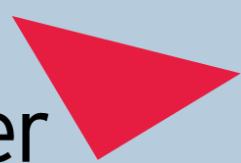


# UNLOCK & Revive

The ingredients needed to deliver accessible online cultural and heritage events that bring positive benefits to people living with dementia and their caregivers



Edinburgh Napier  
UNIVERSITY



THE UNIVERSITY  
of EDINBURGH

AN EDINBURGH HERITAGE PARTNERSHIP PROJECT ENGAGING PEOPLE LIVING WITH DEMENTIA



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# 1. EXECUTIVE SUMMARY

## 1.1 THE UNLOCK & REVIVE PROJECT

Unlock & Revive is a multi-disciplinary action-research project that involves multiple partners. It is a highly collaborative project aimed at supporting the wellbeing of people living with dementia (PWD) and their caregivers in the Edinburgh and Lothian area, through online cultural engagement events. The programme was set up in response to Covid-19 to provide some form of weekly social cultural activity for the PWD community.

The Unlock & Revive project brought together 7 Edinburgh-based cultural and heritage organisations to offer weekly online sessions created specifically for PWD and their caregivers. 30 online sessions were delivered across a 3-month period from April – June 2021.

## 1.2 AIM AND OBJECTIVES

The aim of the Unlock & Revive project is to identify the active ingredients needed to deliver accessible online cultural and heritage events that would bring positive benefits to people living with dementia and their caregivers.

The objectives of the action research project are outlined in Figure 1.

