

Evaluation of the House of Memories Family Carers Awareness Day

INSTITUTE OF CULTURAL CAPITAL

RAFAELA NEIVA GANGA, GAYLE WHELAN & KERRY WILSON

Crossing Boundaries: The value of museums in dementia care

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EXECUTIVE SUMMARY

House of Memories is an award-winning dementia awareness programme led by National Museums Liverpool (NML) in the UK. The original health and social care model, launched in 2012 with funding from the Department of Health, was designed to support carers working in health and social care sectors and ancillary public services to provide person-centred care and promote living well with dementia. The programme was subsequently developed and delivered in different regional settings with a range of national partners and support from statutory health commissioners. More than 11,000 health and social care workers have participated in the programme since 2012.

In 2016, NML launched the family carers awareness programme with funding from Department of Health, working in partnership with New Walk Museum and Art Gallery, Leicester; Salford Museum and Art Gallery; and the British Museum, London. Designed specifically for family carers and community-based volunteers, the half-day programme uses museum collections and resources to advocate empathic communication with people living with dementia; enable greater understanding within the care community of a person's history and life experience; empower family carers with information and ideas that they can use on a daily basis; promoting community wellbeing and resilience.

Researchers at the Institute of Cultural Capital (ICC) evaluated the programme as part of the *Crossing Boundaries* study, complementing successive evaluations of *House of Memories* health and social care model(s) (2013-16). Researchers used a mixed-method approach, combining quantitative profiling of participants' care responsibilities and museum engagement; standardised measures of subjective wellbeing and care burden (adaptations of the Warwick-Edinburgh Mental Wellbeing Scale and Zarit Burden Interview); participant observation of live sessions; qualitative interviewing with programme partners; and social value research including social return on investment analysis (SROI).

Data show positive outcomes concerning the understanding and practice of person-centred care, including strategies to reduce the stigma associated with dementia; to support living well with the condition; to promote dignity, respect and compassion in dementia care; and to combat isolation, social exclusion and loneliness.

Outcomes were attributed to the positive experience created by museum educators and staff. Observation data illustrate the value of the sophisticated, professional interpersonal skills of

the lead facilitator and of the trust placed in the museum environment as a welcoming space to share personal stories and experiences of dementia care. Getting to know more about dementia was also a key outcome, illustrating the quality of programme content regarding dementia as a clinical condition and its various presentations.

Concerning the wellbeing of participating carers themselves, data show a substantial improvement in self-reported mood upon immediate completion of the session. Longitudinal assessment of subjective wellbeing and perceived burden also show marginal improvements, albeit within a relatively short timescale (approximately 8-week period before and after participating in the programme).

Profiling of care responsibilities and perceived burden shows that the research sample can mostly be defined as ‘care managers’, combining looking after parents with dementia and other midlife responsibilities including work and younger family members, with an enhanced likelihood of experiencing depression in caring roles. Museum visitor profiles suggest that the sample mostly values the experience in a *Recharging* capacity (whereby museum visiting is motivated by a desire for a contemplative or restorative experience). The correlation between the three substantiates the future potential value of *House of Memories* to family carers, both as a personal support mechanism and in helping to improve the lived experience of dementia care.

From a strategic perspective, social value data validates the personal outcomes of the programme relating to subjective wellbeing, dementia knowledge and awareness and person-centred care practices. As a social return on investment for commissioners and key stakeholders, analysis shows an SROI ratio of **£1: £18.73** over a projected five-year period. The programme’s strategic value is reiterated through qualitative interview data with programme partners, who reflect on the impact of being in a collaborative relationship with *House of Memories* as a reputable national programme upon local developments in integrated health and social care and in promoting the value of museums as civic assets in regional public health agendas.

The research has acted as a valuable methodological testing ground for incorporating the family carers model into the full *Crossing Boundaries* study. Key learning outcomes to take forward include continued assessment of the impact upon family carer wellbeing and resilience (consistent with ongoing research on the health and social care model) alongside more detailed, longitudinal critical incident analysis of the ways in which *House of Memories* is utilised by participants and impacts upon the longer-term quality of care.

THE EVALUATION

The full research report describes in detail the methodology and resulting findings of a study designed to evaluate *House of Memories Family Carers Awareness Day* programme for informal caregivers¹ of people with dementia, led and delivered by National Museums Liverpool (NML), November – December 2016.

The study forms part of the practice-based research programme *Crossing Boundaries: The value of museums in dementia care*², developed in 2016 to consider the holistic cross-sector value and impact of *House of Memories*, NML's pioneering dementia awareness programme. The research combines standardised measures of subjective wellbeing; assessment of professional development outcomes using a situated learning theory and communities of practice framework; and social value research approaches including social return on investment (SROI).

Crossing Boundaries builds upon successive evaluation studies that demonstrate, with both quantitative and qualitative evidence, the many benefits of museum services using reminiscence and memory related activities for people with dementia and their formal and informal caregivers. Equally, it makes operational and strategic recommendations regarding the future development of *House of Memories*, and suggests methodology design adjustments for ongoing research.

Researchers at the Institute of Cultural Capital (ICC) are grateful to all *House of Memories Family Carers Awareness Day* delegates, to partner museum staff members and to the *House of Memories* team for kindly sharing with us their thoughts and experiences of the programme.

¹ According to Schoenmakers, Buntinx, & Delepeleire (2010) an informal caregiver is a 'person who, for evident reasons and on a regular basis, provides care for a care demanding person, in his/her immediate environment and who is not part of a formal or professional organization'.

² <http://iccliverpool.ac.uk/crossing-boundaries/>

INTRODUCTION

Dementia and Alzheimer disease, in England and Wales, are currently the leading cause of death for men and women aged 80 years and over. Dementia and Alzheimer disease have replaced ischemic heart diseases as the leading cause, in part because people are living longer, there is a better understanding of dementia, and improved diagnosis is also likely to have helped increased reporting of dementia as the certified cause of death (Office for National Statistics, 2015).

Dementia refers to a variety of diseases that are characterized by a progressive cognitive and overall decline. There is no cure for dementia, but culture and art-led programmes have been recurrent in literature as particularly beneficial strategies for improving the quality of life for people with dementia and their caregivers (formal and informal) (Camic, Baker, & Tischler, 2015; Rosenberg, 2009). It has been shown that cultural and artistic engagement can lead to a decrease in depression (Musella, et al., 2009), as well as an increase in positive feelings such as enthusiasm and enjoyment (MacPherson, Bird, Anderson, Davis, & Blair, 2009), and an improvement in the subjective wellbeing of people with a diagnosis of dementia and their caregivers (Kinney & Rentz, 2005).

People with dementia can commonly require high levels of care, most of which is provided by informal or family caregivers. The effects of being a family caregiver are frequently associated with high rates of burden³, physical and mental illness, and social isolation, as well as financial hardship. Dementia family carers tend to experience significant burden performing their caregiving role, associated, particularly, with the difficulty to cope with the condition and behaviour alterations of the person with dementia. In addition, the degenerative nature of the condition associated with its unpredictable course increases considerably the caring challenges (Zwaanswijk, Peeters, Beek, Meerveld, & Francke, 2013). The literature presents a correlation between caring for a person for a prolonged period and mental and physical health distress (Schulz & Martire, 2004). The sense of burden therefore is closely related to the amount of time spent on caregiving, and the nature of care given (e.g. personal care and domestic care).

Caregivers can be perceived as invisible second patients as their needs are second to the people they care about. However, the health and wellbeing of informal caregivers are critical to the

³ In the scope of this research, we make use of the concept of Burden as it is defined by Zarit, Reever, & Bach-Peterson (1980).

quality of life of the care recipients, but also are crucial to a sustainable national health care system for an aging society. Zwaanswijk, Peeters, Beek, Meerveld, & Francken (2013) argue that it is common for caregivers to have poor access to additional support and information from formal services, and therefore, can be inadequately prepared to provide care. However, without caregivers, people with dementia would have a poorer quality of life and would need institutional care sooner. This scenario would translate into heavy costs for the national health care system. In this sense, providing support to informal caregivers is essential to relieve the deleterious impacts of caring, and to promote better dementia care and reduce longer-term health care expenditure.

In 2012, National Museums Liverpool (NML), with funding from the Department of Health (UK), created *House of Memories* as a museums-led dementia awareness training programme that provides dementia carers (formal and informal) with resources to support people to live well with the condition. This programme uses museum collections as a stimulus for engagement and conversation with people with dementia drawing upon reminiscence therapy techniques.

Museum collections can be understood as the objectification of a collective memory – a narrative of the past and the present told by an assembly of objects. Those objects can appeal to common, but also to very personal stories and memories. Sharing those memories can help to preserve or even build social ties between people with dementia and their formal and informal caregivers, hence museums are ‘natural’ centres for reminiscing. As David Carr (2000, p. 251) argues museums and museums’ collections, as houses of objects, can be instrumental in dementia care: ‘There is no more likely place than the museum for the meeting of recorded history and living memory’.

Within the UK there is growing momentum around arts and cultural commissioning within social and public services, illustrated by a propensity of referral schemes such as ‘arts on prescription’. In this context, reminiscence therapy techniques have become increasingly popular within the museum field, with numerous projects that have been shown to have therapeutic value, and cognitive benefits for people with dementia (cf. Goulding, 2013; Windle, *et al.*, 2014; Young, Camic, & Tischler, 2015; Chatterjee & Noble, 2013).

House of Memories began as a full-day museums-based training intervention combining dramatic set pieces, forum theatre, interactive facilitation, museum and gallery tours, reminiscence therapy techniques and museum education activities. The programme is

supplemented by training resources including the *My House of Memories app*, which can be downloaded for use in a range of settings. The programme has also been adapted and developed for delivery in different professional environments, and with several national and international partner museums.

The *House of Memories Family Carers Awareness Day*, designed specifically for family carers and community volunteers, addresses the fact that dementia is not an isolated condition; it affects the whole community, with particular implications for family caregivers (Lynch, et al., 2009).

In this context, this study sought to develop an empirical understanding of the impact of *House of Memories Family Carers' Awareness Day* (across four participating museums) on the subjective wellbeing of a sample of participating dementia carers and the subsequent perception of their 'culture of care'. The study also explored how the process of engaging with museum collections in the social and physical context of a museum, and with the *My House of Memories app*, affects caregivers perceptions and uses of non-medical approaches and museum-led dementia care.

RESEARCH METHODOLOGY

House of Memories Dementia Awareness for Family Carers was a half-day programme for informal carers that took place in three regions across England (North, Midlands, and South), including Museum of Liverpool (25th November 2016), in collaboration with the following partner museums:

- New Walk Museum and Art Gallery, Leicester (2nd November 2016);
- Salford Museum and Art Gallery (14th November 2016);
- British Museum, London (1st December 2016).

The half-day awareness workshop combined a facilitated introduction to dementia through character-based documentary films to help understand the experience of living with dementia and being a carer; dementia-friendly museum activities specific to each setting; and opportunity to try out the *My House of Memories app*, which can be used in multiple care settings. In addition, the programme included as handouts an *Activity Planner* and a *Memory Tree* adapted to each partner museum. Local representatives from the regional Alzheimer's Society, and similar organizations supported the workshop, in order to provide information on additional support services.

Aiming to develop memory resources that are culturally relevant and accessible to informal carers, the *Dementia Awareness for Family Carers* model set out to:

- Advocate the value of compassionate and empathic communication with people living with dementia;
- Promote entitlement for a positive lifestyle and wellbeing for people living with dementia;
- Enable greater understanding within the care community of a person's history and life experience;
- Support individuals who are at risk of associated loneliness and isolation;
- Connect family carers across England (North, Midlands, and South);
- Empower family carers with information and ideas that they can use on daily basis;
- Enable diverse community representation;
- Positively inform and support communities and individuals caring for people living with dementia;
- Promote community wellbeing and resilience;

- Support the person living with dementia through reference and connections to shared life experiences, dreams, and histories.

The *Crossing Boundaries* research team at the ICC designed a research strategy for the *House of Memories Dementia Awareness for Family Carers* model that was consistent with past evaluation studies – *Northern* (2013) and the *Midlands* (2014) models, and *Pilot House of Memories Train the Trainer Programme* (2015/2016).

Considering that *Crossing Boundaries* work package 2 (WP2 - Wellbeing and Culture of Care) assesses the impact of *House of Memories* on dementia caregivers' subjective wellbeing, and the subsequent 'culture of care' within practicing communities, the research aimed to:

- Assess the impact of *House of Memories Dementia Awareness for Family Carers* model on the **subjective well-being of participating dementia carers and the 'culture of care'**, with specific reference to:
 - reducing the perceived stigma associated with dementia by raising awareness;
 - increasing the notion of how to live well with the condition;
 - promoting dignity, respect, and compassion in care;
 - combating isolation, social exclusion, and loneliness;
 - promoting independence;
 - promoting and encouraging an alternative to prescription based drugs;
- Share learning with full range of arts and cultural sectors on modelling responsive culture-led interventions in dementia field and other key health and social care priorities, by **assessing the transferability, adaptability, and, impact of the existing model** within and across the three distinct partner museums and gallery services;
- **Inform policy and strategic development** of the 'dementia friendly' cultural sector in England.

The evaluation was framed by existing studies on the impact of arts and culture on subjective wellbeing, including studies within the dementia field (Brooker, 2007; Camic, Baker, & Tischler, 2015). The research methodology design (Figure 1) comprises two online surveys – applied before and after the training to a total of 50 informal carers – including two standardised measures of subjective wellbeing adapted from the 12-item Zarit Burden Interview (Ballesteros, et al., 2012), and the Warwick-Edinburgh Mental Well-being scale (Warwick Medical School, 2017). This is consistent with previous *House of Memories* evaluation studies and aims to assess the impact of the programme on the subjective wellbeing of carers. Participant

observation of eight museum-led intervention sessions (two at each partner museum) along with a series of eight semi-structured interviews with museum staff have been conducted to explore in-depth the impact of the programme across the participating museums.

Finally, a Social Return on Investment (SROI) workshop was run in order to determine the social value and relative cost benefit of the *House of Memories Family Carers Awareness Day*. Testing the emerging findings of the research techniques above as valid impact indicators, the SROI helps to inform participating stakeholders and supports policy and strategic development of a 'dementia friendly' cultural sector in England (Nicholls, Lawlor, Neitzert, & Goodspeed, 2012; Throsby, 2001).

