

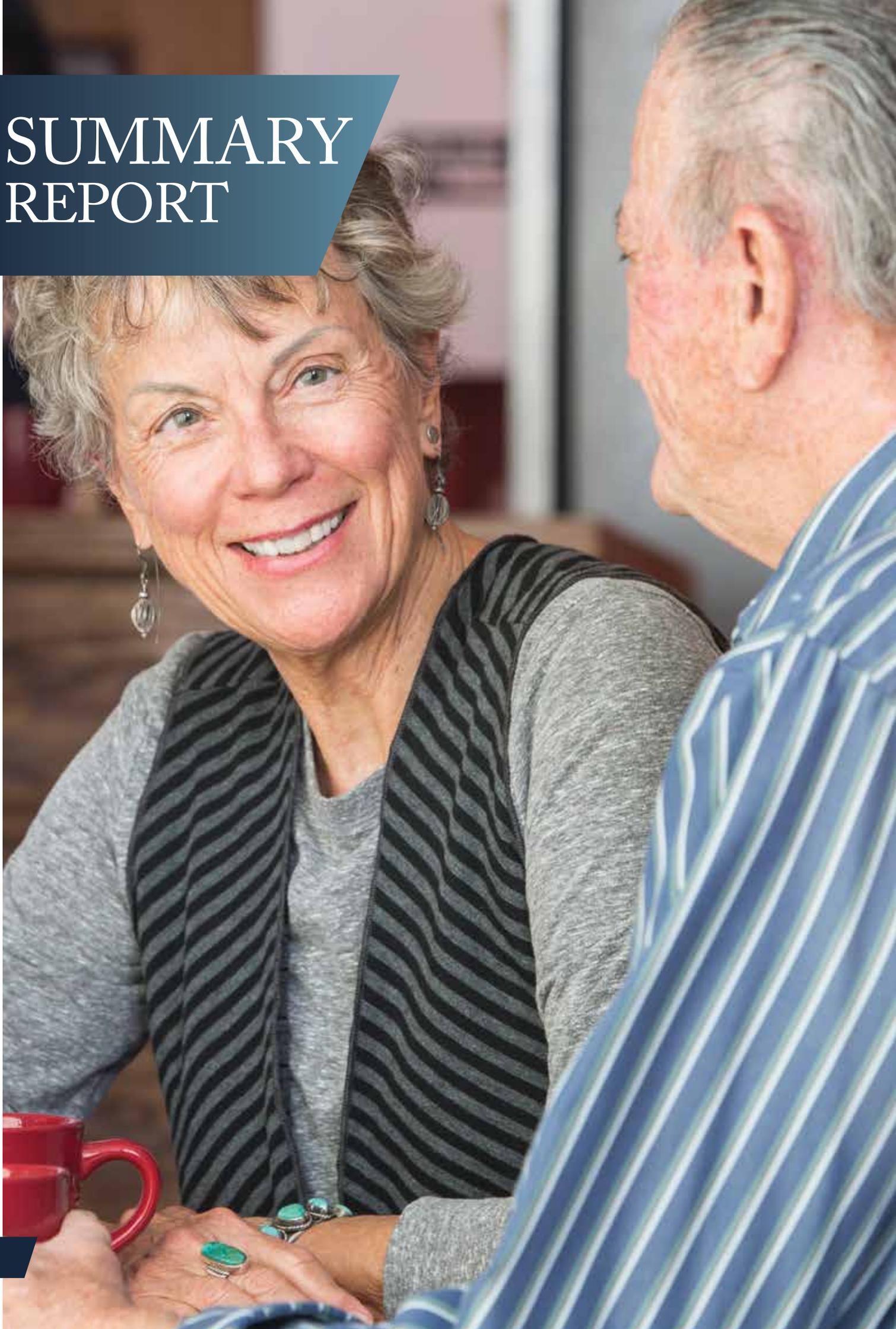


# MAKING THE UK VISITOR ECONOMY MORE DEMENTIA-FRIENDLY:

Lessons from the visitor attraction sector

Summary report

# SUMMARY REPORT



## MAKING THE UK VISITOR ECONOMY MORE DEMENTIA-FRIENDLY: LESSONS FROM THE VISITOR ATTRACTION SECTOR

### SUMMARY REPORT

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### Key Points

- Headline findings of the first international study focusing on businesses in the visitor economy and development of dementia-friendly initiatives.
- The Prime Minister's Dementia Challenge (2012) set out that UK businesses should become dementia-friendly by 2020.
- Businesses in the visitor industry can play a role in helping people 'live well with dementia', in line with the national dementia strategy.
- Constraints and opportunities exist in the visitor economy sector in increasing accessibility to customers with dementia.