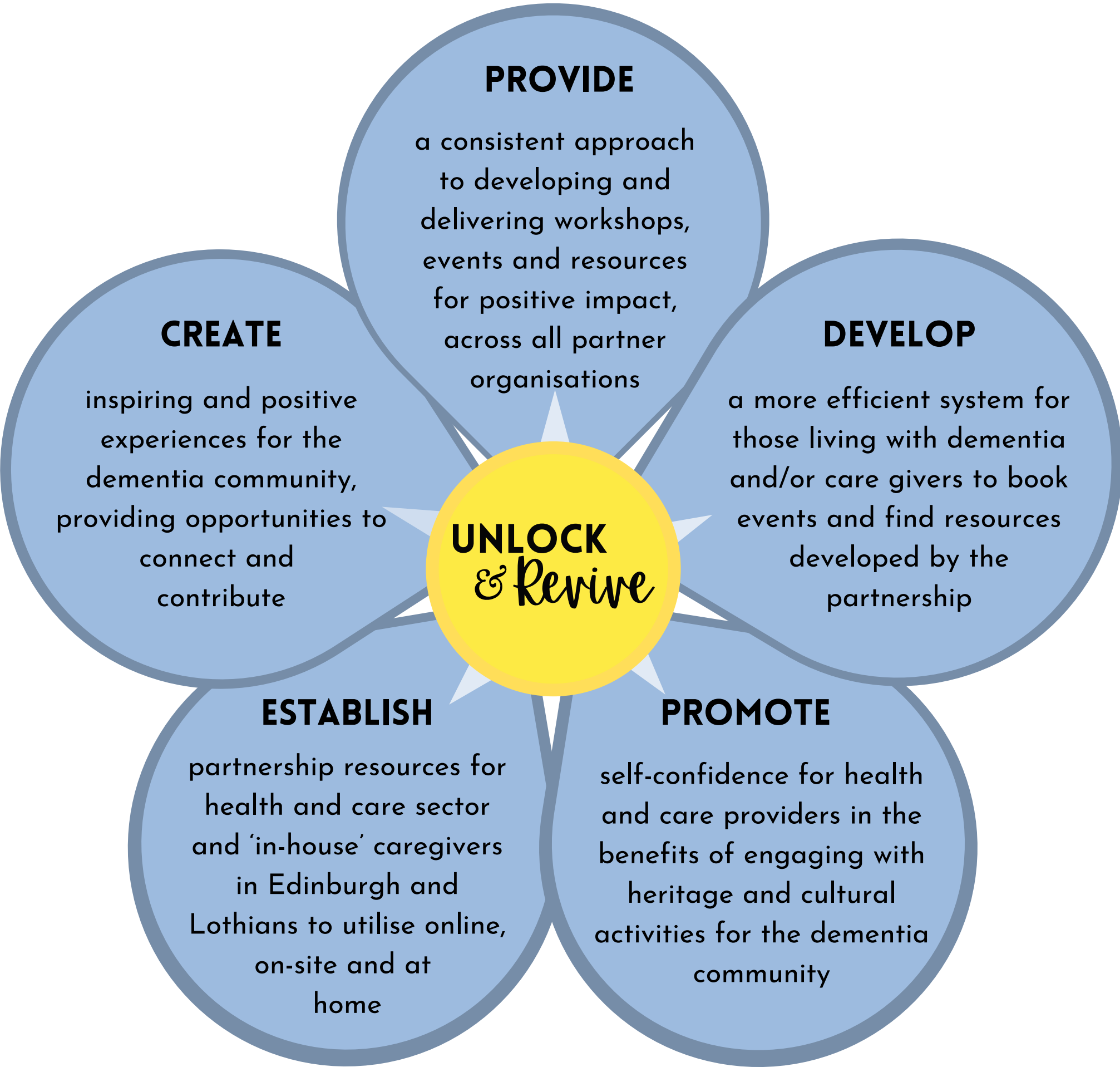


Figure 1: Unlock & Revive Project Objectives

CULTURAL AND HERITAGE PARTNERS



RESEARCH PARTNERS



TRAINING AND DEVELOPMENT PARTNER







### 1.3 KEY FINDINGS

- Online events provide an opportunity to connect communities from remote and international locations
- There is clear evidence that digital events provide opportunities for social connection and stimulation for individuals unable to attend live events due to mobility and/or transportation barriers
- Participating in online group activities from the comfort of a home-like environment encourages attendees' engagement and boosts their sense of wellbeing
- Weekly participation in these online Dementia Socials provides a welcome structure to attendees allowing them to feel more connected to others within the dementia community and building self confidence
- Participants have identified that weekly participation in these Dementia Socials helps establish a new-found appreciation for leisure activities and hobbies (i.e. gardening, harvesting, painting), increase subject-specific knowledge and verbally engage people with dementia through sensory triggers
- Participants told us that they are comfortable attending online events using Zoom and would prefer this to any other type of digital meeting platform
- Although 100% of participants told us they prefer to attend Dementia Socials in-person, all expressed their appreciation and enjoyment of online socials and see it as useful option for a hybrid event model in the future
- The target audience of Dementia Socials prefer engagement over education, as engagement is often more accessible, participatory and measurable for people with dementia rather than attempting to teach them something new
- Having a mid-morning start time for an online event tends to be the preferred start time for the people with dementia community
- The format for in-person events does not easily transfer to a digital delivery model and accommodations should be made to facilitate maximum engagement and participation from participants when delivering events online
- Using social media platforms to advertise socials often does not reach the intended audience, so consideration should be paid to a more grassroots approach to community engagement and advertising



## 1.4 RECOMMENDATIONS

This action research project has identified multiple areas of good practice and several areas for development and consideration. The key recommendations of this report have been broken into 3 sections:

### 1.4.1 OUTREACH AND ENGAGEMENT

- A digital version of the Social Magazine should be created and accessible from a single access point. Information should include all Dementia Socials event dates, times, themes, links and contact details
- Similar wording should be used to describe each Dementia Social for ease of organisation-specific website searches and wider online searches (i.e. Dementia Social instead of Library Social)
- When advertising, consider your intended audience and if your event is 'geared towards those affected by dementia' or simply 'dementia-friendly'?
- Frequent communication should be circulated to event subscribers to ensure the target audience is aware of upcoming events
- Relationships should be forged with local health care providers, care homes and community groups to encourage new participation from those affected by dementia
- Advanced planning should be carried out by each organisation together with the people with dementia community to understand participant interests, consumer needs and good practices
- The establishment of a 'Carer and Community Network' could potentially act as a gatekeeping resource for Dementia Socials
- Pre-event interactions from event facilitators help to build digital confidence and event familiarity