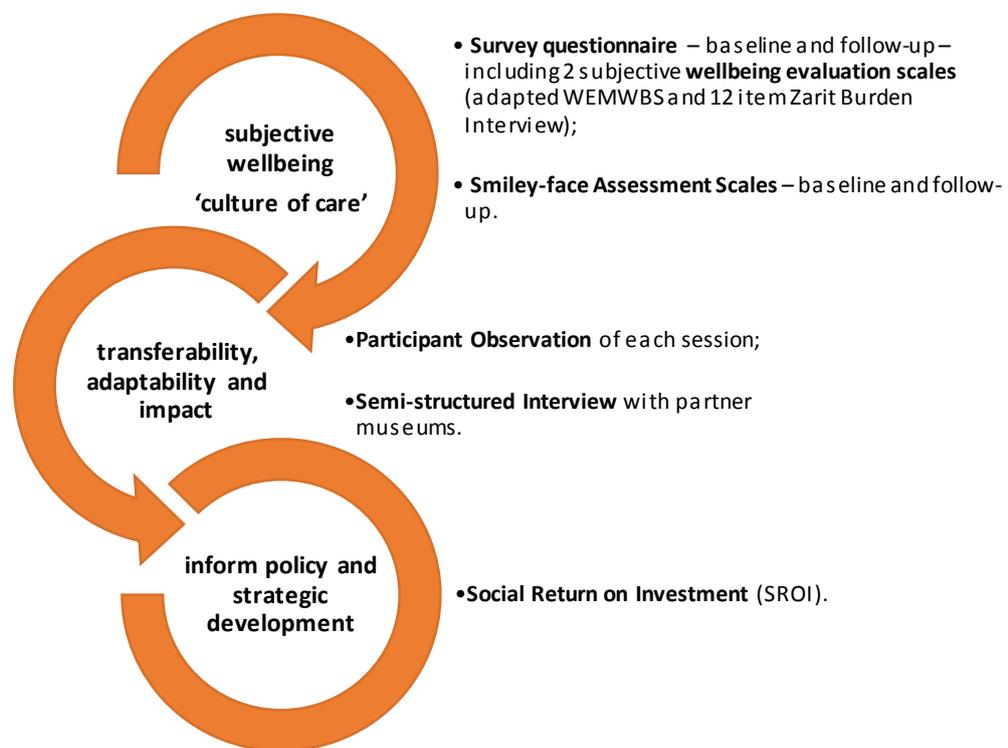


Figure 1 – Crossing Boundaries Work Package 2 - Wellbeing and Culture of Care – research methodology design

Research Methods

Survey questionnaire

A survey divided into two parts was applied, one at baseline (approximately 4 weeks prior to the workshop), and one as a follow-up (4 weeks after the workshop). Both instruments included

a standardised measure of subjective wellbeing adapted from existing, reliable research tools consistent with previous *House of Memories* evaluation studies.

Common sections

The section '**Dementia and Museums**' aims to understand the participation and engagement with museums and other arts and cultural forms pre and post-*House of Memories* awareness day, including questions on frequency of memory and reminiscence activities at a museum, and the influence of *House of Memories Family Carers Awareness Day* on the decision to return to the museum. This section aims to draft carers' cultural profiles, perceptions, attitudes, and practices towards museums and similar organizations.

The section '**Your Experience of Dementia Care**' differs from part 1 to part 2. In survey 1, the first part of the section is designed to draft respondents' care profiles, concerning cohabitation and relationship with the person with dementia, stage of dementia, hours per week spent on care and how long they have been caring for someone with dementia. On both parts, carers are asked to reply to two subjective wellbeing evaluation scales.

Following previous *House of Memories* evaluation studies (cf. WP1 reports), the first subjective wellbeing evaluation scale used is a 5-item adaptation of the Warwick-Edinburgh Mental Wellbeing Scale (Warwick Medical School, 2017) (WEMWBS), already tested at *Midlands model* (2014), and *Pilot House of Memories Train the Trainer Programme* (2015/2016). The five items include measures of interest in new approaches to dementia care; optimism; feeling good about oneself; cheerfulness and confidence. The second scale is a 12-item version of the Zarit Burden Interview for the Assessment of Dementia Caregivers' Burden (Table 1), adapted by Ballesteros, *et al.* (2012).

This scale was introduced in the evaluation research methodology design of WP2 for several reasons. First, it measures the subjective burden for informal carers using multidimensional characteristics: social, physical, financial and emotional burden, as well as the relation with the person with dementia; secondly, it provides evidence for two underlying factors for the scale: role strain and personal strain. Originally, this scale was built under the definition of subjective burden as 'One's subjective belief that current and future resources are insufficient to meet role demands' (Zarit, Reever, & Bach-Peterson, 1980). It has been widely validated and extensively studied, translated into several languages, and it is concise and user-friendly, besides the sensitive nature of the topic under question. Regarding carers of people with dementia, the

results showed that the 12-item ZBI had the highest correlation comparing with the 22-item ZBI (Cronbach's alpha > 0.70) ($r = 0.952$) (Higginson, Gao, & Jackson, 2010).

Table 1 - 12-item version Zarit Burden Interview for the Assessment of Dementia Caregivers' Burden

- 2. Not enough time for myself
- 3. Stressed by caring & other responsibilities
- 8. Relative's dependence on you
- 9. Feeling strained due to relative
- 10. Health decrease
- 11. Lack of privacy
- 12. Lack of social life
- 16. Unable to care much longer
- 17. Lost control of life
- 18. Leave the care to someone else
- 19. Uncertain about what to do
- 22. Overall feeling of burden

On both scales, a Likert scale format was followed (Table 2), whereby respondents were asked to identify the extent to which they agreed with given statements, coded as follows:

Table 2 - Subjective well-being scales coding

	WEMWBS	ZBI
Strongly disagree	1	0
Disagree	2	1
Undecided	3	2
Agree	4	3
Strongly agree	5	4

Sections specific to each part

The first part of the survey included a section dedicated to **sociodemographic** information. Subsequent sections of the survey collected information on delegates' **experiences with House of Memories**, especially concerning degree of satisfaction and relevance of the *House of Memories Family Carers Awareness Day* on reducing stigma associated with dementia, and possible effects of the use of *My House of Memories app* on the care receiver.

Interview

A series of eight semi-structured interviews were conducted to explore in-depth the transferability, adaptability, and impact of the existing model within and across the three separate and distinct partner museum and gallery services. The criteria for the selection of the interviewees was based on their involvement with the partnership with NML, and with the delivery of *House of Memories Family Carers Awareness Day* (Table 3). In the case of the British Museum, the Citi Money Gallery Curator was also interviewed due to the curatorial process of selecting objects from the Citi Money Gallery collection and support material for the *My House of Memories* app.

Table 3 - Interviewees by partner museum

New Walk Museum and Art Gallery (Leicester)	Business Development Manager Culture and Heritage Development Office
British Museum (London)	Citi Money Gallery Curator Citi Money Education Manager Head of Community and Partnerships
Salford Museum and Art Gallery	Libraries and Heritage Manager for Children and Families
Museum of Liverpool	Relationship Programme Manager House of Memories Creative Director

The interview guide with museum partners was divided into 5 parts:

- Beginning / Icebreaker: interviewees professional details, with a special focus on their current role on memory and dementia related programmes;
- Museum memory and dementia related activities/programme: detailed description of the museum's existing memory and dementia related activities/programme;
- Partnership with National Museums Liverpool (NML): nature, purpose, and challenges of the partnership with NML; and specific impact of the relationship with NML on museum's memory and dementia related activities/programme;
- Transferability of House of Memories: critical analysis of the transferability, and adaptability of House of Memories activities in the museum;
- The future of the museum's memory and dementia related activities/programmes.

After full transcription, the interviews were subject to content analysis using *N'Vivo* software, according to the categories and subcategories presented in table 4.

Table 4 - Content Analysis tree of categories and subcategories

Name	Sources	References
House of Memories	7	39
Impact	4	6
Transferability	4	16
Museum Dementia Activities	6	32
Currently	5	16
Future	6	16
Partnership NML	7	51
Challenges	6	25
Professional details	6	13

Smiley-face Assessment Scale

The smiley-face assessment scale is a self-report research instrument using a graphic response system (Figure 2) with five faces ranging from very sad to very happy (coded from 1 to 5). It was used on site to measure the delegates' emotional state immediately before and immediately after each session (Rosenberg, Parsa, Humble, & McGee, 2009).



Figure 2 - Smiley-face Assessment Scale

Participant Observation

All eight sessions of the *House of Memories Family Carers Awareness Day* were observed by at least one member of *Crossing Boundaries* project team. Observations were conducted in order to understand the situated transferability and adaptability of the existing model within

and across the three separate and distinct museum and gallery services, and were focused on three main issues:

- Museum and gallery space: use and appropriateness of available physical space, local museum/gallery visibility, and branding, ease of navigation;
- Event organisation: number of delegates, flow of registration process and type and volume of available information on other relevant services provided in local area, particularly related to dementia care; and information availability or access to information on participating museum and gallery services;
- Workshop information and communication: programme and agenda clarity, House of Memories support materials and branding, the level of delegate participation and engagement, type and nature of comments/observations made, and atmosphere in the room.

Additional data

As part of *House of Memories* social media dissemination, NML's Marketing Department invited delegates during coffee-breaks to write down their thoughts so far on the *House of Memories Family Carers Awareness Day*. NML Marketing Department kindly shared these responses with the *Crossing Boundaries* team. Due to the rich and thoughtful comments from delegates, it was our decision to integrate the results of this marketing strategy in the research design.

Social Return on Investment (SROI)

SROI is a framework for assessing the social value that is created as a result of an intervention through the perspective of its key stakeholders – those who are directly affected and whom experience change as a result of engagement. An SROI was conducted on the *House of Memories Family Carers' Awareness Day* to assess the social, environmental and economic impacts, capturing subjective qualitative evidence not gathered elsewhere in the evaluation.

The Public Value (Social Value) Act 2012 requires that public authorities consider how services they procure or commission can improve the wider economic, social and environmental wellbeing within communities. However, more public bodies and organisations are choosing to adopt methods to assess their value, often specifically using SROI to demonstrate cost-effectiveness and consider wider value. This wider value is measured in terms

of what is created (or destroyed) by the intervention and involves balancing the costs of investment with subjective wider values, or social value. The SROI ratio is typically expressed as ‘for every £1 invested, £x of social value is created’ (Nicholls et al., 2012).

As a ratio of monetised social value, SROI represents much more than just a cost ratio of impacts and benefits – it identifies a story of change. SROI analyses can provide key insight into areas of the intervention where additional social value could be created and maximised (Day and Jones, 2014). This SROI uses the actual costs of implementing the family carers’ awareness day balanced with subjective measures which take into consideration both the positive, negative and any unintended impacts to assess the overall value created by the *House of Memories* intervention.

There are several overarching principles to undertaking an SROI analysis, which include involving stakeholders in the research; understanding the impact and what changes; valuing what matters; not over claiming; and being transparent in the results. SROI analysis involves four distinct stages: scoping; engagement activities; results and feedback.

Scoping was undertaken during project planning between the research team and the intervention commissioners. This set out how data would be gathered, where and when. Engagement activities involved questionnaires and a focus group to gather richer data on the personal impacts of the awareness programme and dementia on the lives of family carers. Results have been imported and calculated into a pre-set Excel spreadsheet (the impact map), designed by the SROI Network (now Social Value UK).

SUBJECTIVE WELLBEING AND THE ‘CULTURE OF CARE’

Sociodemographic data

Survey data analysis was based on 66 usable responses.

The majority of caregivers (91%) were women, and almost 70% are 50 or more years old. The large majority were white (85%) In relation to marital status, 57% were married, and 29% were single (Figure 3).

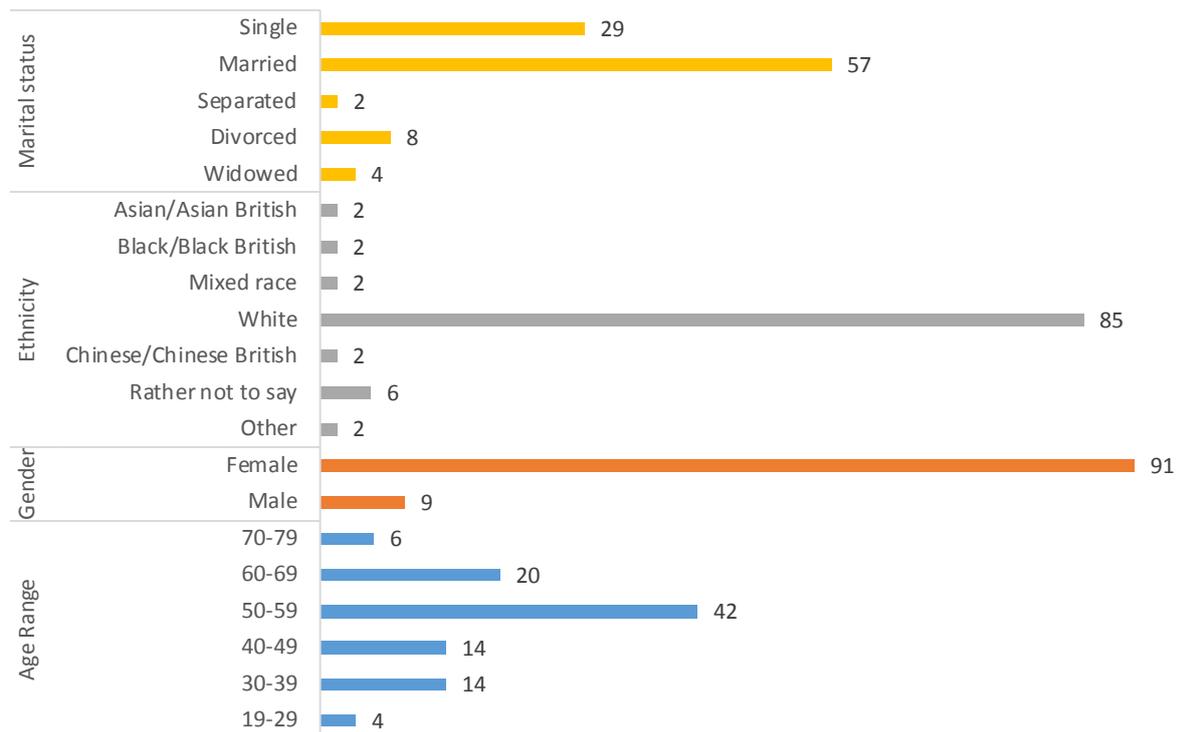


Figure 3 - Sociodemographic Characteristics [% - n=66]

More than half of the caregivers (60%) were employed by others, while 30% were retired or a full time carer, and most affirmed that they had enough money (66%). However, almost one third of the sample declared that they had some financial difficulty (23%) or a lot of financial difficulty (8%) (Figure 4).

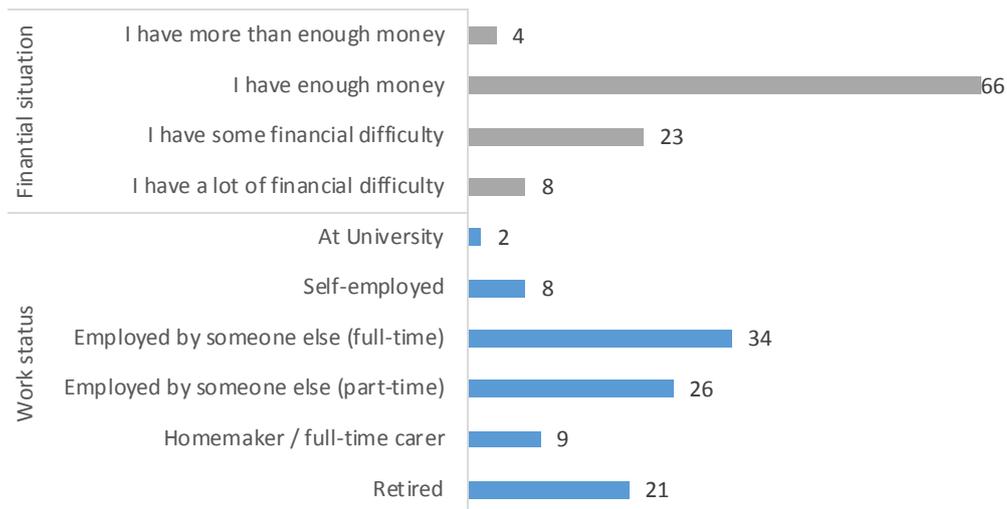


Figure 4 - Work status and financial situation [% - n=66]

Almost half of participating caregivers were ‘adult children’ eg. caring for a parent (47%), while only 8% were spouses or partners of a person living with dementia. The remaining group were mainly volunteer carers. The large majority of participants did not share the same house (85%) as the person with dementia. The main interest in dementia care was caring for a loved one (40%), or for a friend, family member, or neighbour (28%) (Figure 5).