### Introduction

This summary report presents findings of the first international study on developing dementia-friendly initiatives in the visitor economy<sup>1</sup>. This study is part of a wider programme of research on helping the UK visitor economy to become more dementia-friendly. It is a work stream of the Prime Ministerial Working Group on Dementia concerning Air Transport and Tourism. It is set in the context of the Prime Minister's Dementia Challenge that UK businesses should become dementia-friendly by 2020<sup>2</sup>.

An estimated 46.8 million people are affected by dementia worldwide, a figure expected to double every 20 years reaching around 131.5 million by 2050<sup>3</sup>. In the UK, some 850,000 people have a dementia diagnosis. This report is designed to stimulate discussion about the significance of dementia for the visitor economy and actions to help support the development of dementia-friendly initiatives. It highlights the challenges facing businesses and organisations in anticipating, meeting and enhancing visitor experiences for those living with dementia. The study findings have global implications for countries with ageing populations and increasing rates of dementia.

<sup>1</sup> The full study is published as 'Business engagement in a civil society: Transitioning towards a dementia-friendly visitor economy', *Tourism Management*, Volume 61, August 2017, Pages 110-128, Joanne Connell, Stephen J. Page, Ian Sheriff, Julia Hibbert. The article can be accessed at [www.sciencedirect.com/science/article/pii/S0261517716302667](http://www.sciencedirect.com/science/article/pii/S0261517716302667).

<sup>2</sup> See for updates on the implementation of the Challenge: [www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan](http://www.gov.uk/government/publications/challenge-on-dementia-2020-implementation-plan).

<sup>3</sup> Alzheimer's Disease International (2015). *World Alzheimer Report: The global impact of dementia. An analysis of prevalence, incidence, cost and trends. Summary sheet.* URL: [www.alz.co.uk/research/WorldAlzheimerReport2015-sheet.pdf](http://www.alz.co.uk/research/WorldAlzheimerReport2015-sheet.pdf).

## The visitor economy

The UK visitor economy is a key component of the UK service sector and it generates around £113 billion in visitor spending<sup>4</sup>. The visitor economy is a **broad term** that embraces the services and economic activities that support the needs of visitors during leisure trips, day visits and holidays. The range of tourism and hospitality-related businesses and organisations that have 'touchpoints' with visitors is broad and includes:

- accommodation providers (serviced and non-serviced);
- food and beverage services (e.g. restaurants, pubs and cafés);
- travel companies (airlines, cruise lines, travel agencies and tour operators);
- travel infrastructure (e.g. transport services, public transport, airports);
- visitor attractions;
- cultural attractions (e.g. festivals and events);
- visitor and information services, including guided tours and booking services;
- leisure shopping (related to visits to tourist sites and attractions rather than shopping in general);
- other associated activities (e.g. car parking services, public space management, destination marketing organisations, websites, apps).

## Ageing, disability and dementia

Dementia is a condition most strongly correlated with age. Of the 850,000 diagnosed cases in the UK, 805,000 are aged 65 and over, while 40,000 have 'early-onset dementia' (i.e. before the age of 65). This equates to about 1 in 14 people over the age of 65.

In the UK, it is common knowledge that we have an **ageing population**: over 30% of the population is aged 50 or over, while 18% of the population is aged 65 and over, with a growing number of very old people aged 90 or over<sup>5</sup>. An ageing population poses many challenges for visitor-facing businesses that may need to rethink their business models, especially the way they engage with their customers, the visitor journey and experience, and the needs and expectations of ageing customers.