## 1.4.2 EVENT DELIVERY

- **Zoom is the preferred platform** for online event delivery for the dementia community
- **Delivery Team:** The successful delivery of digital events requires expert coordination between the event organiser(s), facilitator(s)/presenter(s), community liaison(s) (if applicable), community members, carers, and person(s) with and/or affected by dementia. Both organisers and attendees noted the benefit of admin support for session presenters (ie. designated person to let members in, oversee chat box interactions, provide tech support with slide decks and A/V) who can also monitor participants' wellbeing in the event a nurse is unavailable
- Where possible, Zoom's 'spotlight' function should be used by presenters to reduce the number of screens seen by attendees
- All participant **mics should be muted** during presentations to reduce noise and disruption
- Socials should be curated to **include short interactive presentations/narratives** so as not to overload participants with information
- Socials should **use simple and accessible language and supplemental visuals** (PowerPoints, photographs, images) within presentations and discussions and should avoid using 'lecture-style', text-heavy delivery formats
- More time should be allocated for **participant-led discussions** throughout each event, as this is highly valued by carers and family members and is seen to be more effective at encouraging people with dementia to engage
- Presenters should use multi-sensory triggers to **create engaging narratives centred around significant themes, places, and/or locations** (sensory engagement involving images, videos, words, etc. aid in memory stimulation)
- **Small numbers of attendees** are ideal for close monitoring of attendees' wellbeing
- Online events for the dementia community should **last no longer than 60 minutes**