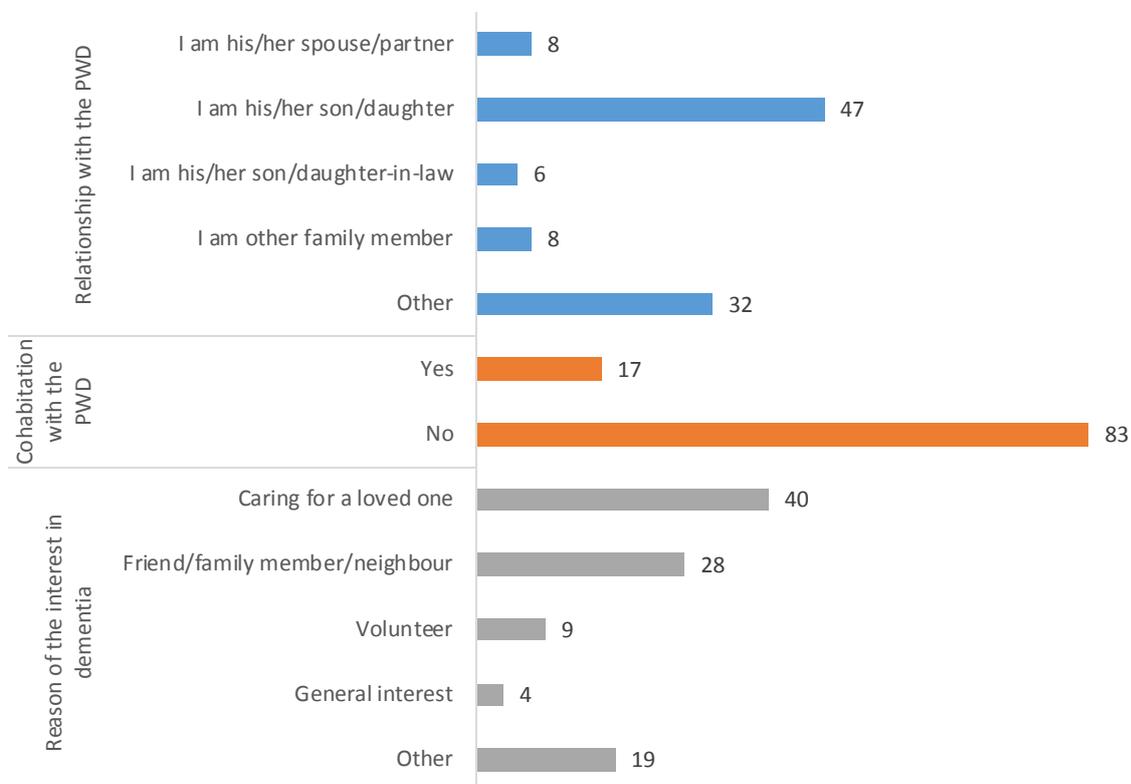


Figure 5 - Relationship and cohabitation with PWD, and reason of the interest in dementia [% - n=66]

Therefore, the typical profile of a dementia caregiver that attended *House of Memories* is a married, middle-aged or older female child of a person with dementia that works full time, and lives in her own house, with enough money to live on. This profile is generally defined as care managers (Archbold, 1981).

House of Memories Family Carers Awareness Day - level of satisfaction

When asked about the level of satisfaction with the relevant *House of Memories* session, the large majority responded positively. In fact, the item *Overall experience* is rated only positively (38% positive; 62% extreme positive). Other items were also rated 100% positive: *Information about House of Memories* (41% positive; 59% extremely positive), and *Relevance of the documentary films* (21% positive; 79% extremely positive) (Figure 6).

We can furthermore show that *House of Memories Family Carers Awareness Day* achieves its main aims and objectives:

- Reducing the perceived stigma associated with dementia by raising awareness:
 - The majority of respondents (41% positive; 41% extremely positive) consider the session they attended contributed to reducing the stigma associated with dementia;
- How to live well with the condition:
 - The vast majority of respondents (52% positive; 34% extremely positive) consider the session they attended contributed to learning how to live well with what they have;
- Promoting dignity, respect, and compassion in care:
 - The vast majority of respondents (59% positive; 38% extremely positive) consider that the session they attended contributed to promoting dignity, respect, and compassion in care;
- Combating isolation, social exclusion, and loneliness:
 - The vast majority of respondents (52% positive; 24% extremely positive) considered the session they attended contributed to getting to know other carers and reduce isolation, social exclusion, and loneliness.

Feedback collated through *House of Memories* social media comments from delegates reinforced these findings:

The films made the subject come to life. Memory App unlocks a lot of things. Mention of key phrases helpful: live in the moment; focus on the things you can do; dementia doesn't mean stupid; music can be deeply embedded; meet the person where they think they are (British Museum delegate).

To know you're not alone. Meeting people who understand. Help is out there! House of Memories - very informative (Museum of Liverpool delegate).

Brilliant course, eye opening and knowledgeable. Learned a lot! (Museum of Liverpool delegate).

It has been a very interesting afternoon so far! The different thoughts and views gave food for thought as each carer had tales to tell which were very worth listening to and to take on board! (Salford Museum and Art Gallery delegate)

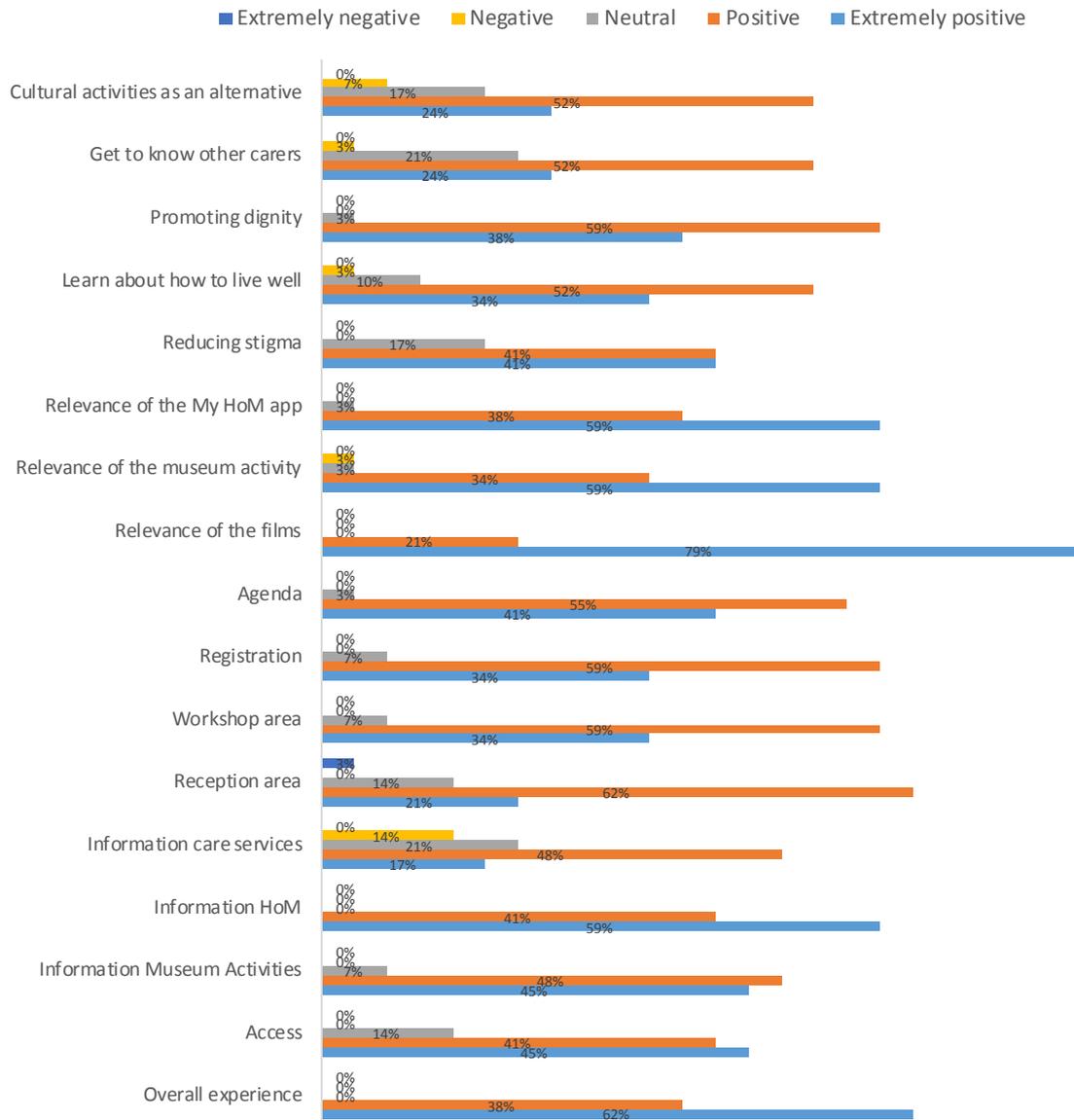


Figure 6 - Levels of satisfaction with House of Memories Family Carers Awareness Day [% - n=66]

When asked ‘What would you do differently?’ informal carers raised some concerns around balancing caring and away time: ‘Nothing it was at an excellent level... I thought everyone stuck to time as many of us are carers with limited time off!’ / ‘I would make more time available. It all felt very rushed’. Furthermore, it was suggested a ‘more hands on ideas and less video watching’ approach; and the possibility to share the session with the person with dementia – some delegates did actually share the session with the person they were caring for. At Salford Museum and Art Gallery, the session was held within the gallery of the Victorian permanent collection – painting, sculpture, and furniture. There were also some education materials in the room along with a trolley with material for children to dress-up. Between

refreshments and the beginning of the session, one of the delegates was holding a folder with information on the exhibition. However, as far as it was observed, the exhibition did not start any conversations amongst delegates.

The item *Reception area* is the only item evaluated with some extremely negative (3%) responses. The percentage is insignificant; however, it is helpful to reference other research instruments in order to understand why that item had a negative evaluation. Observation data provided some information on how difficult it was to find the workshop room in the case of The British Museum:

'The reception area was just outside the workshop room, beneath the BM Great Court at the Clore Education Centre. However, there was no sign at the main entrance or any other part of the museum, just by the registration desk and on the workshop room. Staff on the Museum information desk were not able to inform me about the location of the workshop' (Observation Note, British Museum).

The majority (93%) of respondents would recommend *House of Memories Family Carers Awareness Day* to family members or friends (Figure 13).



Figure 7 - Recommend *House of Memories dementia awareness for family carers' workshop* to a friend or a family member [% - n=66]

Beyond the very positive levels of satisfaction, we were interested to understand the most enjoyable moments of the session. A *Positive experience created by educators and staff* was selected by the majority of respondents (55%), illustrating the importance of the empathy created by *House of Memories* and partner museum teams with family caregivers. In fact, through observation it is possible to emphasise that sharing real stories was a recurrent technique used to positively engage participants.

The skilled facilitation of the session(s) was an important factor in enabling such empathic connections to be made. This included making time to meet and chat with individual participants before the workshop formally began and unobtrusively asking participants about their interest in the session and personal dementia care experiences. Gradually as the session progresses, participants are sensitively invited by name to share their thoughts and reflections on workshop content (e.g. documentary film stories), encouraging a sense of active engagement and community building. The impact of such interpersonal facilitation has been integral to the success of previous iterations of *House of Memories* and is undoubtedly a core cultural quality of the family carer adaptation.

At the same time, *Getting to know more about dementia* is highlighted by almost one third (24%) of the sample, which demonstrates that creating dementia awareness is still necessary (Figure 8). We can conclude that this particular programme, as a cultural intervention, can play an important role in a society in which it is estimated that 1 million will be affected by a form of dementia by 2025 and 2 million by 2051 (Alzheimer's Society, 2017).

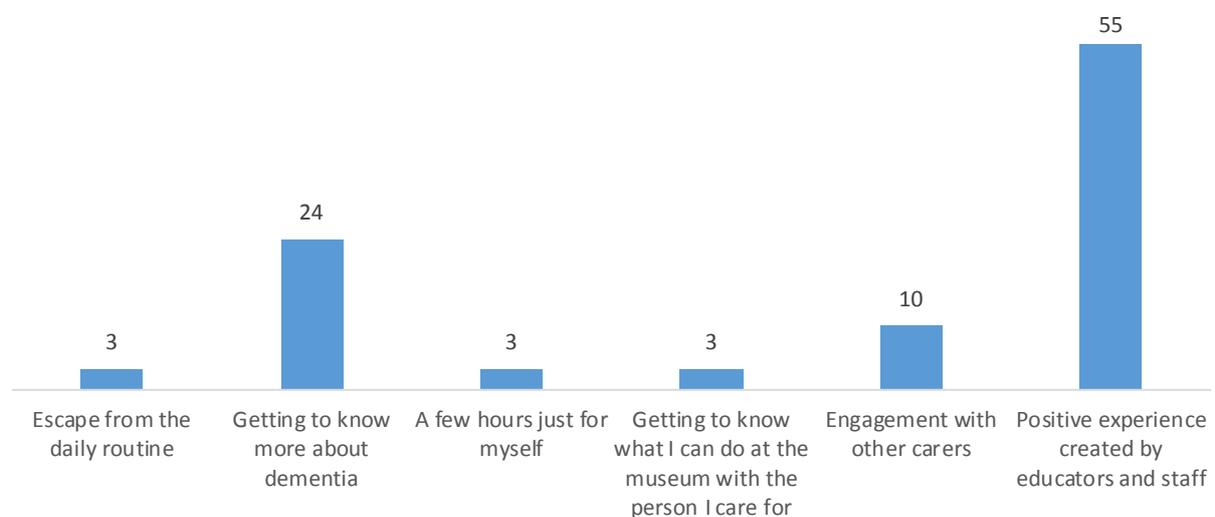


Figure 8 - Most enjoy about the *House of Memories* dementia awareness for family carers [% - n=66]

Subjective wellbeing

Despite the importance of family members as a resource and support mechanism for people with dementia (Department of Health, 2009) it is not uncommon for informal carers to be perceived as 'silent patients', in that their own health and subjective wellbeing can become

second to the needs of the person they care for (Alzheimer's Society, 2016). Considering this issue and the aim of *House of Memories* to give voice to these 'silent patients', it was also an aim of the evaluation to assess the immediate impact of the programme on delegates mood, and for that we used a Smiley-Face Assessment Scale (Rosenberg, Parsa, Humble, & McGee, 2009).

