for dementia care: Influences of value and perceived ease of use. Journal of Applied Gerontology, 38(9), 1305-1323.

In a workshop held in November 2023, prior to service launch, Social Finance convened partners from Leicestershire County Council (LCC), Leicester Leicestershire and Rutland Integrated Care Board (LLR ICB) and Age UK to co-design outcomes for the Early Care Technology pilot. We agree on three overarching outcomes to measure success:

1. **Unpaid Carer Wellbeing**. To understand whether implementing care technology early on increases or maintains wellbeing amongst unpaid carers, ultimately offsetting or delaying carer breakdown. This would be measured by introducing the Zarit Burden Screen survey to act as a proxy for wellbeing.[25]
2. **Emergency Healthcare.** To understand whether implementing care technology early on reduces lower-grade illness or discomfort, and therefore decreases the use of emergency healthcare. Initially, we wanted to use data directly from LLR ICB to understand usage of emergency healthcare before and during their participation in the pilot. Due to data collection and data sharing protocols, this was not possible. Instead, we relied on self-reported usage of emergency healthcare through a series of survey questions asked by the team at Age UK and LCC. This decreased the validity of the data collected and therefore did not form the basis of our analysis.
3. **Adoption of Technology.** To understand whether implementing care technology early on means there is better adoption amongst older people living with dementia and their unpaid carers. We planned to collect this via interviews with unpaid carers involved in the pilot. Additionally, we aimed to see if we could review quantitative data on technology usage that is routinely collected and analysed by PA Consulting and compare to the existing care technology pathways data collection systems for care technology.

Our aim was to support LLC to collect outcomes-focused data that could indicate the impact of the service and help shape future iterations of the model for potential commissioning.

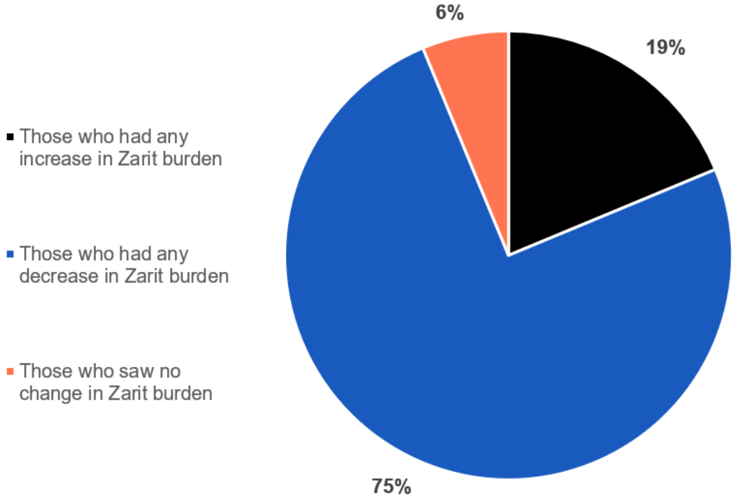
What did we learn with LCC?

During the last six months, the Early Care Technology team have collected a vast wealth of data on both direct users and unpaid carers who accessed the service. The pilot enabled care technology assessors to understand and match the most suitable types of technology to the needs of users and unpaid carers, leading to a person-centered intervention that considered the wider determinants of health.

Of the 16 users with comparable baseline and outcomes data, after six weeks of the service, 75% (12) saw a decrease in their Zarit burden scale which indicated a positive outcome.