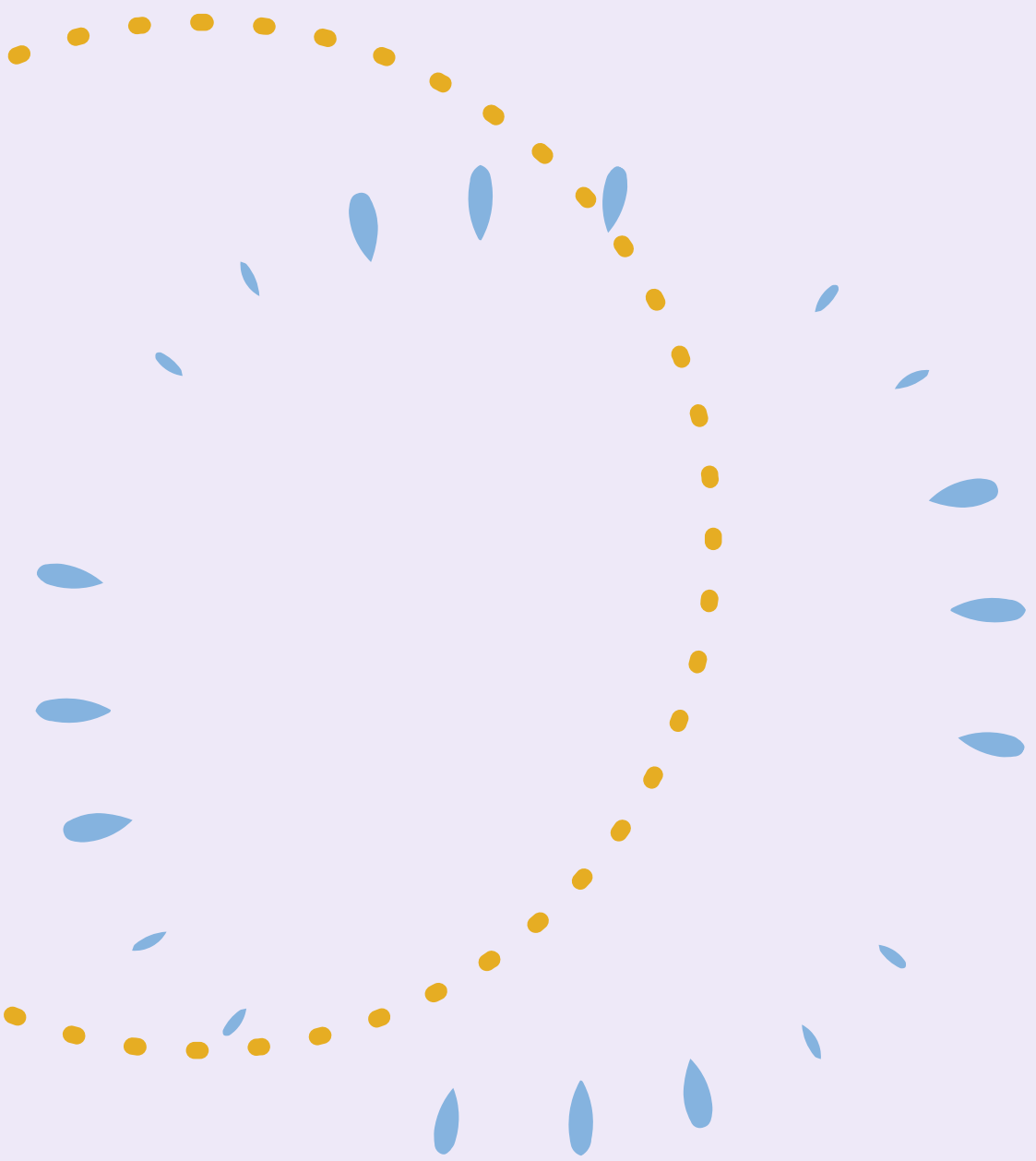
## 1.4.3 EVENT LONGEVITY

- Organisations curating online events for the dementia community should **opt for long term engagement rather than stand alone events**
- Each Dementia Social should **establish a routine** for the continuation of monthly events. This should include a mutually agreed upon schedule with delivery format, day, time and length of the event considered
- Organisers should ensure all event facilitators, guest speakers, and volunteers **have up-to-date Dementia Training** from a reputable institution (i.e. Alzheimer's Scotland or Age Scotland)
- Event organisers should **provide an opportunity for participants to share event feedback** and recommendations should be thoughtfully onboarded
- Online events should continue in partnership with face-to-face events



## 2. INTRODUCTION

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Dementia is a progressive disorder that affects how the brain works, and in particular the ability to remember, think and reason. It is not a disease in itself, but rather a syndrome comprised of symptoms that may accompany a number of diseases that affect the brain, including: Alzheimer's disease; vascular dementia; frontotemporal dementia or Lewy bodies dementia (NHS, 2021).

According to NHS Scotland (2021), people living with dementia may experience any number of the following:

- Memory loss
- Disorientation or confusion
- Difficulty with understanding, thinking speed and reduction in mental sharpness
- Cognitive or motor impairments (i.e. thinking, rationalising, concentrating, planning, understanding, verbal communication, mobility, etc.);
- Changes in mood, personality or behaviour;
- Difficulty doing things they used to find easy (i.e. socialising, reading, gardening etc.)

By connecting PWD through environments that can temporally withstand the course of the disorder (such as music, various visual art forms and sensory experiences), it may be possible to better foster connections with others and their environments and wider communities. Events that foster engagement using familiar objects and places may serve as catalysts for connection for those affected by dementia (Phillips & Evans, 2018).

However, the Covid-19 pandemic has forced cultural and heritage organisations to close to the public, causing a pivot from physical events to online events across many industries globally.