Knowing that carers are just as important as those with dementia (The British Museum delegate)

We can state that the respondents' moods were enhanced as a result of the *House of Memories* experience (Figure 9). On the arrival at the museum half of delegates declared that they felt positive (54%), but a significant number reported feeling neutral (38%); after the session, it is possible to observe a substantively visible change in mood as almost all delegates (92%) self-reported to be *Somewhat happy* (25%) or *Very happy* (67%).

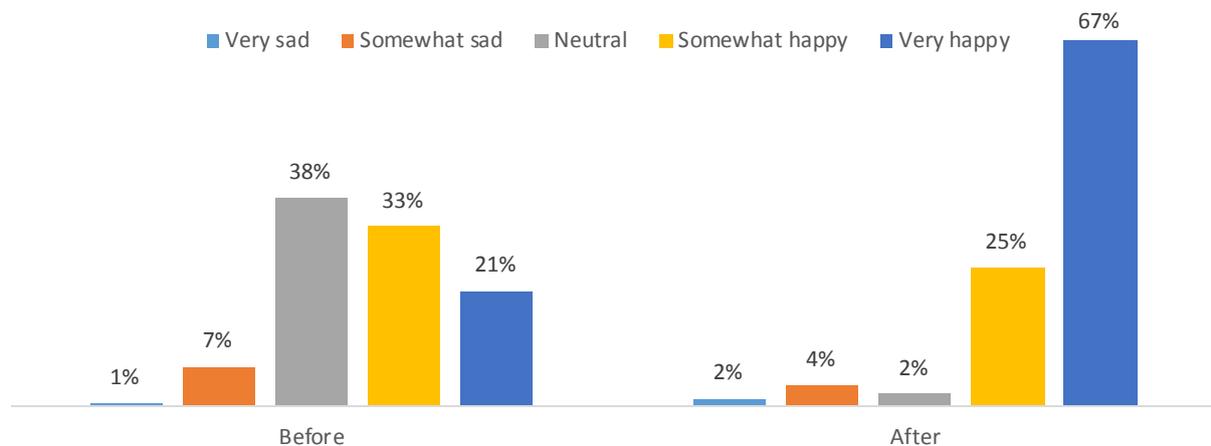


Figure 9 - Smiley-Face Assessment Scale [% - n=147]

Dementia is associated with physically and emotionally demanding care for long periods. Ory, Hoffman, & Yee (1999) argue that dementia caregivers experience higher levels of burden than other caregivers, for the reasons already mentioned in this report. The time that caregivers spend on average in caring for someone with daily-based activities (personal or domestic) or supervision has a direct impact on the carers' subjective wellbeing.

House of Memories Family Carers Awareness Day participants spend on average 11.5 hours per week on domestic care, and 4.57 hours on personal care. In terms of care responsibility

duration, 86% of the delegates have been caring for someone for less than 5 years (Figure 10). As addressed by Archbold (1981) adult children (caring for a parent) and other relatives tend to be more care managers than care providers⁴, which could help to explain the care profile of our sample – married middle-aged or older female children of the person with dementia that works full time.

A survey conducted in 2003 to 227 US dementia caregivers stated that approximately one quarter provided 40 hours of care or more per week – significantly higher compared with the average time we found in our sample. When considering the length of care in years, our sample shared a common pattern: more than two thirds of caregivers had continued the caring commitment for more than 1 year and one third for 5 or more years (Brodaty & Donkin, 2009).

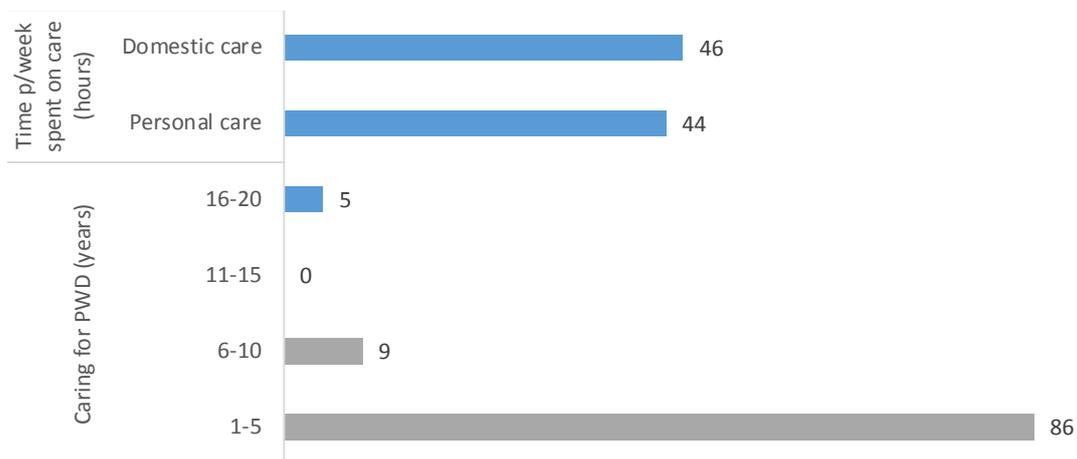


Figure 10 - Average of hours per week spent on care, and years of caring for someone with dementia [% - n=66]

Zwaanswijk, Peeters, Beek, Meerveld, & Francke (2013) argue that informal carers face challenges regardless of the stage of dementia, as those challenges are mainly due to the informal caregiver's struggle to adjust to changes in the behaviour of the person with dementia.

Considering *House of Memories* delegates, nearly one-third (24%) did not know the dementia stage of the person they are caring for, while the majority (52%) are caring for someone with a moderate state of the disease (Figure 11).

⁴ Care providers deliver hands-on care as personal care (dressing, bathing, feeding), or domestic care (cleaning, grocery shopping) and care managers organize for others to provide care (Archbold, 1981).

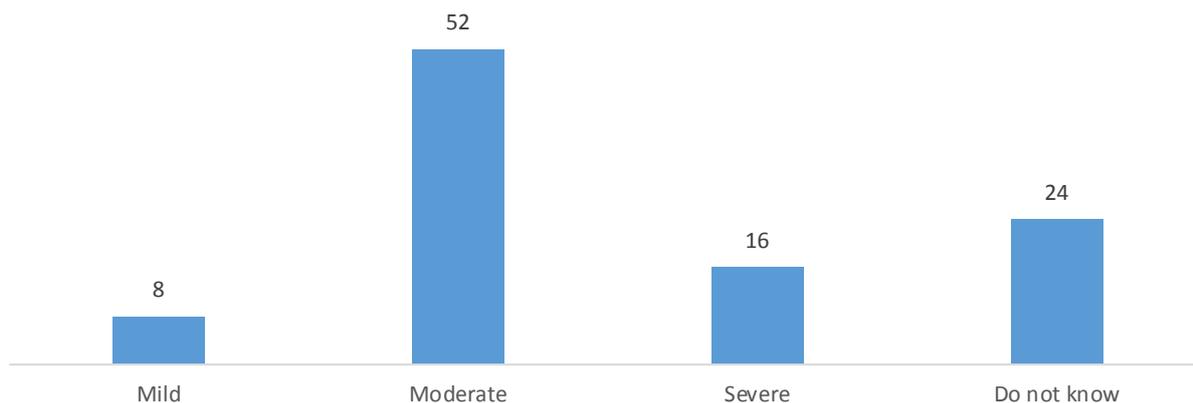


Figure 11 - Stage dementia [% - n=66]

Subjective Wellbeing Measures

The impact of caring on caregivers is a diverse and complex phenomenon. It is not this study's ambition to address it comprehensively. There are many factors that can influence a caregiver's perceptions of their role and its impact, thus our analysis focuses on indicators of burden and subjective wellbeing comprised in the Warwick-Edinburgh Mental Wellbeing Scale, and the Zarit Burden Interview (ZBI) for the Assessment of Dementia Caregivers' Burden.

Despite the fact that care managers report lower levels of stress compared to care providers, the former still face several challenges. Considering the predominant sociodemographic profile of our sample – adult children – there is still a need to balance the caring commitment with professional careers, relationships, social life, and family responsibilities among other issues. Consequently, the risk for burden and associated conditions such as stress, depression and other social and health complications is still present. Furthermore, caregivers' perception of poor wellbeing may impact indirectly on the health of care-recipients.

Considering George & Gwyther's (1986) definition of burden, it can be conceptualized as the set of objective and subjective problems that may be experienced by a caregiver. Objective problems include activities (time and care tasks), facts (effects on physical and psychological health), and events (social, economic, and occupational impacts); subjective problems are related to attitudes and emotional reactions of caregivers (guilt, stress, and concerns). Our focus is on the subjective dimension of burden.

As already stated in this report two subjective wellbeing measures were applied at baseline and followed-up approximately 4-weeks after the session. Although the sample size is not sufficiently large enough to undertake inferable statistical analysis, descriptive statistics can be used to substantiate evaluation findings. In addition, it is crucial to emphasise that the

evaluation is focused alone on the impact of one 3-hour long session on the subjective well-being of participating informal dementia carers.

WEMWBS results should be presented as a mean score with a 95% confidence interval. According to Stewart-Brown & Janmohamed (2008), the best estimates range would be 3 to 8 WEMWBS points difference between 'before' and 'after' time points. In our sample we can only observe 1 point of difference, meaning that beside being statistically minor, there is demonstrable improvement on subjective wellbeing over the course of approximately 8 weeks – the time frame between baseline and follow-up data collection (Figure 12).

On the 12-item ZBI each question is scored using a five-point Likert scale from 0 to 4 (never to almost always), with a range of summed scores of 0-48 (Ballesteros, et al., 2012). Considering a cut-off score ranging from 24-26 has significant predictive validity for identifying caregivers at risk for depression (Schreiner, Morimoto, Arai, & Zarit, 2006), it is possible to state that family caregivers that attended *House of Memories Family Carers Awareness Day* are at risk for depression (mean=26 at baseline and mean=27 at follow-up) (Figure 19).

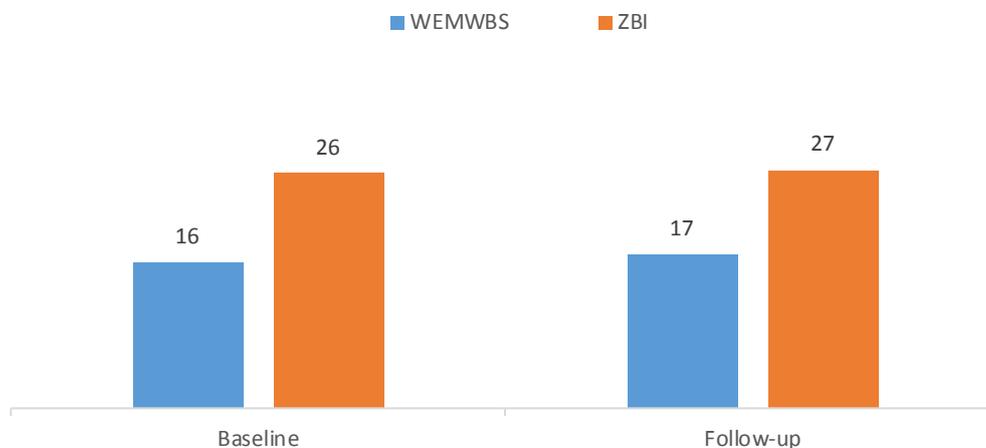


Figure 12 - Compared WEMWBS and ZBI means between baseline and follow-up [% - n=66]

Museums and Dementia Care

John Falk (2009) perceives museum visits as part of people's lives. This author has been developing a model of visitor experience analysis that reconceptualises the field from a holistic perspective using the 'lens' of visitors' identity and motivations. The model proposes to understand visitor experiences in the scope of their own identity, decision-making and

meaning-making strategies, memory, and leisure preferences; in this sense, the author tries to understand visitors beyond their socio-demographic features. Five key types of visitors were identified: i) *Explorers* (motivated by personal curiosity); ii) *Facilitators* (motivated by other people and their needs); iii) *Experience-Seekers* (motivated by the desire to see and experience a place); iv) *Professional/Hobbyists* (motivated by specific knowledge-related goals); v) *Rechargers* (motivated by a desire for a contemplative or restorative experience).

Considering Falk’s (2009) visitors’ profiles, it is possible to perceive that half of the respondents identified themselves with attitudes and values close to what this theoretical approach generally considers the *Rechargers* (45%) at baseline, but at follow-up, apparently, the profile of a majority of respondents changed to *Experience-seekers* (42%) (Figure 13).

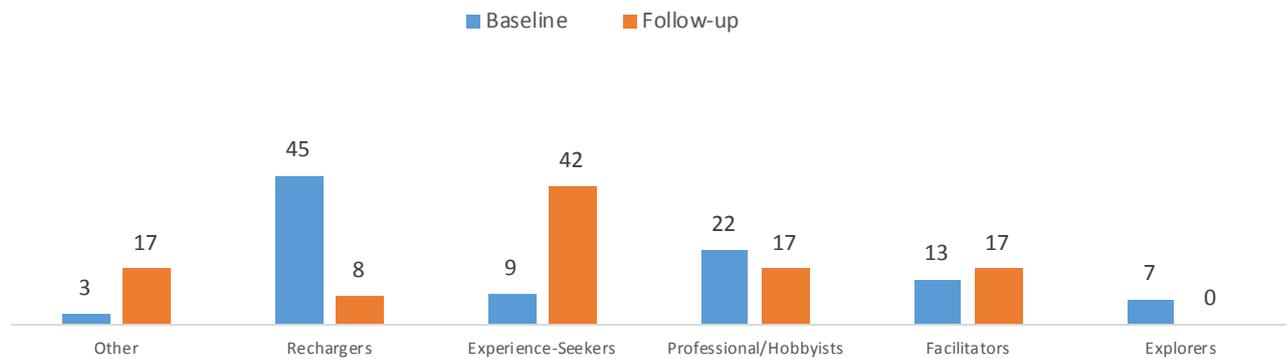


Figure 13 - Museum Visitors' Profiles [% - n=66]

It is not possible however to substantiate *House of Memories* as the major influence on this profile change, due to the fact that the majority did not agree (33%) or were undecided (33%) on how *House of Memories Family Carers Awareness Day* influenced their decision to visit a museum in the evaluation period after the session (Figure 14).

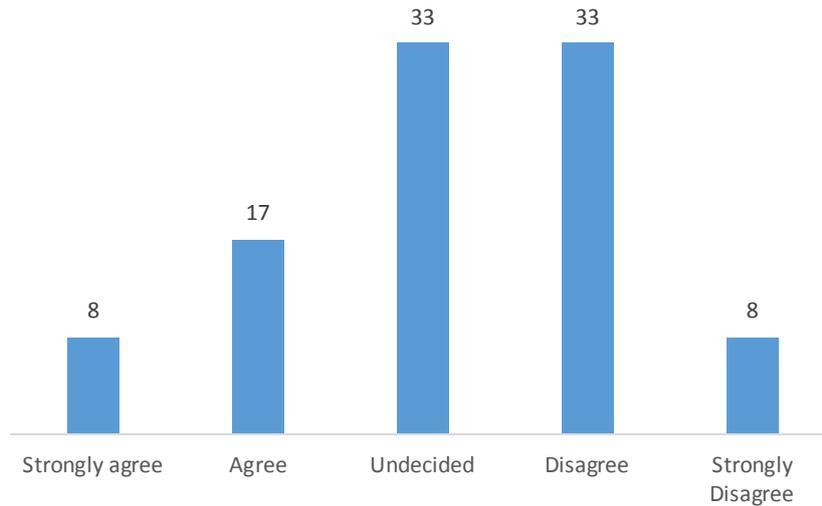


Figure 14 - Influence of House of Memories dementia awareness for family carers' workshop on decision to visit a museum [% - n=66]

However, the majority tend to visit a museum with family and friends (61% baseline; 58% follow-up), which regularly is a common feature of *Facilitators* (13% baseline; 17% follow-up), a profile with a small expression of our sample. *Facilitators* place the museum visit as part of a family or leisure time, motivated by other people's needs (Figure 15).