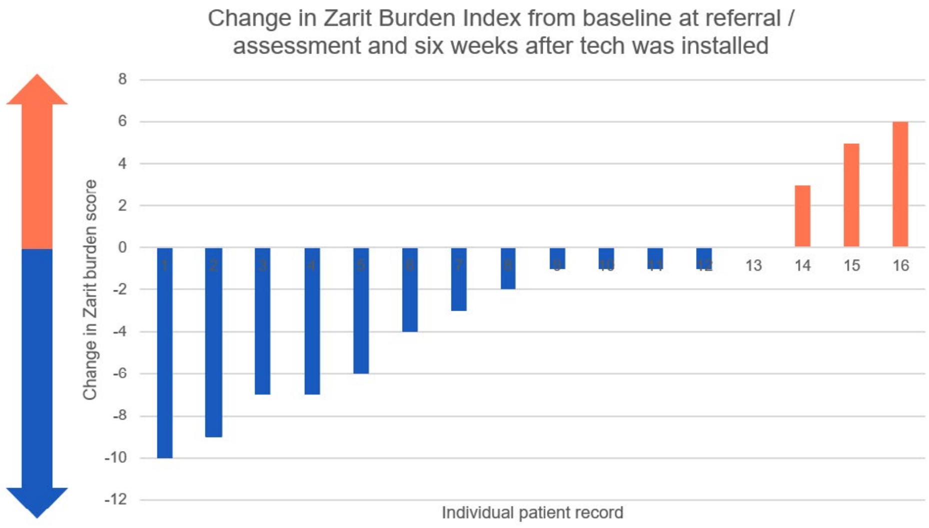
---

[25] Zarit Burden Interview (apa.org)



OF 35 RESPONSES COLLECTED, 16 WERE ABLE TO BE ANALYSED IN DETAIL; N = 16

Most of these users saw a significant reduction (a decrease in the burden by 4 or more points) which indicated that the care technology had had a beneficial impact. It is important to caveat that we received a small sample size of data based on the early stages of the project so outcomes at this stage may not be entirely representative of the wider target cohort.



OF 35 RESPONSES COLLECTED, 16 WERE ABLE TO BE ANALYSED IN DETAIL; N = 16

1. Pivoting to focus on unpaid carers

Our original focus was on adoption and adherence and health usage, however our collaboration with multiple place-based partners highlighted the critical importance of including unpaid carers. As a result, we shifted our primary outcome collection efforts to focus on unpaid carer wellbeing.

The rationale behind this decision is rooted in the understanding that technology, while beneficial in providing reassurance through monitoring systems or medication reminders, can also introduce new challenges for unpaid carers.

These individuals are often already managing their own health issues, fulfilling other care responsibilities, and maintaining economic activity. Introducing technology into the care process can be both a relief and an additional burden. Therefore, it is essential to evaluate how this technology impacts the wellbeing of unpaid carers, as a decrease in their wellbeing is frequently cited as a reason for moving their loved ones into institutional care – an outcome that significantly increases costs for local authorities.[26]

By framing the outcomes in this way, LCC can articulate its impact beyond the traditional remit of crisis intervention, embracing a preventive approach to care. We hypothesized that early intervention, supported by care technology, could prevent or delay the need for more intensive adult social care services, thereby reducing long-term costs.

Due to the limited amount of data available, we supplemented our findings with deep dives into cases which highlighted how the Early Care Technology pilot had provided unpaid carers with much-needed reassurance and peace of mind. See the example below:

For one carer, a wife whose husband has been diagnosed with bladder cancer and struggles with aggression, the introduction of this technology, particularly a tracker on his keyring, has been invaluable. It has not only helped to calm her worries but also allowed her to feel more relaxed, knowing she can rely on the system if needed.

- The lifeline device has been used effectively, reducing her stress by providing immediate assistance during emergencies and making her husband more independent.
- The daily use of technology like MemRabel has proven extremely helpful, as it alleviates the constant questions about the day and time, giving the service user a sense of autonomy and reducing the carer's strain. Additionally, medication prompts have restored some of the user's independence, further easing the carer's burden.

---

[26] Brown, E. L., Ruggiano, N., Li, J., Clarke, P. J., Kay, E. S., & Hristidis, V. (2019). Caregivers' willingness to adopt new technologies for dementia care: Influences of value and perceived ease of use. Journal of Applied Gerontology, 38(9), 1305-1323

> The technology has also been a great comfort to the wider family, neighbours, and responders, providing peace of mind and ensuring that support is available even when the carer is occupied elsewhere in the house.

Overall, while there is still some adjustment required, particularly in upskilling and supporting carers to use the technology effectively, the pilot has shown early indications of reducing stress for unpaid carers, via qualitative feedback, and enhanced the independence and safety of those they care for.

Interestingly, several of the assessments highlighted how the care technology service was able to help unpaid carers better utilise the existing technology in their home, rather than having to add in new, and more alien equipment. In one case, the assessor was able to upskill an unpaid carer on how to use existing EchoDot to set up reminders rather than install new technology. In this case, the unpaid carer saw a significant reduction in their unpaid carer burden at six weeks after assessment.

2. Streamlining data collection and analysis processes

Our initial aims and expectations were to map a base understanding of the impact Early Care Technology could have on unpaid carer wellbeing and to explore the relationship between effective adult social care interventions and reduced emergency healthcare usage.