In response, many in-person cultural and heritage organisations had to move their programming online, including their programming of events for the PWD community. In terms of hosting and facilitating inclusive events, the novelty of digital engagement has undoubtedly introduced unforeseen challenges for organisers and participants alike. Given the specificity of participants' needs, the Unlock & Revive action research project was set up to identify good practice in the co-creation and co-production of online events for the dementia community.



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**In total, the Unlock & Revive programme delivered 30 online events across nine outputs from April to June 2021. There were 2 strands to the Unlock & Revive programme: GLAM Dementia Socials and Community Care Partner Events**

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## GLAM DEMENTIA SOCIALS

Pre-pandemic, the GLAM Dementia Socials (Galleries, Gardens, Libraries, Art, Museums and Music) were publicly bookable in-person dementia-friendly events with regular audiences of 30-40 attendees. The onset of Covid-19 restrictions then forced these events to move online. A key difficulty was then getting the word out to their previous attendees that these sessions had moved online but noting that, as lockdown prolonged, some of the previous in-person attendees attended the online GLAM Dementia Socials.

Each of the 7 Cultural & Heritage organisations within the GLAM series hosted 3 events throughout the Unlock & Revive action research project (i.e. one event per month per organisation from April – June 2021).

GLAM Dementia Socials programming strand was evaluated by Edinburgh Napier University Business School in collaboration with Edinburgh Napier University's School of Health & Social Care.

## COMMUNITY CARE PARTNER EVENTS

A second programming strand comprised of bespoke online drop-in events for the dementia community made available only via community care partners. This programming strand was evaluated by Lothian Birth Cohorts at the University of Edinburgh in collaboration with Edinburgh Napier University's School of Health & Social Care. Findings and recommendations from the evaluation of this programming strand are presented in a separate report.

## GALLERY SOCIALS

A series hosted by a small group of resident artists from the National Galleries of Scotland. Each session has been carefully curated to digitally highlight current major art exhibitions or broader themes based on wider collections throughout the Gallery archives.

## GARDEN SOCIALS

A series hosted by Royal Botanic Garden Edinburgh's Cottage Operations Coordinator, Laura Gallagher, and Community Engagement Manager, Amy Leach. These sessions often spotlight workshops with specialist staff that offer tips, tricks and tasty insights on gardening, harvesting and cooking from home and holistically connecting with nature.

## LIBRARY SOCIALS

A series hosted by the National Library of Scotland's Learning and Outreach Officer, Beverley Casebow, delivered in conjunction with guest speakers. This series offers attendees an in-depth insight into the storied collections of literature, music and poetry on offer within the Library.

## ART IN THE CITY SOCIALS

A series hosted by City of Edinburgh Council's Outreach and Access Manager and Open Museum Curator, Diana Morton. Each social provides a monthly opportunity to discuss art, artists and artistic periods throughout history based on new exhibitions or topics specific to Museums & Galleries Edinburgh. Unlike other events within the GLAM Socials, the Art in the City Socials were only available to the public who were on a mailing list from an Edinburgh Museums and Galleries database, so these events were 'drop in' rather than bookable by the wider public.

## MUSEUM SOCIALS

A series hosted by National Museums Scotland's Community Engagement Officer Laura Bennison, delivered in conjunction with visiting guest speakers. These socials offer attendees an insight into life behind the scenes at the Museum and provide an opportunity for participants to digitally engage with artefacts from within the collection.

## MUSIC SOCIALS

A series hosted by University of Edinburgh Museum's St. Cecilia's Hall's Learning and Engagement Curator, Dr Sarah Deters. These socials provided an opportunity for virtual tea and cake, endeavoured to educate participants on a central musical theme ranging from Mary Queen of Scots' favourite instruments to the evolution of Rock n' Roll and ended with a live-streamed musical performance by visiting musicians.