Businesses in the visitor economy are more **dependent on older consumers** than often acknowledged: the Barclay's report *An Ageing Population (2015)*<sup>6</sup> highlights that only 5% of businesses recognise the importance of this market segment.

Given the growing number of older people in our society, the **prevalence of dementia** is likely to increase. Dementia is a major cause of disability in older people but in its early stages is often considered as a hidden condition that is not easily identified in the same way as a physical disability.

VisitEngland research states that 'nearly one in five tourism day trips in England were taken by people with an impairment and their travelling companions', and 'over half a million people with a health condition or impairment visit England from abroad each year'<sup>7</sup>. While much attention of UK tourism organisations has focused on the **accessibility agenda** as a market segment worth £12 billion (of which £3 billion is spent on overnight trips in England), the needs of people with hidden health conditions are less well understood and thereby catered to. Indeed, the significance of dementia as a **hidden condition** deserving greater attention from tourism organisations is demonstrated by the fact that, in 2016, dementia replaced heart disease as the leading cause of death, accounting for 11.6% of all recorded deaths in England and Wales.

<sup>4</sup> VisitBritain/Deloitte (2013). Tourism, jobs and growth [www.visitbritain.org/visitor-economy-facts](http://www.visitbritain.org/visitor-economy-facts).

<sup>5</sup> Office for National Statistics (2016). Population Estimates for UK, England and Wales, Scotland and Northern Ireland: mid-2016 [www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2016#uk-population-continues-to-age](http://www.ons.gov.uk/peoplepopulationandcommunity/populationandmigration/populationestimates/bulletins/annualmidyearpopulationestimates/mid2016#uk-population-continues-to-age).

<sup>6</sup> Barclays (2015). *An ageing population: The untapped potential for hospitality and leisure businesses*. London: Barclays.

<sup>7</sup> VisitEngland [www.visitbritain.org/providing-access-all](http://www.visitbritain.org/providing-access-all).

Dementia is a term used to describe a large spectrum of symptoms created by disease of the brain. Alzheimer's disease is the most commonly known cause of dementia, accounting for around two-thirds of cases<sup>8</sup> but there are many other types of dementia such as Vascular Dementia and Dementia with Lewy bodies<sup>9</sup>. Dementia is a complex condition that often interacts with other illnesses. It poses distinct difficulties for people due to degenerative cognitive function that may affect memory, communication and behaviour, create sensory disturbances, sleeping problems, behavioural changes, and induce other symptoms that worsen progressively.

### **Living well with dementia: The case for the visitor economy to become dementia-friendly**

There is a growing recognition globally that the well-being of people with dementia is well served by seeking to maintain independence to 'live well' as the disease progresses through time and the range of constraints imposed by the condition grow. Part of living well encompasses a degree of normality in leisure choices, such as being able to take day trips, visits to attractions and holidays, especially in the early stages of dementia where cognitive impairment may be less constraining. Research shows that maintaining participation in meaningful activities (for example, outdoor recreation) can reduce the effects of dementia. Visits to favourite places and spaces may not just help promote physical health but can stimulate memory and emotional well-being. Furthermore, getting out and about in the way a person has been used to may help to avoid the stress of being confined to the home, during a time when their geographical range of activity may be reduced due to the progression of their condition.

Why is this relevant to the visitor economy? New challenges face businesses in accommodating an ageing population from the baby boomer generation, with record levels of disposable income and a well-developed pattern of leisure consumption based on holidays and leisure activities. The prevailing thinking on the best way to approach the life changes which dementia brings may best be understood in 'living well with dementia': tourism and leisure have a role to play in this.

Several studies show that being out of the home setting can help lessen the rapid mental deterioration associated with the condition thereby reducing the escalation of medical intervention and care required to meet growing dependence needs<sup>10</sup>.

Accordingly, visitor-facing businesses and organisations have a role to play in helping people with dementia and their carers to continue to live meaningful leisure lives. This means addressing the barriers to an often 'hidden condition'. With over 850,000 people with dementia in the UK, and their carers and families, this is a significant market of at least 1.7 million people. Developing a more dementia-friendly visitor economy is important given the different touchpoints within the visitor journey, and the potential for positive impact on visitor experience. It raises the need for a more holistic vision of becoming dementia-friendly as embodied in the principles behind developing dementia-friendly communities as illustrated in Table 1.