Through this approach, we sought to provide LCC and PA Consulting with the tools to demonstrate the broader benefits of the Early Care Technology, and technology more broadly, once they have sufficient data points and infrastructure to analyse the impact. This will ultimately support the development, and where relevant, the sustainability of these interventions.

It was ambitious to aim to collect full impact data in the small-time frame of this project. System-wide outcomes frameworks that capture person-centered, service and system wide outcomes take time to develop and co-design. A longer testing time frame was needed to test this outcomes framework within the live service, modify intervention design, access wider health data, and analyse data and outcomes.

A key ambition was to review participants' healthcare usage; both planned and unplanned. We identified emergency healthcare usage as a crucial indicator of the success of adult social care interventions. However, collecting data on this outcome is often challenging due to funding silos and differing data collection priorities.

Though the ICB provided funding for this programme, it was difficult to connect adult social care and health data for individuals. We believed that effective local adult social care services would naturally lead to reduced A&E attendance by improving the health, health literacy, and trust among older people living with dementia and their unpaid carers. Despite this seemingly straightforward premise, the lack of justifiable incentives, particularly financial ones, makes it difficult to gather the necessary data to validate this assumption.

Our early modelling based on assumptions prior to service launch and without academic rigour, has suggested that Early Care Technology could save LCC up to £1,510 per older person living with dementia using LCC services. We would want to test these assumptions via longer impact data from the service to understand if early care technology can reduce escalation for older people living with dementia their and unpaid carers.

3. A key early conversation in the design and implementation process is needed to confirm the actual process of data analysis

The service has collected a wealth of data on individuals at referral, assessment and follow up. However much of the data was designed to be reviewed in isolation at a case per case basis which limited analysis to understand potential aggregate insights or intersections as part of business as usual.

For future scale, mapping out how the data is collected, stored and linked can enable pragmatic solutions for aggregate analysis as part of business as usual. This will also enable data feedback loops to change practice more efficiently and can limit the data collection burden on frontline and / or asking users for the same data at multiple intervals. This would enable more practical application of an outcomes frameworks and test of key performance indicators. There’s a need to change the focus of data collection from activity to outcomes and a need for dedicated resource to effectively drive the monitoring, analysis and synthesis of data collection as part of business as usual.

What do we recommend for similar services?

There are two key reflections that have implications for other areas looking to provide early technical support for older people living with dementia and unpaid carers:

1. Incorporate metrics for unpaid carers

Unpaid carers are a key part of the health and social care system and are valuable in understanding how best to provide proactive and preventative support. Feedback from this service highlights that capturing data from unpaid carers, can demonstrate the pain points and best ways to reinforce resilience in unpaid carers as they learn to support older people living with dementia and other needs. We are aware that not every older person living with dementia will have an unpaid carer nor will people have one, easily identifiable unpaid carer.

However, capturing how their caring role affects them will help build a case for more proactive support across the health and social care system. We are particularly interested in standardising data collection to build an an evidence base on how supporting unpaid carers will provide better preventative support for older people living with dementia. We recommend the Zarit Burden Screen as a metric of carer wellbeing but we are aware that other metrics and measurements are available.

2. Plan data collection processes up front to minimise data burden

Iterating data capture needs to be part of 'business as usual' to ensure that data collection, data analysis and data sharing does not become a pain point for service delivery nor mitigate the service's impact. We recommend that services, including but not limited to care technology services, map and share their data collection points and processes to ensure that data captured diligently by frontline users is utilised in future analysis. This practice will also enable data to shift from an activity to an outcomes focus by aligning the data points that matter to different stakeholders.

The process of upfront outcomes mapping was incredibly valuable in this case study to align stakeholders. However it needed to also include mapping how that data would be analysed once collected to ensure that outcome analysis was incorporated as business as usual.

Expanding Care Technology re-routes to scale

The learnings from the Early Care Technology service have real potential to be scaled to other areas –including neighbouring local authorities as part of the ICB footprint. We also believe that this model of care aligns well with social investment [link in report to features that make it applicable to social investment] and we are actively seeking ways to support the scaling of Early Care Technology.

We would recommend a blended finance approach to further build an evidence case for the project's impact. The potential for using technology to promote independence at home, divert need away from acute care and support carer wellbeing could work in the context of a social outcomes partnership if an outcomes payer recognises and is willing to pay for the system and person-led benefits that the use of technology generates.