Rechargers, in this context, are motivated to visit a museum in order to experience restorative moments. Considering that the ZBI mean score indicates that family caregivers that attended *House of Memories Family Carers Awareness Day* are at risk for depression, it is understandable how museums are perceived as contemplative places for physical, intellectual and emotional recharge.

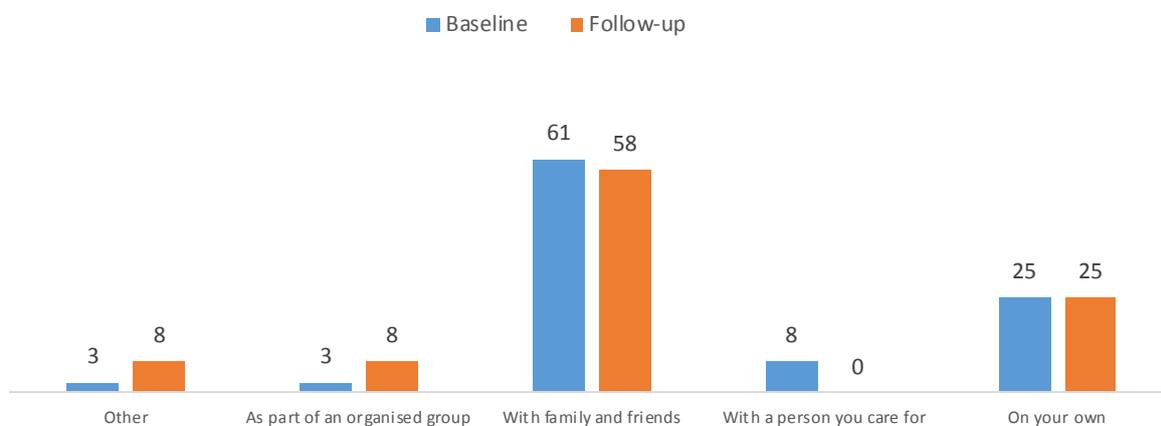


Figure 15 - With whom tend to visit museums [% - n=66]

Bearing in mind the use of museums for memory or reminiscence activities before *House of Memories Family Carers Awareness Day*, the vast majority agree it is important, but 91% never used museums for this purpose beforehand (Figure 16).



Figure 16 - Ever taken part in memory or reminiscence activities at a museum before House of Memories Family Carers Awareness Day [% - n=66]

Such cultural practices are perceived as important for several reasons. Almost one-third of the respondents state *Improve the quality of life and feeling of well-being* (26%) as the main reason to do memory or reminiscence activities at a museum (Figure 17).

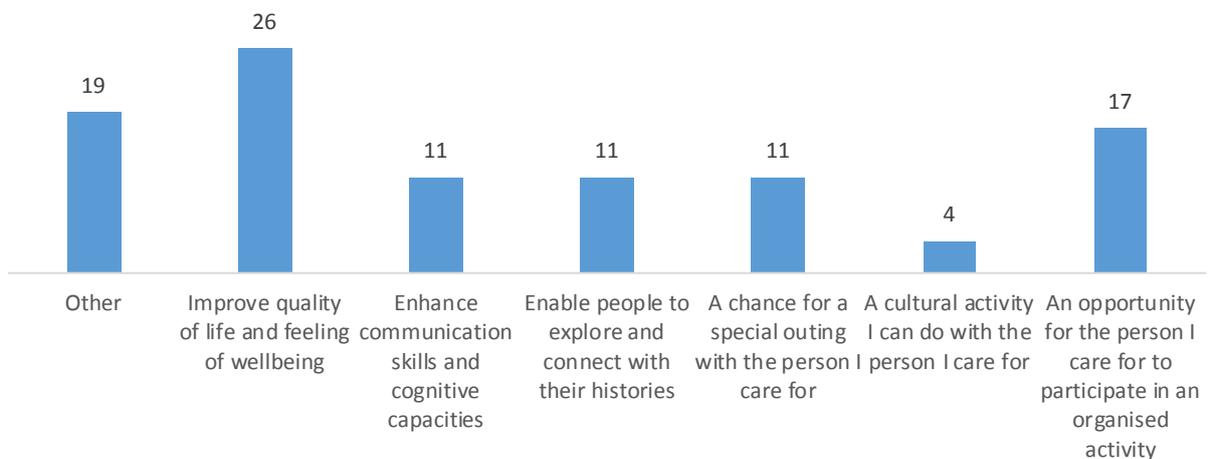


Figure 17 - Reasons to participate in memory or reminiscence activities in museums or galleries [% - n=66]

My House of Memories app

The second part of the active session is split between a *My House of Memories app* introduction and a museum-based activity. The *My House of Memories app* presentation aims to train informal carers to confidently use the app with the person with dementia, therefore it was in the interests of our evaluation to understand also the uses of mobile and other devices in

dementia caring practices. The majority of carers (75%) never used an *iPad* before for memory or reminiscence activities, mainly (60%) due to unfamiliarity with any digital resources (Figure 18).

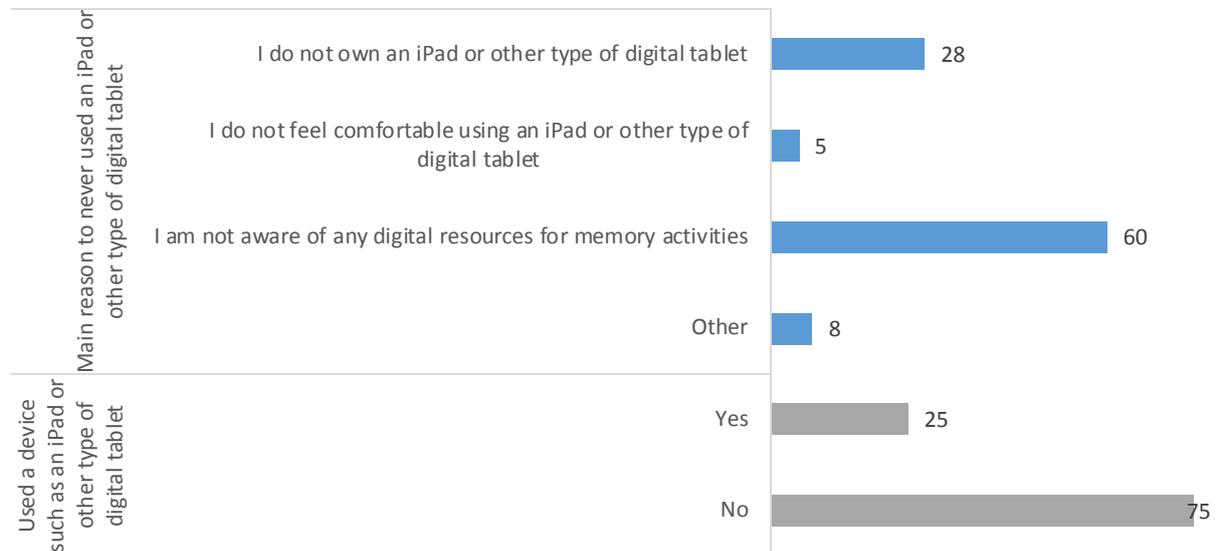


Figure 18 - Ever used and main reason to never used a device such as an *iPad* or another type of digital tablet to do memory activities [% - n=66]

Besides the fact that the majority have never used a museum or a mobile device for memory or reminiscence activities before *House of Memories Family Carers Awareness Day*, delegates state they consider those important in dementia caring:

Learning about the app was very useful and feel that will benefit Mum.

Certainly, help with conversation (Museum of Liverpool delegate).

However, this is not reflected by use of the *My House of Memories app* in their daily caring practice within the limited period of the evaluation. Almost 60% of the sample did not reply to the question ‘*How many times [have you] used House of Memories app in the last month?*’ Respondents that used the app reported positive effects. Nearly two-thirds declared that the person they are caring for is in *a better mood* (29%) or more responsive to the environment (29%) (Figure 21).

Museum memory and dementia related activities/programme

British Museum

The British Museum offers a health and wellbeing programme, entitled *Shared Experiences* that has been running for about 10 years. Working in partnership with health and wellbeing organisations, it aims to reach out to older people who are not using the museum. The British Museum does not offer a dementia oriented programme, however, individuals who are living with dementia join *Shared Experiences*. Museum staff are trained as Dementia Friends⁵.

According to the British Museum staff interviewed, there is a broader approach towards an age friendly museum as it considers *'older visitors, but also the broader spectrum of all the stakeholders, everyone, from staff through visitors, through volunteers, through donors, through members...how we are preparing for the aging demographic [...] Dementia is just a segment of what we do here'*

The British Museum uses its collection creatively as conversation starters, focusing on the present physical relation with objects. Questions such as 'What do you think this is?' or 'What do you think this is used for?' are used to trigger a dialogical engagement without expectations of accuracy considering objects' historical or anthropological contexts. Again, in the words of a British Museum interviewee *'Actually, the fact that you don't know it's not a problem, probably no one knows. Everyone in the group understands there is no expectations to know what it is. That is a kind of leveller, particularly, with a group with dementia that may not be able to remember things that everyone else does'*.

New Walk Museum and Art Gallery

New Walk Museum and Art Gallery is part of Leicester City Council Arts and Museums Service that sets access for socially disadvantaged groups at the heart of their municipal museum strategy. Health and wellbeing inequalities are issues that are on New Walk Museum and Art Gallery's agenda and, currently, dementia is a pressing matter:

'City Council that has the responsibility, we are here to serve our citizens and part of that is to serve people with dementia'.

⁵ <https://www.dementiafriends.org.uk/>

Leicester City Council Arts and Museums Service runs four museums, two heritage buildings, an art service, a culture service, and funds a significant number of organisations. Across those sites, they offer a multiplicity of memory and dementia activities (community exhibitions, museum memory trails, thematic loan boxes, and memory bags that can be used within the museum) that were shaped from the partnership with NML:

'We had the opportunity in 2014 to do some work to deliver the House of Memories training for Social Carers. That was our introduction to House of Memories and Liverpool's work. We delivered the training for 200 carers, and also enabled us to develop a number of objects and resources that we then have the legacy of having in our museums. That was the start of our dementia related journey' (New Walk Museum and Art Gallery).

Leicester pays particular attention towards the representation of the memories of several communities, given that the city population is significantly diverse. People from ethnic minorities are less likely to have access to and to use mental health services (LaFontaine, Ahuja, Bradbury, Phillips, & Oyebode, 2007). Lack of understanding about dementia, language and cultural barriers, ethnocentric attitudes and incorrect assumptions are the main cause and New Walk Museum and Art Gallery is aware of that:

'[in] Leicester we are so diverse! We have one road that has 20 languages. We are quite integrated, which is lovely, but those role models are important. I think it's quite a taboo and I think we are going to tackle that taboo that dementia is not just because you are getting old. It's a little bit more than that' (New Walk Museum and Art Gallery).

Salford Museum and Art Gallery

Salford Museum and Art Gallery has a long established reminiscence programme for people living with dementia, which has run for at least 12 years, involving reminiscence training sessions for care professionals, guided tours at the museum, reminiscence tours at the Victorian Street and thematic reminiscence loan boxes. From the partnership with NML boxes specific for people with dementia were created based on time slip techniques.

'They focused on being creative. We now have four of those boxes. So, NML founded two of them' (Salford Museum and Art Gallery).

Partnership with National Museums Liverpool

British Museum

The British Museum founded, in 2012, the Age Collective Network that became the *Age Friendly Museums Network*, in 2014. The British Museum is a founder member along with the Glasgow Life, National Museums Northern Ireland, National Museums Wales, Manchester Museum and the Whitworth.

Although the partnership with NML started with the community and partnership team, it has been developed by the Citi Money Gallery team, as it was perceived that the coins and medals collections would fit best in the *House of Memories* programme. These collections include objects from recent history (for instance, ten shilling notes), things that people could easily remember, because everyone has contact with currency, which makes money a good conversation starter.

The involvement with the *House of Memories* programme included several stages, such as the contribution to *My House of Memories app* with objects, providing one of the training sessions on how to use the app; and participation on the health and social care model.

The two national museums have different approaches towards dementia, however, The British Museum interviewed staff state *'That doesn't mean we can't learn from doing projects together'*.

New Walk Museum and Art Gallery

The partnership with NML was crucial for the development of New Walk Museum and Art Gallery reminiscence and memory related programmes. This partnership started with a refugee project arising from an existing academic connection between staff from both organisations. Positive and enriching process and outcomes fuelled the partnership and encouraged Leicester to welcome the invitation to join the national *House of Memories* network:

'The whole process was really good. Also, I supposed the key thing is, once we decided we were going to do the project, the material they sent through was really useful because it helped to demonstrate that we'll be working with a partner'.

The partnership with NML matched the city agenda on dementia, as the city had reconfigured its Dementia Action Alliance focus on a wide and integrated approach of the multiple

organizations in the urban landscape. Through that process, apparently, New Walk Museum and Art Gallery built on the credibility of *House of Memories* and on its national profile in order to foster the museums' recognition across different sectors and networks in dementia caring:

'The National Museums Liverpool approach was really useful. I think it's fair to say it helped in lots of ways. With our partners as well, with people outside our sector... People who are not in our sector also recognize the credibility of NML, so by association we've been quite fortunate to be able to prove it. This is good quality stuff, and we are a part of it. It's really an advantage to work with Liverpool on this stuff [...] I think that probably really helped us and accelerated our journey, certainly working with partners in the social and health care sector' (New Walk Museum and Art Gallery).

In addition, the perception of the work process is highly positive:

'I really enjoy working with Liverpool, not just because I like the people because the system is so good because the support provided was excellent'. [...] I think there has been a very open and honest communication. Liverpool has been explicitly clear in terms of what we were about to do and embark on. We are taking pride in matching that. [...] I think I have to say it's the friendliest partnership I have ever experienced. I think it is mutual respect. I think there is a genuine warm friendship among us. I think that comes across in the sessions. I certainly feel it when they are around. It's a pleasure work with them and I hope they feel the same (New Walk Museum and Art Gallery).

Salford Museum and Art Gallery

Salford Museum and Art Gallery's partnership with NML started during the second year of funding for the social and health care professionals training model, entitled Northern Model, and the connection was built on a community engagement network for the North West museums. The long lasting partnership is perceived by Salford Museum and Art Gallery as a positive, especially given that *House of Memories* has built a recognizable national profile:

'Since then, they have been doing it in different parts of the country and they come back to us. Which is great that they came back to us as part of this family carer model. It's much more geographically spread across the country now, so it's good to be asked to be part of something

that is quite high profile now and received a lot of attention nationally. House of Memories has been well received, is award winning and that kind of thing' (Salford Museum and Art Gallery).