<sup>8</sup> See: [www.alzheimersresearchuk.org/about-dementia/types-of-dementia](http://www.alzheimersresearchuk.org/about-dementia/types-of-dementia).

<sup>9</sup> See: [www.alzheimers.org.uk/info/20007/types\\_of\\_dementia](http://www.alzheimers.org.uk/info/20007/types_of_dementia).

<sup>10</sup> See e.g. Duggan, S., Blackman, T., Martyr, A., & Van Schaik, P. (2008). The impact of early dementia on outdoor life. *A shrinking world? Dementia*, 7(2), 191-204, and Roland, K. P. & N. L. Chappell (2015). Meaningful activity for persons with dementia: Family caregiver perspectives. *American Journal of Alzheimer's Disease and other Dementias*, 30(6): 559-568.

**Table 1: Characteristics of a Dementia-Friendly Community**

<p>Helps people with dementia to:</p> <ul style="list-style-type: none"> <li>■ find their way around easily and to travel around the area</li> <li>■ feel safe when out and about</li> <li>■ access everyday facilities and services (e.g. banks, shops, cafés and cinemas as well as healthcare services)</li> <li>■ maintain social networks and participation in community activities</li> </ul> <p>Promotes education and public awareness of dementia</p> <p>Empowers people with dementia to contribute to service development and integrates needs in planning</p> <p>Recognises that people with dementia are a valuable part of the community</p> <p>Supports caregivers</p> <p>Supports organisations, services and businesses to work towards becoming dementia-friendly</p> <p>Brings together stakeholders to establish action plans, and evaluate progress</p>
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Source: adapted from Connell et al (2017)

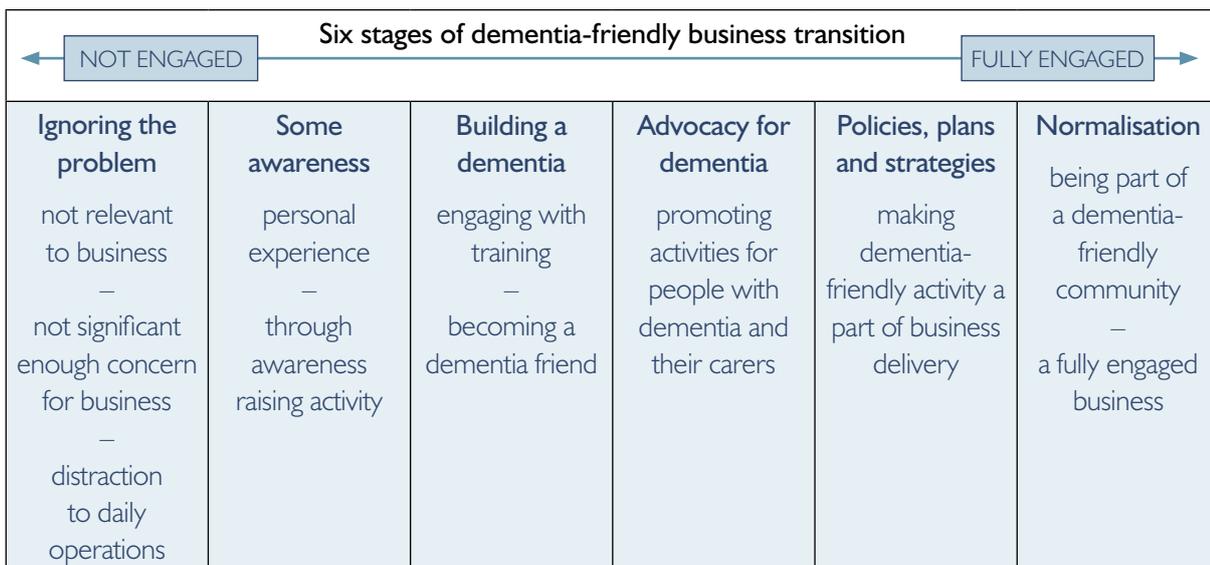
To embrace the dementia-friendly community principles enshrined in Table 1, the Prime Minister’s Dementia Challenge (2012) set out that UK businesses should become dementia-friendly

by 2020. One of the underlying reasons for this study was to understand how one sector of the visitor economy (i.e. visitor attractions) was embracing the ethos of becoming dementia-friendly.