Develop talent

The existing Early Care Technology service has in-house expertise and trained staff with abroad knowledge of the variety of care technology initiatives available. This enabled each assessment and installation to be personalised for the individual's presenting needs. To ensure that this service is scaled effectively, staff employed would need experience of the variety of care technology available to help break down any barriers I use and adoption of care technology and ensure that the support remains personalised.

Create feedback loops

The Early Care Technology service in LCC has only been running for 6 months as of the 1st September 2024 and is very much in its early stages. To ensure it continues to ensure that it remains outcomes-focused, based on the early outcomes framework, there needs to be business as usual feedback loops from data collection at the frontline through to data analysis. This will ensure that all data collected at all touchpoints are utilised to both present the impact of a service as well as feedback into service adaptation as it could potentially scale to other areas

Build the Evidence Base

As outlined in the outcomes framework, one of the measures to understand the success of an earlier service is ensuring it provides effective support for unpaid carers. Scaling of an Early Care Technology service needs to ensure that there is systematic collection of unpaid carer measures to build the evidence base behind intervening early. Ideally, this will be supplemented by academic evaluations demonstrating the cost benefit of an earlier proactive intervention at home but agreement on similar, aligned or even the same measure to understand the impact on unpaid carers will help direct funding to support them ahead of burnout and crisis.

Endnotes

1 NHS North Kensington Major Incident Response. 2024. "What is Cultural Competency?" [Online]. Available: https://www.grenfell.nhs.uk/cultural-competence. [Accessed 2024].

2 F. Lewis. 2015. "Estimation of Future Cases of Dementia from Those Born in 2015." [Online]. Available: https://www.ohe.org/publications/estimation-future-cases-dementia-those-born-2015/. [Accessed 2024].

2 NIHR. 2021. "Multiple long-term conditions (multimorbidity): making sense of the evidence." [Online]. Available: https://evidence.nihr.ac.uk/collection/making-sense-of-the-evidence-multiple-long-term-conditions-multimorbidity/. [Accessed 2024].

4 Carers UK. 2023. "Unpaid care in England and Wales valued at £445 million per day." [Online]. Available: https://www.carersuk.org/press-releases/unpaid-care-in-england-and-wales-valued-at-445-million-per-day/. [Accessed 2024].

5 Office for National Statistics. 2023. "Profile of the older population living in England and Wales in 2021 and changes since 2011." [Online]. Available: https://www.ons.gov.uk/peoplepopulationandcommunity/birthsdeathsandmarriages/ageing/articles/profileoftheolderpopulationlivinginenglandandwalesin2021andchangessince2011/2023-04-03.. [Accessed 2024].

6 A. Lewis, H. Cromarty and C. Barton. 2021. "Housing an ageing population: a reading list." [Online]. Available: https://commonslibrary.parliament.uk/research-briefings/cbp-9239/. [Accessed 2024].

7 NIHR. 2018. "Multi-morbidity predicted to increase in the UK over the next 20 years." [Online]. Available: https://evidence.nihr.ac.uk/alert/multi-morbidity-predicted-to-increase-in-the-uk-over-the-next-20-years. [Accessed 2024].

8 J. Pearson-Stuttard, M. Ezzati and E. W. Gregg. 2019. "Multimorbidity – a defining challenge for health systems." *The Lancet, Public Health*.

9 NIHR Evidence. 2023. "Multiple long-term conditions (multimorbidity) and inequality – addressing the challenge: insights from research." [Online]. Available: https://evidence.nihr.ac.uk/collection/multiple-long-term-conditions-multimorbidity-and-inequality-addressing-the-challenge-insights-from-research/. [Accessed 2024].

10 Department of Health and Social Care. 2023. "Chief Medical Officer's annual report 2023: health in an ageing society." Gov UK.

11 NHS Strategy Unit. 2019. "New models of care – what's the evidence?" NHS.

12 Alzheimer's Society. 2021. "How many people have dementia in the UK?" [Online]. Available: https://www.alzheimers.org.uk/blog/how-many-people-have-dementia-uk. [Accessed 2024].

13 NICE. 2018. "18. Assessing and managing comorbidities," in *Dementia: Assessment, management and support for people living with dementia and their carers*.