The funding given to deliver the Northern Model was used by Salford to improve their reminiscence programme by developing two new memory boxes, and the programme impacts positively on museum audiences:

'The first year of involvement for the Northern Model, 2013 maybe, that was interesting because that was so well received. We were full. We had lots and lots of people, relatively to what we normally get. A lot of people came along and were people not just from Salford. Normally, our audience is a local one. But, there were professionals coming from Manchester and different parts of Greater Manchester and Cheshire. I think there was an increase of awareness just outside of the city about what we did that came from that event, which was really well attended. Actually, even now we still get inquiries from people about House of Memories events in Salford' (Salford Museum and Art Gallery).

As with the Leicester case study, the national recognition of *House of Memories*, but also the robustness of the framework, supported Salford Museum and Art Gallery to argue the importance of local state investment in museum dementia care programmes:

'The packs that we had for that, sheets given out to people being trained have been a really good tool, actually, we can take them to senior management and people within the Council and Health commissions. To show to that kind of audience what we have been doing and I suppose to make the argument that cultural organisations have something to offer to what may be normally seen as a kind of clinical need of people with dementia. Actually, trying to underline the importance of social interventions and what cultural spaces can offer... It has been quite helpful for that, and for gallery trails and that kind of thing... that help people to have access. Just that awareness and advocacy of being a national programme that is really high profile' (Salford Museum and Art Gallery).

Transferability, Impact, and Challenges

British Museum

House of Memories Family Carers Awareness Day was perceived by British Museum staff as a 'mainly *House of Memories* event', as the first part of the session is focused on *House of*

Memories content, and the second part of the session is dedicated to experiencing *My House of Memories* app and museum-based activities. In the case of the British Museum, it is also a chance to introduce different parts of the collection, because lesser-known objects from the collection and some discursive material are part of the app.

'It was actually really good, because I think that is exactly what museum's collections should be used for. It was certainly a very positive experience, because it opened up all these kind of other uses for our collection. It helped to open up other parts of the collection that are not usually looked at, made me think about objects that we don't think about that often' (Citi Money Gallery Curator).

For the British Museum staff interviewed, the session retained the *House of Memories* identity, while the museum activity was focused on what the British Museum could offer to family carers, particularly the engagement with the handling collection:

'What we do is to encourage people to use objects maybe in a fairly different way, which just gives people more options. In terms of family carers using objects in a very creative way, [...] I don't know how difficult it would be for a family member to facilitate that. So, it's trying to give people choices' (Citi Money Gallery Curator).

As this programme is a part of a long-lasting partnership, in the opinion of the interviewed British Museum staff, the *House of Memories Family Carers Awareness Day* did not face any particular challenges, beyond the management of the identity of two large national museums:

'We are a national museum, so just in terms the site itself we are very different from other small and local museums. It's really important we made the literature and any photography and visuals around it actually represent what we have here. If somebody picked up the calendar and wanted to use it then they would already have an understanding of what they could use and see at the British Museum. So, that was really important that we are able to feed into that. Obviously, it's quite a long process because it's making sure that the House of Memories visual identity matches or we can incorporate the British Museum visual identity' (British Museum).

Considering the impact of the partnership with NML, British Museum staff members shared that the museum will continue to have a health and wellbeing strand, and in particular, will keep working with objects from the Citi Money Gallery handling collection to work with communities. Equally, *House of Memories* is perceived as a 'good starting tool', a 'very good leverage to continue to work with all of these much wider audiences'. As the Citi Money Gallery

Curator stated, for the British Museum the health and wellbeing programme is not an audience issue, but it is a matter of ethics, as it has become more acute in terms of the number of people living with dementia:

'I think it's really important that the museum gets involved with these projects because it makes sure the collection is relevant to as many people as possible, which is surely the point of British Museum collections... to make sure they can be used in as many different ways as possible'

In addition, *House of Memories* as a whole is perceived as a very flexible project with multiple possibilities of expansion, particularly in relation to the use of digital technology to make use of something that cannot be accessed within the physical museum:

'I think the beauty of the app is this project can be updated forever as well. There is an element [that] should never at any point get out of date. You can always update the content, you can always update the way in which the programme is structured, but it'll always at the heart of it have objects, there will always be stories that you can tell with these objects. That is ongoing, so I think it can continue for as long as people adjust to it. I like the fact there are multi-platforms, you have the app, but also there are other materials that you can use if you are not comfortable with the app, or technology, there is always a way to use the House of Memories project with your family' (Citi Money Gallery Curator).

[New Walk Museum and Art Gallery](#)

New Walk Museum and Art Gallery apparently benefits from the partnership with National Museum Liverpool as a '*starting point*' to their 'dementia journey', as the Liverpool model was perceived as a framework that works:

'I think it was relatively straight forward. I think the formula, the template for it is quite easily adaptable' (New Walk Museum and Art Gallery).

In addition, *House of Memories* supported Leicester to recognise what their role in dementia care could be:

'I think what was really useful was having something that helps you to understand what the museum role could be. When Brian said: 'We are not experts on dementia. We are experts on museums. What we can do is this, we can contribute to the agenda. We have a responsibility to say 'This is what we can do'. It's not being everything to everybody, it was knowing that we

have a product, we are a certain type of organisation and this is how we can contribute. That made it very clear and very simple to follow in a way and don't get side-tracked. It was almost like having a frame for how we would do our work' (New Walk Museum and Art Gallery).

New Walk Museum and Art Gallery was aware of its museum audiences, but also considered the city's particular demographic features – 30% of the Leicester population is Asian – so, it was a priority to make their reminiscence activity supporting materials meaningful to as many people as possible:

'We knew for a fact that we need to have an Asian memory box. I remember the curator at the time saying to me 'I didn't realize that elderly Asian woman would be interested in our industrial collection.' 'Yeah, they still used it back home' (New Walk Museum and Art Gallery).

Concerning the impact of the partnership with NML, the commitment of the museum with evaluating the *House of Memories* programme is perceived as highly significant as *'you can demonstrate to people the impact of what you do. There is nothing more powerful [...] it's important to have numbers, but is more important to know the qualitative research and the information that comes with that. The peoples' experiences that actually benefit from that'* (New Walk Museum and Art Gallery).

The recognition of the importance of demonstrating impact through ongoing evaluations is perceived by New Walk Museum and Art Gallery, as not just as a way to demonstrate results, but also as an example of good practice from NML to take on-board:

'That is what Liverpool is really good at. To have that whole process from conception to running the project, to delivering and then evaluating it. It's nicely signed up. It's great. The package is there, we can use it to demonstrate to people and say: 'It does work'. Because this is the document to prove it. I think the evaluation of it is a really important part of the programme. Evaluation tends to be seen as a luxury when in fact it's a necessity' (New Walk Museum and Art Gallery).

Previous collaboration with NML for the health and social care professionals training model is perceived as having had a positive impact on Leicester's large range of arts, culture and health sectors on modelling responsive culture-led interventions in dementia:

'I think our work had a huge impact on the health and social care professionals. That was new for us, definitely. It was a really powerful training, people are still talking about it [...] I think it stays with you a little bit' (New Walk Museum and Art Gallery).

Concerning, the *House of Memories Family Carers Awareness Day* at the time interviews were conducted museum staff could only share their own perceptions of the impact of the programme, based on their daily practice. However, it is their understanding that, concerning family carers support, this social problem is still in its early days and raising awareness, and sharing information on how to get support is the next necessary step. Survey questionnaire results have shown that almost one-third of our sample did not know the dementia stage of the person they were caring for:

'Yes, there is engagement. People are interested. I think we have a lot of work to do still. But, I think it's part of the problem with dementia awareness in general. It never ceases to shock me how little people know about dementia given how prevalent it is. So, I think that even people who are caring for people who are living with dementia they still don't know a lot about it. So, I think we've got a bit more engagement work to do to let people know we are here, we have these resources. We are not trying to solve the problem; we are trying to contribute to making people live better with dementia' (New Walk Museum and Art Gallery).

Leicester city region is embracing a dementia awareness agenda, and New Walk Museum and Art Gallery as part of the city municipality is keen to work very closely with the city's Dementia Action Alliance to make Leicester a dementia friendly city. New Walk Museum and Art Gallery's reminiscence and memory related activities form an integral part of this strategy, strongly influenced by *House of Memories*, and will be developed to embrace the city's diverse demography, in terms of age and ethnicity:

'We want to make sure more people know that we have them (memory boxes and bags). So, we are planning, in the spring next year, to do a quite big promotional try-out. Any other resources we want to create will have to be in place and actually just launch it [...] Children are a whole area for us, potentially. Boxes and the objects have the power to be so intergenerational [...] it has to be an enjoyable afternoon or day for the supporter person. It's not just the person living with dementia; it's everybody that is coming into the museum. There is a lot of intergenerational work and that is good because we can contribute to sort of educating people about dementia for future generations as well. And to take the stigma or awkwardness or embarrassment out' (New Walk Museum and Art Gallery).

Considering New Walk Museum and Art Gallery started 'their dementia journey' with the partnership with *House of Memories*, the challenges faced were those commonly associated with starting a new project, such as training staff and finding resources for delivery. Training

museum staff and supporting them to understand the demands associated with dementia was incorporated in ‘*normal training for customer care*’ and integrated in daily museum activity:

‘When we do reminisce sessions with elderly people, that may not have dementia, they are still an excellent tool. So, I think staff got quite excited about it, they are taking pride in it’ (New Walk Museum and Art Gallery).

Concerning the transferability of *House of Memories Family Carers Awareness Day*, museum staff raised important issues. It was understood that ‘*House of Memories has a very Liverpool focus*’. Although the activity programme and handout material is adapted to every museum collection, the documentary films in particular are considered to be fairly ‘*Liverpool centric*’:

‘It would be nice to have a local slant to that. So, that person could actually see something in themselves in those. Because the images, and the museums, and the people, because you have to see yourselves in somebody to be able to properly engage with something. That is probably the only barrier with the film footage yesterday’ (New Walk Museum and Art Gallery).

Particularly aware of the role of museums in cultural recognition, New Walk Museum and Art Gallery was sensitive to the fact that the *House of Memories* documentary films, by embracing Liverpool-centric common cultural features, (for instance, the accent, the architecture – Museum of Liverpool and Liverpool Cathedral – the football anthem), may not be appealing to a Leicester local audience.

Equally, the length of the session was mentioned as a point for reflection. Although all the objectives were achieved on time, it ‘*felt rushed*’. Time is a pressing matter for someone that is caring for others, so the balance between giving enough time for sharing moments, and not overwhelming carers with lengthy sessions is a delicate one:

‘It was definitely the desire to linger a little bit more. Maybe a timing issue, if we want to have the video and if you want to have the interactive sessions, maybe looking into something that runs from 9h30 am to 2 pm, maybe have lunch as well’ (New Walk Museum and Art Gallery).

[Salford Museum and Art Gallery](#)

Before the partnership with NML, Salford had an already well-established reminiscence programme, well embedded into their curatorial programme and collection, with particular attention to the Victorian Street. In the words of Salford Museum and Art Gallery interviewed

staff *'so while I think it has been good, it didn't completely turn around how we work. We already work along that kind of trajectory. It just fitted in very well. It's been a really good opportunity'*.

In relation to the *House of Memories Family Carers Awareness Day* sessions, two major suggestions emerged from the interview with museum staff. One was related with time issues, and as with Leicester, was recognised that it is necessary to find a good balance between time commitment for carers and giving enough time to meet session aims. In addition, the starting time of the sessions was raised, in order to accommodate commuting time and caring responsibilities. On the documentary films, Salford museum staff suggested that it could be interesting for family carers to see more role models in terms of different cultural and creative activities:

'That film about... they are trying new things like live drawing and that kind of stuff. I wonder if this maybe more opportunity for testimonies or case studies from other carers who have been in a similar position... what they found helpful if they were able to have a couple of hours away from the people they care for what they have found beneficial to do with that time' (Salford Museum and Art Gallery).

Salford Museum and Art Gallery, apparently, is also looking for a more integrated cultural strategy on dementia care, which will facilitate an integrated programme across different service areas, libraries and museums in the Salford city region:

'That would be something like a menu across all different areas ... improve people's vascular health, reading for the brain, singing for the brain, museum visits as part of that but not specifically focused on the museum. Because we are really well placed as a Trust to lead on that stuff because we offer so many different services around the city... So, in my perspective [we need] to become more strategic regarding dementia, but bread and butter services (museum tours and loan boxes) still carry on' (Salford Museum and Art Gallery).

INFORM POLICY AND STRATEGIC DEVELOPMENT

Social Return on Investment (SROI)

The following section outlines the methods used to calculate the SROI and the specific approaches taken to arrive at a ratio.

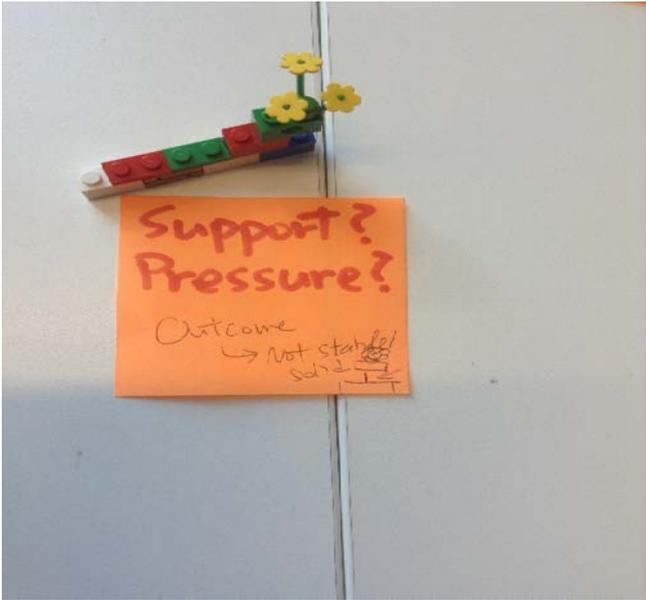
To support the calculation of the SROI, researchers held a focus group with eight family carers who had previously attended training sessions in London, Liverpool and Leicester. This served to verify changes as gathered by other research methods in this evaluation, and to gain more data to complete the SROI process.

As part of this focus group, attendees were asked to model in Lego their experience of caring for someone with dementia. This helped to add rich detail and to act as a benchmark for the feelings following the *House of Memories* training.



Heart-breaking. My head is in among the bricks. I've got a lack of training on the ground. There's a lot of pressure.

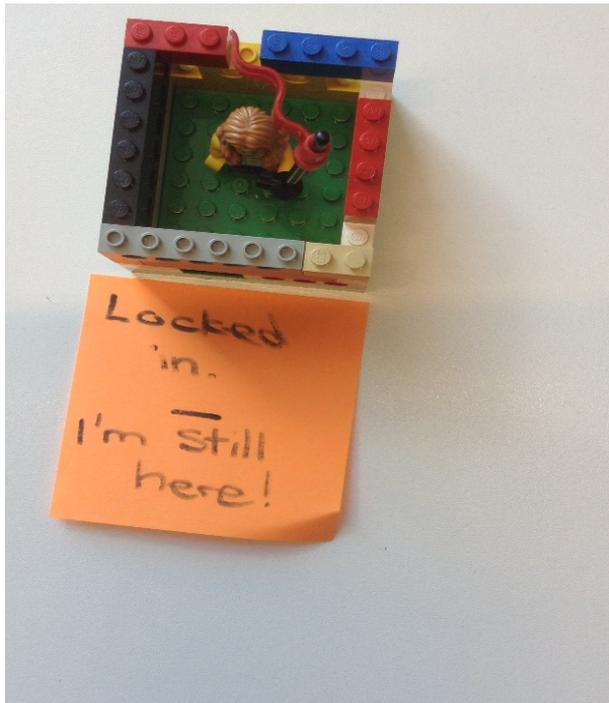
I've started to build the blocks up, that's the learning - the support. The flowers on the top are my hope to flourish in among all this.