**Becoming dementia-friendly: A model**

To structure our study, we developed the framework in Figure 1, adapting the idea from the World Health Organisation of the six stages of understanding dementia as part of society.

**Figure 1: The six stages of dementia-friendly business transition<sup>11</sup>**



Adapting this model to the business setting enabled us to map business experience of dementia to gauge progress towards a greater integration of people with dementia into their business activities and practices.

<sup>11</sup> Source: Connell et al. (2017) based on World Health Organization. (2012). Dementia. A public health priority. Alzheimer’s Disease International and World Health Organization.

## Research study

This was an exploratory study to examine dementia awareness, perception, experience and practice within businesses. While it may not be representative of the entire visitor economy, the study aimed to set out issues and practice that might assist future development of a more dementia-friendly visitor economy. The study used two sources of primary data to assess these issues:

- A small sample survey of visitor economy businesses circulated online, delivered to visitor attractions in Scotland in 2016 in partnership with a major trade association to help gauge interest, awareness and practice in this sector.
- In-depth interviews with 20 tourism organisations and visitor attractions and providers of dementia services.

The focus on visitor attractions was selected for two important reasons:

- Visitor attractions have a diverse appeal, deriving their markets from a diverse range of visitors (e.g. residents, day trippers and tourists)<sup>12</sup> and so is widely representative of the general population with differing needs.
- Visitor attractions possess a wide range of activities that embody many aspects of the visitor economy (e.g. a core activity focus, retailing, hospitality and other services). They are complex businesses where visitor needs must be understood and accommodated across a range of experiential activities.

## Study findings

We combined the results from the two studies and mapped them across the six-stage model in Figure 1 so that we could depict the progress and challenges for the sector and progress towards becoming dementia-friendly.

### Stage 1: Ignoring the problem

Few respondents saw dementia as an unimportant issue for the visitor economy and most considered the development of dementia-friendly initiatives as important for the sector. The main issue highlighted by the interviews was a *lack of awareness* of dementia. Dementia-friendly initiatives are simply 'not on the radar' and a lack of engagement was due to lack of knowledge and awareness rather than intent.

Some visitor attraction managers mentioned work they were aware of with autism (often corroborating the findings from other studies)<sup>13</sup> so 'hidden conditions' were understood as opposed to simply referring to the wider accessibility debate around disability. Yet as one respondent stated, '...dementia is quite...unattractive' as a topic compared to other social issues around the accessibility debate.

Obstacles to becoming dementia-friendly cited by visitor businesses and organisations in the study included:

- Not being a significant enough issue for the visitor attraction sector due to a lack of knowledge and awareness, potentially indicating the ineffectiveness of communication.
- A distraction to daily operational issues given a squeeze on staff time and resources in the sector.
- Resource constraints (e.g. the cost of staffing and availability of capital to fund dementia-friendly activities given these were not viewed as core to the organisation).
- Businesses are faced with too many remits (i.e. social and environmental demands/campaigns all worthy of support).
- Problems of seasonality and peak workloads challenging businesses ability to prioritise time for this activity.
- Perception that the needs of people with dementia are addressed by their carers (who may also want free entry).
- Some view dementia as covered under their widening accessibility agenda rather than one needing separate attention.

### Stage 2: Some Awareness

Two thirds of respondents identified dementia as a brain disease and similar numbers had heard of the term 'dementia-friendly' although many were not fully sure what the term really meant. While there was a limited understanding of the disease in general terms for most of the businesses in this study, most recognised that people with dementia would engage in activities in the visitor economy (such as eating out and going on holiday), refuting the dominant image of the late stage of the disease.