14 R. Wittenberg, B. Hu, L. Barraza-Araiza and A. Rehill (2019) "Projections of Older People Living with Dementia and Costs of Dementia Care in the United Kingdom, 2019–2040".

15 Alzheimer's Society. 2024. "Facts for the media about dementia." [Online]. Available: https://www.alzheimers.org.uk/about-us/news-and-media/facts-media#:~:text=The%20annual%2C%20per%20person%20cost,with%20dementia%20and%20their%20families.. [Accessed 2024].

16 D. Foster. 2024. "Introducing a cap on care costs." [Online]. Available: https://commonslibrary.parliament.uk/research-briefings/cbp-9315/. [Accessed 2024].

17 Carers Trust. 2024. "Carers Trust responds to new data showing brutal health impact of being an unpaid carer." [Online]. Available: https://www.carersuk.org/press-releases/unpaid-care-in-england-and-wales-valued-at-445-million-per-day/. [Accessed 2024].

18 Alzheimer's Research UK. 2021. "The Economic Impact of Dementia." [Online]. Available: https://dementiastatistics.org/statistics/the-economic-impact-of-dementia/#:~:text=In%202018%2C%20the%20global%20cost,expected%20to%20double%20by%202030.&text=projection%20cost%202050-,World%20Alzheimer%20Report%202015%20The%20Global%20Impact%20of%20Demen. [Accessed 2024].

19 Alzheimer's Society. 2016. "Fix Dementia Care: Homecare." [Online]. Available: https://www.alzheimers.org.uk/sites/default/files/migrate/downloads/fix_dementia_care_homecare_report.pdf. [Accessed 2024].

20 London Borough of Hounslow. 2023. "Health and Care Scrutiny Panel Meeting: 7– 9pm, 22 February 2023."

21 Alzheimer's Society, World Alzheimer's Month, 2024.

22 B. A. Springate and G. Tremont. 2014. "Dimensions of caregiver burden in dementia: impact of demographic, mood, and care recipient variables," *The American Journal of Geriatric Psychiatry*.

23 Nuffield Trust. 2021. "Ethnicity coding in English health service datasets." [Online]. Available: https://www.nuffieldtrust.org.uk/research/ethnicity-coding-in-english-health-service-datasets. [Accessed 2024].

24 G. Iqbal, M. R. Johnson, A. Szczepura, S. Wilson, A. Gumber and J. A. Dunn. 2012. "UK ethnicity data collection for healthcare statistics: the South Asian perspective," *BMC Public Health*.

25 Alzheimer's Research UK. 2022. "Inequalities in Dementia." [Online]. Available: https://dementiastatistics.org/perceptions-and-inequalities/inequalities/. [Accessed 2024].

26 The Technology for our Ageing Population: Panel for Innovation. 2024. "The revised TAPPI principles." [Online]. Available: https://www.housinglin.org.uk/tappi/principles/the-revised-tappi-principles/. [Accessed 2024].

27 N. Nijhof, L., J. E. W. C. van Gemert-Pijnen, R. Woolrych and A. Sixsmith. 2013. "An evaluation of preventive sensor technology for dementia care," *Journal of Telemedicine and Telecare*.

28 G. Hughes, S. E. Shaw and T. Greenhalgh. 2020. "Rethinking Integrated Care: A Systematic Hermeneutic Review of the Literature on Integrated Care Strategies and Concepts," *The Milbank Quarterly*.

29 Bradford Teaching Hospitals NHS Foundation Trust. 2023. "New REACT service helps patients in the last year of life receive treatment and care at home." [Online]. Available: https://www.bradfordhospitals.nhs.uk/new-react-service-helps-patients-in-the-last-year-of-life-receive-treatment-and-care-at-home/. [Accessed 2024].

30 New Local. 2023. "How building trust can help tackle health inequalities." [Online]. Available: https://www.newlocal.org.uk/articles/trust-can-help-tackle-health-inequalities/ [Accessed 2024].

31 J. Harlock, S. Wilson and M. Thornton. 2023. "Valuing the role of the voluntary, community, faith and social enterprise sector in social care research, full report."

32 B. Gorham and M. Wood. 2023. "Unlocking the power of health beyond the hospital."

Social Finance Ltd
87 Vauxhall Walk
London
SE11 5HJ
—
info@socialfinance.org.uk
+44 (0) 20 7770 6836

socialfinance.org.uk

Publication date: October 2024