The long and winding road. I've felt like that over the past year – just muddled through. You don't know what to expect. This is my journey, me at the beginning and further down the path, but not at the end. I've often felt fear, frustration, disjointed and lack of coordination. Now there's a change, I've met lots of people who I've stayed friends with. There's still a way to go.

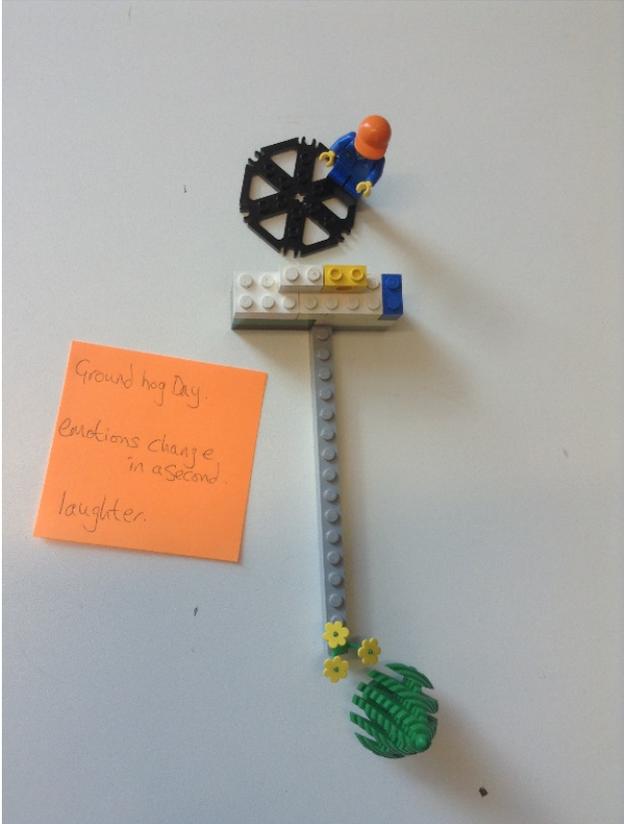
There are moments of bewilderment and at other times, joy. This is us in the park. The great part is keeping an active mind. Remembering the fun, laughter, sharing memories. It's been difficult, but there are now opportunities to learn about each other.





Mum has lost the ability to communicate well. It's hard to see in her face what she means. She's locked in almost. I think we're all to some extent in denial, and locked in, frustrated. The flag says 'I'm still here'.

It feels like you're going round in a circle – that it's groundhog day. Mum's personality has changed completely. She used to be quite bitter and now she's happy, she laughs. There's a wall between, dividing the happy from the sad. It's life limiting, but she seems at peace [in a care home]. No one is perfect, but with help Mum is getting a better quality of life.



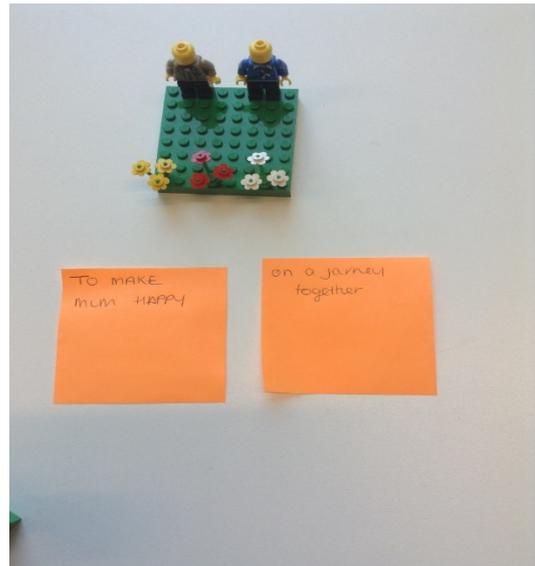


There is a variety of experiences with dementia - I never know who I'm dealing with and that's the extent of dementia. I'm at the beginning stages of learning. There's a grey area in the middle where you know nothing.

I do most of the work for Mum. I want to flit but I need to be considerate. You can't plan, you just need to go with the flow. Dealing with dementia is a challenge and there's distraction with that. I've chosen the dog also as the distraction – going out for a walk and meeting people, to go into the city and see things, go to the park, visit exhibitions, museums. Be mobile. The steps are if Mum's tired. We'll sit down. But it's also repetition [up and down]. But it's important to be where the person wants to be.



I just want to make Mum happy. We're on a journey together and the training is not the end, it's along the road of understanding. At times, I've not known where to go to, but this [the training] has been positive.



These discussions with the family carers pointed to the many aspects to dementia they have all experienced. All were agreed that the training had impacted upon their life. It had given them ideas, ways to get through the day, activities and people to link up with, new friends etc. The networks that had been set up were seen as extremely beneficial: additionally, the training in itself had been an opportunity to meet others whose lives were also affected by dementia and to share stories.

A large impact of the training had been on knowledge: many people reported having only known about dementia through their own, often isolated, personal experiences. They had learned more about clinical definitions of dementia as well as its progression. One resounding impact had been the realisation among many of the family carers was that they were not alone. While each family circumstance may be unique to them, their story and their experiences were mirrored among the group, with words such as bewilderment, unknown, distraction, heart-breaking, locked-in among many of the negative descriptions.

There was also lots of discussion within the group on how they are now better able to improve the care they can offer their family member with dementia, and how the term distraction initially was a negative, it was now considered a positive. The training had equipped them with ideas and techniques so that using reminiscence therapy and attending art and museum venues were a way of making that experience more meaningful and serving as a distraction for both the dementia sufferer and the family carer.

Stakeholders and reported changes

The research identified five main stakeholders: the participants attending the *House of Memories* training, National Museums Liverpool, the family member with dementia (patient), the local authority and the NHS in relation to its National Dementia Strategy (Department of Health, 2009). The NHS outcome of dementia awareness was reported as part of participants' outcomes and valued in that stakeholder group (Figure 23).

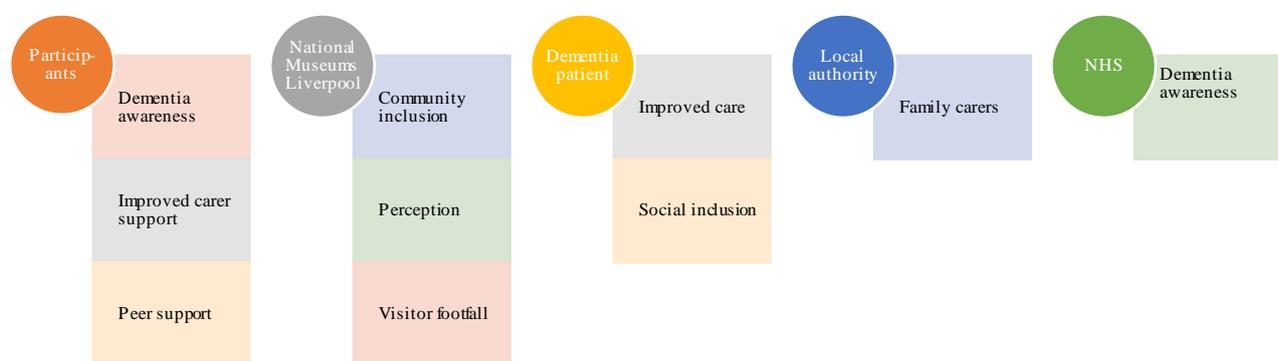


Figure 21: Key stakeholders and their changes

Inputs

Department of Health invested £62,150 for National Museums Liverpool to deliver the Family Carers Awareness Day over twelve months during 2016/2017, involving just over 600 family carers. This SROI prospectively looks at the impact of this programme with 176 individuals already having participated in training, and a potential further 440 to participate in additional sessions over the coming months. To assess the impact of this initial investment, the SROI considers impact over the next five years.

Outputs

The outputs describe, in numerical terms, the activities that took place as a result of the investment which lead to change (or outcomes) for each of the identified stakeholders.

Quantities

The overall sample quantity was 616 - the maximum potential number of individuals likely to receive the training over the forthcoming year. As each stakeholder change was identified its numerical weighting was based on a range of research methods, including survey questionnaires, interviews and focus groups, this was then extrapolated to represent the wider sample.

Outcomes and valuation

Following a range of research methods identified in the research methodology design section of this report, the changes which were identified were detailed and placed into the Microsoft Excel spreadsheet along with information on how the outcome was measured. All of the changes identified on this impact map were positive. In the course of the analysis some unexpected outcomes were identified, as well as those initially identified as part of the training programme's aims and objectives. Unintended changes included reduced stigma of dementia, improved familial relationships, telling others about the training and feeling good about being family carers.

The following tables list the outcomes, financial proxies, their value and quantity for each stakeholder group. The NHS has been excluded from this as their outcome is also shared with participants and therefore has not been double-counted.

Table 5 - Reported SROI outcomes for participants

Outcomes	Financial Proxy	Value of Proxy	Quantity	Quantity Value (over 1 year)
More confidence in dealing with dementia	Cost of confidence boasting course	£289.99	370	£49,766.85
Greater understanding/awareness of dementia	Cost of a dementia awareness course	£176.99	142	£5,654.83
More able to reduce stigma associated with dementia	Cost of a conference attendance	£276.00	493	£6,1230.60
Increased compassion and dignity in caring	Cost of a compassion-focused workshop	£154.38	572	£35,763.67
Improved relationships with those being cared for	Improved wellbeing, job satisfaction	£780.00	227	£39,838.50

Able to communicate more effectively as a carer	Value of improved learning and operations for an organisation	£149.00	616	£20,651.40
Greater understanding and application or reminiscence therapy	Cost of reminiscence therapy (as part of a clinical trial)	£89.00	548	£10,973.70
Greater role to play in improving standards of care in dementia	Value of improved learning and operations for an organisation	£309.09	554	£7,705.61
Tell others about the training	Cost of a HoM social marketing campaign using facebook and twitter for one year - £750pm X 12	£11,400.00	For 1 year only	£513.00
Care network	Cost of a peer support worker for the group	£16,742.50	For the 1 st year	£7,53.41

Table 6 - Reported SROI outcomes for National Museums Liverpool

Outcomes	Financial Proxy	Value of Proxy	Quantity	Quantity Value (over 1 year)
Community inclusion	Cost per person of museum attendance per year	£33.23	598	£894.22
Perception	Cost of hiring a similar venue for the training	£460	12	£1,987.20
Visitor footfall	Cost of one annual visit to a museum	£33.23	616	£921.14

Table 7 - Reported SROI outcomes for dementia patients

Outcomes	Financial Proxy	Value of Proxy	Quantity	Quantity Value (over 1 year)
Improved care	Living well with dementia	£855	511	£98,303.63
Being socially included	Cost of a social inclusion officer per year	£33.23	616	£10,234.84

Table 8 - Reported SROI outcomes for local authority

Outcomes	Financial Proxy	Value of Proxy	Quantity	Quantity Value (over 1 year)
Non-reliance on LA spending for carer	Cost of one annual visit to a museum	£33.23	616	£39,695.04

Valuation

Having identified outcomes for each stakeholder group, a financial proxy was applied which allowed a monetary value to be placed on the changes experienced by each stakeholder group. In each case, the impact map contains an exact source from where data was gathered to ensure robustness of methodology. Wherever possible, stakeholders were consulted on the appropriateness of these measures. These took place during focus group sessions in which individuals were asked to identify benefits of the training programme and the impact this had on them personally.

Social return calculation and sensitivity analysis

This outlines the rationale behind all indicators and proxies used to calculate the SROI. Statistical considerations of duration, drop-off, reductions in value, deadweight, attribution and displacement are applied. The SROI ratio is calculated. Finally, the sensitivity is assessed to ensure that any one outcome does not have a disproportionate negative or positive impact on the final ratio.

Duration and drop-off

In an SROI analysis, a determination is made to establish the impact duration of each outcome. In the case of the *House of Memories Family Carers Awareness Day* this was based upon the responses and benchmarked data available. The research identified that for some outcomes, changes were maintained during the entire five-year period covered by the SROI. For example, many of the outcomes experienced by participants - knowledge levels, communication, compassion and improving standards of dementia care – were expected to last the full five years. However, for telling others about the training programme, this was expected to last for two years, and the care networks that were introduced as part of the training were expected to last the first year. When considering the length of time changes were expected to continue, both stakeholder opinion and independent research were taken into account.

The value of individual outcomes will depreciate over time; to account for this we apply a ‘drop off’ ratio to each year. This ‘drop off’ is calculated based upon each individual outcome, its impact and the related benchmark data on this change.

For example, the stakeholder outcomes for National Museums Liverpool, were capped at a one year drop off, anticipating that without further engagement, their influence would diminish. This is conservative, but the impact of their work in enticing visitor numbers and reducing social isolation has no comparison. However, it was anticipated that the satisfaction with the museum venue for hosting the training would continue for the five-year period of study.

Deadweight

Deadweight reflects the fact there is the potential for an outcome to have been achieved anyway, without the training having occurred. Deadweight has been calculated based on the fact that for the majority of participants, the outcomes would not have occurred naturally: and the outcomes have been achieved solely because they participated in the awareness programme. All in the focus group reported limited knowledge and identified that the outcomes they were reporting were due to *House of Memories*. However, researchers felt that it was over claiming to list that for all outcomes, 100% of this was achieved solely through the training programme. It was identified that for reducing stigma, 100% of the outcome was attributable to *House of Memories*. Similarly, the effect of the person living with dementia now attending museums was also directly related to their carers' attendance at the awareness session and a 0% deadweight figure was applied. For all other outcomes reported by all stakeholder groups, a 10% figure was applied, acknowledging that a small part of natural occurrence would have happened without the training.

Attribution

As well as factoring in how long outcomes may last, it is also necessary to consider other influential aspects. For example, the change may have occurred irrespective of the training programme, something or someone else may have contributed to achieving that outcome, or it may have displaced activity elsewhere. In calculating the SROI, it is necessary to be pragmatic about the benefits actually provided by the training programme and recognise that the value created has not happened in isolation.

Attribution considers the impact and contribution of external factors which may also have contributed to the outcome occurring. For all outcomes, it has been assumed that there is

significant alternative impact on changes therefore a 50% weighting was applied to all outcomes.

Displacement

Displacement applies when one outcome occurs but at the expense of another outcome, or another stakeholder is adversely affected. In relation to this programme, it is acknowledged that displacement could have occurred in multiple areas as there is a significant amount of alternative support for dementia. Therefore, each outcome was assessed for its likely displacement and an appropriate displacement value applied. For example, the figure for reduction in stigma and promotion of compassion and dignity was set at 10% allowing for the fact that whilst this was achieved mostly and directly as a result of attendance on the training programme, the involvement of others could not be wholly excluded. Similarly, it was identified that displacement by other factors was more likely and greater in outcomes related to social inclusion and enticing visitors to museums and the figure was set at 80% to reflect this. It was felt that there were no other activities displaced by the carer and their family member's attendance at the museum, which is reflected by no displacement being recorded on the impact map.