<sup>12</sup> Connell, J., Page, S. J., & Meyer, D. (2015). Visitor attractions and events: Responding to seasonality. *Tourism Management*, 46, 283-298.

<sup>13</sup> Hamed, H. (2013). Tourism and autism. An initiative study for how travel companies can plan tourism trips for autistic people. *American Journal of Tourism Management* 2 (1), 1-14.



Within the interviews, much discussion focused on participants having some awareness of dementia. But where did the awareness come from and what are the implications of this?

- A major factor influencing adoption of dementia-friendly initiatives was prior experience of family or friends with dementia (most notably parents, grandparents or older relatives).
- One member of staff with an understanding of dementia can make a big difference – often the difference between an organisation placing dementia on the agenda or not.
- Personal connections with dementia can prompt leadership, ambassadors and those prepared to champion actions to promote dementia awareness and dementia-friendly environments.
- Personal knowledge can be shared to raise organisational awareness.
- But the application of personal knowledge is sporadic and cannot be relied on to promote widespread practice.
- Aside from individual connections, knowledge appears largely to be linked to local initiatives (e.g. local authority and local third sector projects) rather than national campaigns (e.g. dementia organisations).

### **Stage 3: Building dementia infrastructure**

The study assessed to what extent businesses were building the infrastructure required to promote dementia awareness. The interviews revealed three major inter-related constraints to developing dementia-friendly initiatives:

**1. Cost:** businesses show some concern about the cost of making adaptations to become dementia-friendly given experiences of compliance with the Disability Discrimination Act (1995) and Equality Act (2010). However, this may be a perception of cost rather than the reality of becoming dementia-friendly which can be relatively inexpensive at a basic level.

**2. Staffing:** limited budgets means that many businesses do not have the staffing capacity to engage in 'extra' activities, i.e. those that are viewed as beyond the scope of core operational tasks. Even where there is a real interest in dementia, some organisations do not have enough staff time to engage in training or developing projects, or simply time to think about putting dementia-friendly actions into place.

**3. Knowledge:** low levels of dementia awareness is a major constraint on businesses engaging with the issue. Essentially, managers know very little about what actions they can take and do not know where to seek information. Support for businesses wishing to become dementia-friendly in terms of practical support and advice is needed. This needs to be easy to access, cost free and delivered in different formats to suit the needs of different business settings.

In addition, **leadership** of dementia awareness in the visitor economy to lead and inspire other businesses to engage emerged as a theme. The discussion was focused on who should lead this intervention, with some agreement that this is best delivered by industry-specific bodies with effective channels of communication with business, such as:

- The Destination Marketing Organisation (i.e. a tourism body at a regional or local level).
- professional bodies/trade associations with a leadership role in sub-sectors of the visitor economy.
- local authorities.

Learning from businesses that had already taken steps to improve their dementia preparedness to **showcase** what can be done and how to do it is a key advocacy role to convince businesses to listen to ambassadors who can demonstrate how easy it is to become dementia-friendly.

#### Stage 4: Advocacy

Two key themes emerged for this stage:

- **Personal advocacy**, where employees with a personal interest or commitment to dementia awareness (but for whom this is not drive their core post) drive initiatives and lobby managers and Board members in organisations to stimulate initiatives. This also highlights the importance of disseminating research and good practice.
- **Business/organisational advocacy**, where a business ambassador is suggested to liaise within and between businesses. This also extends to a visitor advocacy role for people with dementia as visitors. Largely, the research indicates that businesses are keen to find out what dementia-friendly means, how it works in other businesses and what it means for their own setting.

The study finds four approaches to supporting businesses to become dementia-friendly:

### 1. Inspire:

through practice: recognise the value of B2B advice and shared experiences through businesses coming together and learning from each other. Businesses will follow each other so once market leaders are visible to others, practice will be “out there” and will filter through.

### 2. Be ahead of the market:

there is a strategic need to be ahead in the competitive visitor economy and an inherent danger in not looking at market developments: if you do not look “at the size of the market you are not catering for... your competitors will”.