## THE TEAM



### HANNAH STEWART

Hannah Stewart, MSc is the Research Consultant on this project. She is a festival manager & creative content developer with over a decade of experience & has designed, produced & managed festivals across Canada, the UK & the Middle East. She is a PhD Candidate at the Institute for Dark Tourism Research (iDTR) with the University of Central Lancashire (UCLan) specialising in Dark Event Tourism.



### DR STEPHEN SMITH

Dr Stephen Smith trained as a general & mental health nurse & for 15 years worked in the area of palliative care alongside people with dementia. He is an Associate Professor at Edinburgh Napier University where teaching, research & practice improvement activities focus on the development of practice & learning in compassionate care. Stephen is Associate Head, Nursing, at Edinburgh Napier University's School of Health and Social Care. He is also a Consultant Nurse in Compassionate Care at NHS Lothian.



### RUTHANNE BAXTER

Ruthanne Baxter is Museum Services Manager at the University of Edinburgh, where she is also the Lead for Prescribe Culture. She has over 15 years development & project management experience & delivers 'Business of Heritage', Commercial Development, income generation & Audience Development training for rural museums & heritage organisations across Scotland. Ruthanne is a Trustee of the Coastal Museum in North Berwick & is on the Business Events Steering Group, Edinburgh Tourism Action Group.