Calculating the SROI

The results show a social return on investment of £18.73 for every £1 invested over a five-year period based on the assumptions set out above. The SROI identified that most value was gained during the first two years following training.

Table 9 - SROI ratio over a five-year period

SROI rate per £1 invested	Year 1	Year 2	Year 3	Year 4	Year 5
£6.21	£6.00	£2.907	£1.70	£1.11	£18.73

For the initial investment of £62,150, over a five-year period, a total £1.163million was returned in social value, as identified by achieving and exceeding the original aims and objectives of the training programme.

Table 10 - Cumulative Total social value gained over a five- year period

Total Present Value (PV)	Year 1	Year 2	Year 3	Year 4	Year 5
£385,641.05	£758,241.10	£938,204.24	£1,043,842.25	£1,113,024.40	£1,163,990.36

Sensitivity analysis

In calculating the SROI, it has been necessary to make certain assumptions or rely on data for which there is no agreement. During this process, a number of factors are therefore assumed. In such cases, a sensitivity analysis is conducted which tests the influence of this outcome proxy, or statistical figure on the final ratio. This assesses how much influence this has on the final value that has been calculated. Once the researchers are happy that the sensitivity does not overly affect the final ratio, then the amount is recorded and has been detailed in the above sections.

Limitations of SROI method

The process of conducting an SROI analysis relies heavily on qualitative data gathered from stakeholders. The number of engagement activities and methods were limited by time and resources. For example, the majority of those attending the training were unpaid family carers who held other responsibilities including work commitments.

The SROI analysis itself is dependent on the subjective responses given by the research participants at that particular moment in time. The nature of the SROI evaluation in attempting to quantify the unquantifiable (for example, the value of improved confidence or increased knowledge and awareness) also means that it is often quite difficult to elicit meaningful financial outcomes from participants. Where group members were not able to arrive at financial amounts themselves, financial proxies were derived from known proxies used elsewhere in research or from examples given during qualitative data collection (e.g. cost of a course or workshop or attending a conference). To this extent, the SROI proxies presented in this report are subjective and relevant to the individuals on the day that the research was conducted. The ratio presented offers an insight into the impacts which may be gained as a result of the training model, and is not a financial representation of what has actually been spent by stakeholders.

What does this SROI value mean?

In return for an investment of **£62,150** to train up to 616 family carers in dementia awareness care, a total of **£1,163,900.36** of social value was created over a projected five year period, returning an SROI ratio of **£1: £18.73**, when discounting for other attributable factors and the chances that changes would have occurred anyway. However, the potential impact of this training is yet to be fully considered and realised: with every subsequent training session to be delivered through this model, there is the potential for more social value to be gained.

This SROI ratio is in no way comparable with other evaluations where SROI calculations have been used, including previous *House of Memories* training sessions with professional carers and NHS staff members (Wilson and Whelan, 2014; 2016). Each evaluation and SROI needs to be considered on the individual merits of the reported changes that have occurred as a result of engagement with that model of training, and therefore considered in isolation to any other programmes. This value can be used to consider what is working well and what the outcomes of *House of Memories Family Carers Awareness Day* are with regards to dementia awareness, standards of care and personal and professional development of family carers.

KEY LEARNING POINTS

Overall, data confirm the high esteem in which informal caregivers hold *House of Memories*. For many informal caregivers the programme was inherently a socializing activity in which they could share their stories in a safe environment and enjoy a gratifying experience at a cultural venue.

It is fundamental to consider that the increasing number of people with dementia may not be matched by a similar increase in availability of professional care. Therefore, informal caregivers will be integral to the quality of life of people with dementia as their primary source of caring. This scenario will have a heavy impact on social and health services, but also on contemporary societies in general, therefore, museums should be part of a collective response.

This study's research methodology design, which included a variety of qualitative and quantitative research instruments, aimed to shape a comprehensive understanding of the impacts of *House of Memories Family Carers Awareness Day* and to provide suggestions for the future development of the programme.

Considering the Crossing Boundaries WP2 research methodology design, it is our understanding that the retention of survey questionnaire respondents from phase 1 to phase 2 was a major challenge. A longer-term study with a larger sample would allow statistically significant findings to verify and develop the conclusions of this study. That information could be beneficial to evidence the impact of *House of Memories* on informal caregivers' subjective wellbeing, on the relation between cultural and care practices, and how the programme, supported by partner museums, has been providing a valuable contribution to raise awareness on dementia care through an extensive national network across several sectors.

Findings are suggestive of the potential of the *House of Memories* programme to improve the lives of informal caregivers:

- Awareness: one third of the sample did not know the dementia stage of the person they are caring for, and what they most enjoyed was getting to know more about dementia. Almost all (91%) of the delegates had never used a museum for memory or reminiscence activities, and the majority of carers (75%) never used an *iPad* for the same purpose before *House of Memories Family Carers Awareness Day*.

- Recognition: knowing that informal carers are just as important as those with dementia authorised them to also be care receivers, contributing to restore their feelings of self-worth. Museum staff and *House of Memories* staff contribute significantly to improving informal carers confidence, by providing them with tools that would help them to cope with the conditions, in a warm, supportive, interactive, and informative environment.
- Wellbeing: the sample is constituted mostly by care managers, which tend to report lower levels of stress compared with care providers, however their ZBI scores show they are at risk of depression. The family caregivers that attended *House of Memories Family Carers Awareness Day* can also be described as *Rechargers* (museum visitor profiles). Therefore, *House of Memories*, as a motivation to visit a museum, can be perceived as a restorative experience. Smiley-face assessment scales show respondents' moods were notably enhanced because of the *House of Memories* experience. Equally, family caregivers reported that the person they are caring for is in a better mood (29%) or more responsive to the environment (29%) after using the *My House of Memories app*.
- Transferability: Besides the arguably '*Liverpool centric*' feature of *House of Memories* content, the effective transferability, adaptability and impact of the existing model was observed across the three museum and gallery service case studies. All partner museums agree that *House of Memories Family Carers Awareness Day* framework is robust enough to be easily adapted and transferred to other localities, spaces and museum contexts; in addition, *House of Memories Family Carers Awareness Day* model impacted positively within and across the three separate and distinct museum and gallery services.
- Time: the session length was perceived by delegates, partner museum staff, and *House of Memories* staff as an issue that could be improved.
- Social Value: The research found that more than £1m was generated in social value over a five-year period: for every one pound invested into the family carers' programme, a return of £18.73 was generated covering a projected five-year period. However, the potential impact of this training is yet to be fully considered and realised.

Considering the transferability, adaptability and impact of the existing model, the national profile and reputation of *House of Memories* was crucial in supporting regional partners, such as Leicester, to develop their own dementia programme and meet their own local agendas. Working with another national museum, such as the British Museum, was important to raise national awareness and by combining approaches, it can enrich both organisational strategies and practices on culture-led interventions in dementia.

It is important to note the fundamental work to integrate *House of Memories* in national political agendas for dementia care:

'I think it is a good opportunity because NML holds a much stronger position to access that kind of funding directly from the government that smaller museums just can't or would struggle to. Because of the connections and the clout and all that kind of things. So that has been positive'. (Salford Museum and Art Gallery).

'The fact there was a House of Commons reception after our first project was really useful to quote as well. We had some members from the health department that went as well.... I was able to feedback to our political leaders, and they are always impressed with things like this. It was good, our local MP 'Oh yeah, it's really good Leicester is a partner'. As a bigger political lever, it really made a difference' (New Walk Museum and Art Gallery).

Last but not least, a key part of supporting family carers is to facilitate connections with local support organizations such as the Alzheimer's Society, given that museum staff are specialists in museums, not in dementia, and the *House of Memories* sessions are time limited. Alzheimer's Society and other similar support services were present at Liverpool, Leicester and Salford providing information, emotional and general support for family carers:

'Everything that was needed was there, all the support mechanisms for the people that were attending the training as well. We had the Alzheimer's Society, and another organization was there... Age UK. Those structures were in place. They had plenty of staff on hand, as well, who bought into it as well' (House of Memories Creative Director).

REFERENCES

- Alzheimer's Society. (2016, February 4). *Carers for people with dementia struggling in silence*. Retrieved January 20, 2017, from Alzheimer's Society. leading the fight against dementia: https://www.alzheimers.org.uk/site/scripts/news_article.php?newsID=2552
- Alzheimer's Society. (2017, April). *Facts for the media*. Retrieved April 21, 2017, from Alzheimer's Society: https://www.alzheimers.org.uk/info/20027/news_and_media/541/facts_for_the_media
- Archbold, P. (1981). Impact of parent caring on women. *XII International Congress of Gerontology*. Hamburg: International Congress of Gerontology.
- Ballesteros, J., Santos, B., Gonzalez-Fraile, E., Munoz-Hermoso, P., Dominguez-Pancho, A. I., & Martin-Carrasco, M. (2012). Unidimensional 12-Item Zarit Caregiver Burden Interview for the Assessment of Dementia Caregivers' Burden Obtained by Item Response Theory. *Value in Health* 15, 1141-1147.
- Brodsky, H., & Donkin, M. (2009). Family Caregivers of People with Dementia. *Dialogues Clinical Neuroscience*, 11(2), 217-228.
- Brooker, D. (2007). *Person-centred Dementia Care: making services better*. Jessica Kingsley: London.
- Camic, P. M., Baker, E. L., & Tischler, V. (2015). Theorizing How Art Gallery Interventions Impact People With Dementia and Their Caregivers. *The Gerontologist* Vol. 00-00, 1-10.
- Department of Health. (2009). *Living Well with Dementia: A National Dementia Strategy*. London: The Stationary Office.
- Ducharme, F., Lévesque, L., Lachance, L., Kergoat, M., & Coulombe, R. (2011). Challenges associated with transition to caregiver role following diagnostic disclosure of Alzheimer disease: A descriptive study. *International Journal of Nursing Studies*, 48(9):, 1109-1119.
- Falk, J. (2009). *Identity and the Museum Visitor Experience*. London: Routledge.

- George, L., & Gwyther, L. (1986). Caregiver well-being: a multidimensional examination of family caregivers of demented adults. *Gerontologist*, *26*, 253-259.
- Higginson, I., Gao, W., & Jackson, D. (2010). Short-form Zarit Caregiver Burden Interview were valid in advanced conditions. *Journal of Clinical Epidemiology*, *63*, 535-542.
- Kinney, J. M., & Rentz, C. (2005). A Observed wellbeing among individuals with dementia: Memories in the making, an art program, versus other structured activity. *American Journal of Alzheimer's Disease and Other Dementias*, *20*, 220–227. doi:doi:10.1177/1533317505020
- LaFontaine, J., Ahuja, J., Bradbury, N., Phillips, S., & Oyeboode, J. (2007). Understanding dementia amongst people in minority ethnic and cultural groups. *Journal of Advance Nursing*, *60*, 605–614.
- Lynch, K., Baker, J., Lyons, M., Feeley, M., Hanlon, N., O'Brien, M., . . . Cantillon, S. (2009). *Affective Equality. Love, Care and Injustice*. London: Plagrave Macmillan.
- MacPhersona, S., Birdab, M., Andersonab, K., Davisa, T., & Blair, A. (2009). An Art Gallery Access Programme for people with dementia: 'You do it for the moment'. *Ageing and Mental Health Vol. 13-5*, 744–752.
- Musella, O., Carloni, A., De Marino, L., Di Bartolo, E., Gaeta, G., Di Maggio, P., & Fasanaro, A. M. (2009). Visual art improves communication and behaviour of AD patients. *New trends in alzheimer and parkinson related disorders: ADPD*, 15-20.
- Nicholls, J., Lawlor, E., Neitzert, E., & Goodspeed, T. (2012). *A Guide to Social Return on Investment*. Retrieved from The SROI Network: <http://www.thesroinetwork.org/publications/publications>
- Office for National Statistics. (2015). *Deaths registered in England and Wales (Series DR): 2015*. London: Office for National Statistics.
- Ory, M., Hoffman, R., & Yee, J. (1999). Prevalence and impact of caregiving: a detailed comparison between dementia and nondementia caregivers. *Gerontologist*, *39*, 177–185.
- Rosenberg, F. (2009). The MoMA Alzheimer's Project: Programming and resources for making art accessible to people with Alzheimer's disease and their caregivers. *Arts & Health*, *1:1*, 93-97. doi:DOI: 10.1080/17533010802528108

- Rosenberg, F., Parsa, A., Humble, L., & McGee, C. (2009). *Meet Me: Making Art Accessible to People with Dementia*. New York: The Museum of Modern Art.
- Schoenmakers, B., Buntinx, F., & Delepeleire, J. (2010). Factors determining the impact of care-giving on caregivers of elderly patients with dementia. A systematic literature review. *Maturitas*, *66*, 191-200.
- Schreiner, A., Morimoto, T., Arai, Y., & Zarit, S. (2006). Interview, Assessing family caregiver's mental health using a statistically derived cut-off score for the Zarit Burden. *Aging Ment Health*, *10*(2), 107-111.
- Schulz, R., & Martire, L. (2004). Family caregiving of persons with dementia: Prevalence, health effects, and support strategies. *The American Journal of Geriatric Psychiatry*, *2*(3), 240–249.
- Schulz, R., & Martire, L. M. (2004). Family caregiving or persons with dementia: prevalence, health effects and support strategies. *The American Journal of Geriatric Psychiatry*, *12*, 240–249. doi:doi:10.1097/00019442-200405000-00002
- Stewart-Brown, S., & Janmohamed, K. (2008). *Warwick-Edinburgh Mental Well-being Scale. User Guide*. Warwick: NHS Health Scotland.
- Throsby, D. (2001). *Economics and Culture*. Cambridge: University of Cambridge Press.
- Wang, G., Cheng, Q., Wang, Y., Deng, Y.-l., Ren, R.-j., Xu, W., . . . Chen, S.-d. (2008). Alzheimer Disease & Associated Disorders. *Alzheimer Dis Association Disorder*, *22*(4), 321-326.
- Warwick Medical School. (2017, January 19). *Warwick-Edinburgh Mental Wellbeing Scale (WEMWBS)*. Retrieved from Warwick Medical School : <http://www2.warwick.ac.uk/fac/med/research/platform/wemwbs/>
- Zarit, S., Reever, K., & Bach-Peterson, J. (1980). Relatives of the Impaired Elderly: Correlates of feelings of burden. *Gerontologist*, *20*(6), 649-655.
- Zwaanswijk, M., Peeters, J. M., Beek, A. P., Meerveld, J. H., & Francke, A. L. (2013). Informal Caregivers of People with Dementia: Problems, Needs and Support in the Initial Stage and in Subsequent Stages of Dementia: A Questionnaire Survey. *The Open Nursing Journal*, *7*, 6–13.

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The lead author can be contacted as follows:

Dr Rafaela Neiva Ganga
Research Associate, Institute of Cultural Capital
Liverpool John Moores University
John Foster Building, Mount Pleasant
Liverpool, L3 5UZ
R.NeivaGanga@ljmu.ac.uk
+44 (0)151 231 3967

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