### 3. Increase business knowledge of dementia-friendly actions:

given very little knowledge about existing schemes and advice, how dementia-friendly actions are communicated to businesses within the visitor economy needs to be looked at. Businesses need practical advice on steps that they can take, how to achieve these steps and the costs associated.

### 4. Select effective communication channels mode to distribute information and advice:

through practice: recognise the value of B2B advice and shared experiences through businesses coming together and learning from each other. Businesses will follow each other so once market leaders are visible to others, practice will be “out there” and will filter through.



Figure 2: Dementia-friendly initiatives taken by attractions<sup>14</sup>

Setting aside a quiet room for people to take time out
Clearer wording and signage to assist orientation at visitor sites and in buildings
Thinking about appropriate floor surfaces (e.g. replacing floors that create sensory disruptions)
Changing door colours so doors are easy to locate
Hosting a memory café
Holding dementia workshops and events (e.g. reminiscence events)
Providing free tea and cake at dementia-friendly social events
Putting on entertainment sessions
Organising bespoke tours for groups from care homes
Working in partnerships with voluntary groups and care homes
Looking at the effect of physical infrastructure on people with dementia
Changing staff attitude, e.g. dementia awareness training and education
Engaging with local community

### Stage 5: Key proposition

Some 70% of businesses responding to the online survey agreed that 'I would like to make my business more dementia-friendly' but few businesses were planning to make any adaptations. Dementia friendliness was not a key proposition for many organisations. The most dynamic advocates were found within the museum sector where they were viewed as community resources and so needed to adapt to diverse visitor audiences. While building up community provision as a strong underpinning element of the visitor economy is a key issue for these attractions, audience development is essential for all businesses.

Within the interviews, those businesses which had progressed dementia-friendly initiatives advocated a more national approach with new signage, adjustments to the physical environment and investment in staff training.

### Stage 6: Normalisation

This stage emphasises that people with dementia are treated without separating them out into a niche market or group. In the interviews, several participants recognised the need for this normalised approach to the issue which highlighted:

- A moral obligation 'to do the right thing'.
- The necessity of engaging with customers.
- Engaging fully with new design principles and providing training to embrace (rather than meet) visitor needs.
- Reducing the stigma of dementia, accepting it is part of society and a reality for many, which service providers need to build into their customer service approaches.
- Avoiding patronising approaches to people with dementia and their carers.

Some early indicators of practice that promote normalisation are:

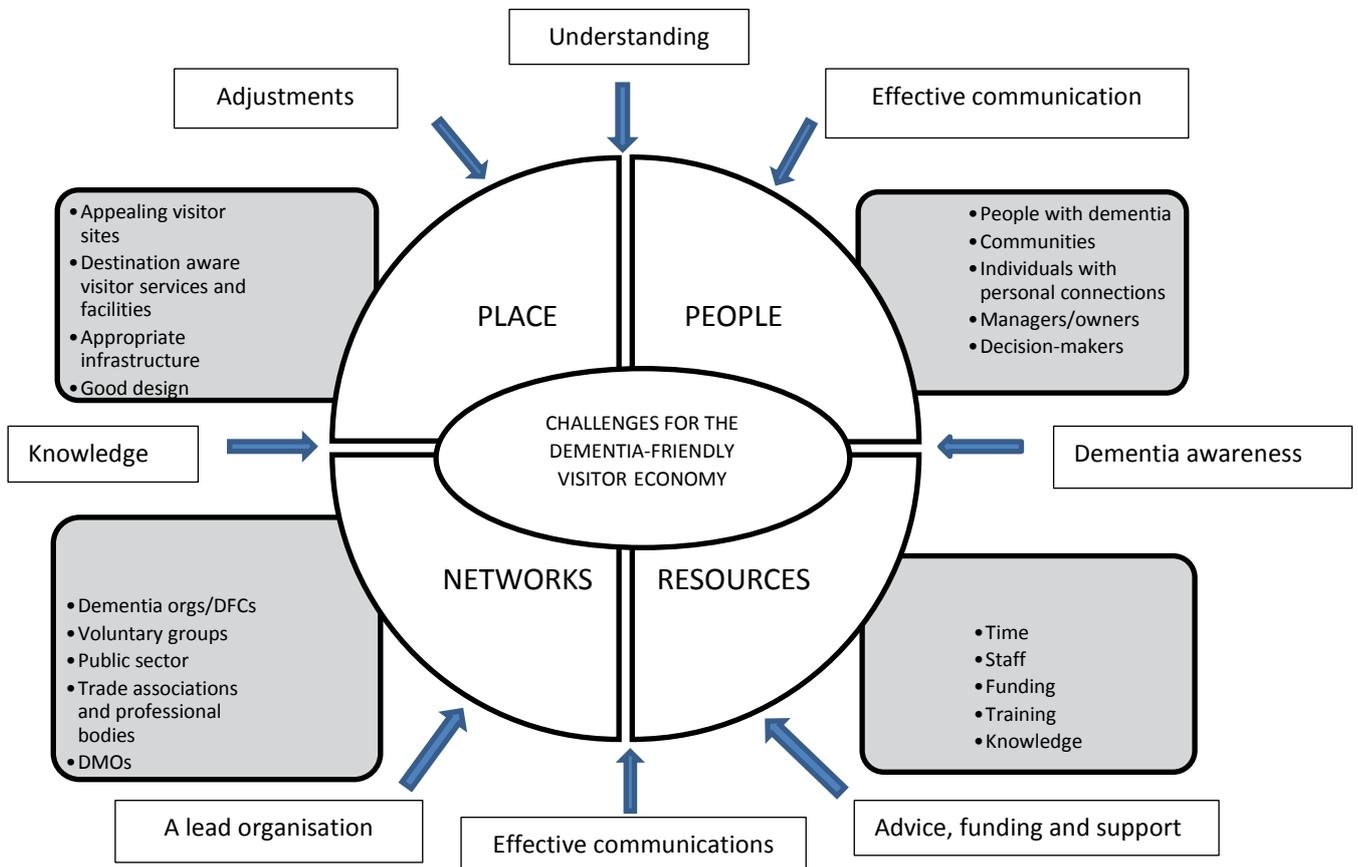
- Providing full place information so visitors can use their own judgement about what may or may not be suitable.
- Not separating people with dementia from the mainstream – much of what is needed to support people with dementia is of huge benefit to the visitor experience for all, such as excellent customer service, clear signage, well-designed spaces and a well-considered visitor journey.

### Implications

Figure 3: Summarises the key challenges in the visitor economy.

1. People with dementia and their carers seeking to enjoy day trips and holidays and to maintain quality of life through these experiences are an emerging market for businesses and organisations in the visitor economy.
2. The topic is a very sensitive one and uncomfortable for many people to discuss. Part of this is related perhaps to lack of knowledge and/or not wanting to say the wrong thing. A low response rate to the online survey may also endorse this point, a feature observed in other studies of business engagement and dementia-related themes.
3. Business owners and managers need more information and to build up their knowledge to communicate headline messages and actions to their staff, or to put initiatives in place.
4. Leadership of this issue appears to be best served by a trade body or professional organisation to promote the approaches and practices needed to become dementia-friendly.
5. Many businesses rolled the discussion into the tourism-accessibility debate. But this allocates dementia to a category or social group and does not move thinking on around the normalisation debate.
6. Problem of small business and limited resources means that developing dementia-friendly initiatives, even when there is a will to do so, can pose challenges in terms of time, money and knowledge.
7. A place-related focus is needed to bring together the issue across the visitor economy but this may not be embracing the normalisation debate (i.e. separating out places as dementia-friendly rather than being an accepted part of business practice).

Figure 4: Challenges for the dementia-friendly visitor economy<sup>15</sup>



Source: Connell et al. (2017) developed from Crampton et al. (2012).  
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<sup>17</sup> Ian Sheriff is a trained social worker and the Academic Partnership Lead for Dementia at Plymouth Medical School, University of Plymouth UK. He Chairs several working groups of the Prime Minister's Dementia Challenge and is a Trustee of the Alzheimer's Society. He was also a leading figure in creating Plymouth City as a dementia-friendly environment.





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