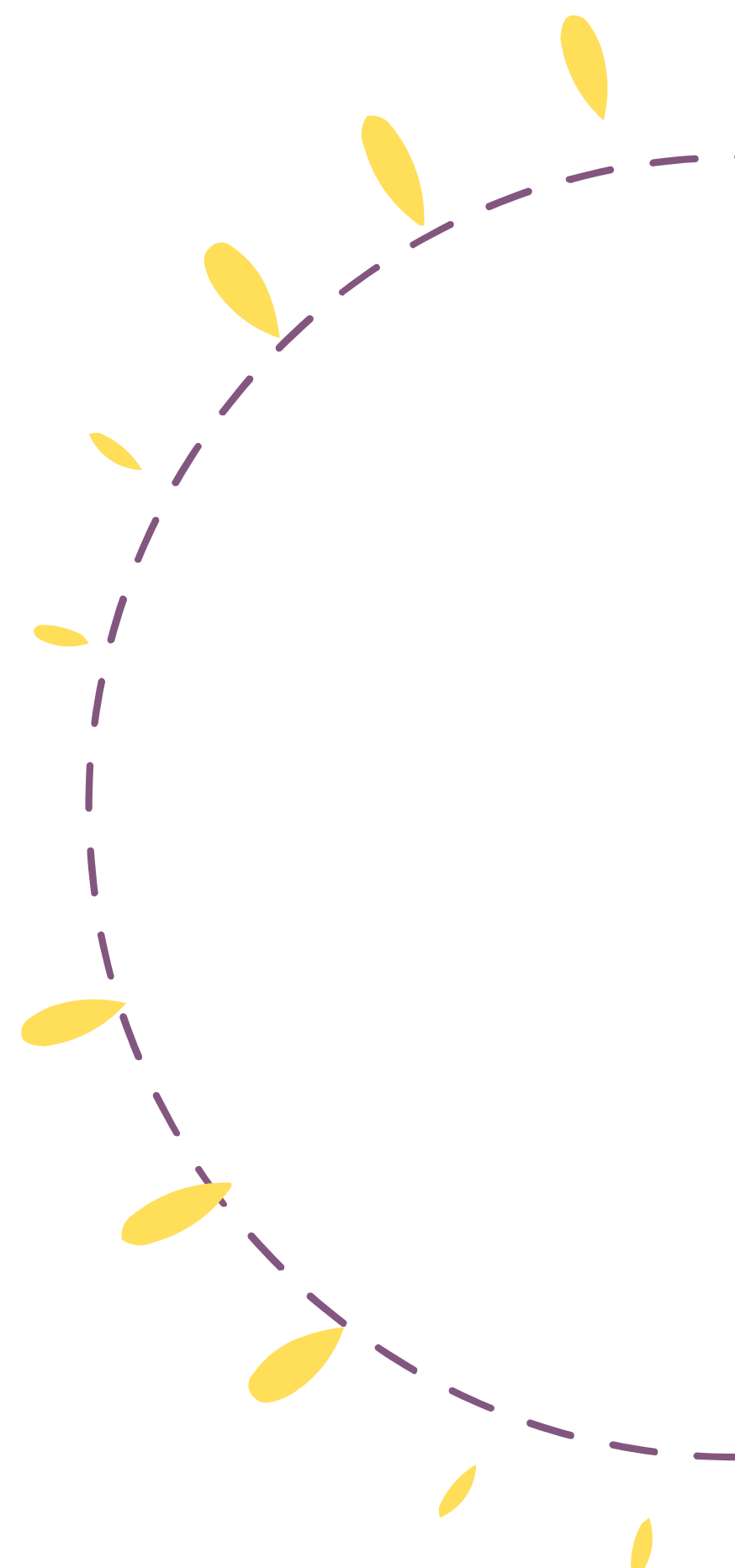
### PROFESSOR JANE ALI-KNIGHT

Professor Jane Ali-Knight is a Professor in Festival and Event Management at Edinburgh Napier University Business School. A recognised academic, she has presented at major international & national conferences & has published widely in the areas of destination development, wellbeing & accessibility, festival & event marketing, management & lifecycles. She has been involved in multidisciplinary research projects examining how festivals, events, visitor attractions and cultural venues can become more accessible for people living with dementia through co-creation and collaboration.



### DR GARY KERR

Dr Gary Kerr is an Associate Professor in Festival & Event Management within the Tourism & Languages Subject Group of Edinburgh Napier University Business School. Gary has facilitated several multidisciplinary research projects which examined how festivals, events, visitor attractions & cultural venues can become more accessible for people living with dementia through co-creation and collaboration. Gary is a festivals and events practitioner & undertakes practical roles within industry to keep his skills relevant. He delivers consultancy & training to festival managers across the world including the Gulf Region & in South Asia.





# 3. METHODOLOGY & DATA COLLECTION

The evaluation of the GLAM Dementia Socials captured the needs of, and constructive feedback from, individuals who identify as part of the dementia community (including people living with dementia, carers, family members, people affected by the disorder) and community professionals involved developing, producing, and delivering the online engagement events.

Our methods comprised three qualitative approaches:

- Observations and attendance at online events produced by the GLAM cultural & heritage partners
- Facilitating online focus groups with PWD and their carers
- Undertaking semi-structured interviews conducted using Microsoft Teams with the event organisers



## **DIRECT OBSERVATION BY RESEARCHERS AT EVENTS**

Researcher(s) participating in sessions collected notes to provide first-hand accounts of the sessions format, content, and dynamics. The notes provide insight into the effectiveness of the series, the interest and level of accessibility within each theme covered and interactions between participants and instructors.

## **FOCUS GROUPS WITH EVENT ATTENDEES**

For each series, all event attendees were invited to join a post-session focus group to share their views, experiences and perspective on accessibility, levels of engagement and overall satisfaction with Dementia Socials being delivered in an online format. Participants provided verbal consent to the focus group being video recorded, and recorded transcripts were used as evidence to evaluate the participants' experiences and perspectives on the delivered online events.

## **SEMI-STRUCTURED INTERVIEWS WITH EVENT ORGAGNISERS**

In terms of social scientific research, interviews are the most widely used method of data generation within qualitative investigations (Edwards & Holland, 2020). Interview types range from structured to semi-structured, reflective to narrative and expert to episodic. Structured interviews are more commonly used more for quantitative data collection, while semi-structured to episodic formats provide qualitative researchers the flexibility required to access the authentic interior of participants' experiences, perceptions and feelings (Flick 2019, Whitaker & Atkinson, 2019). Semi-structured interviews were carried out with each of the event organisers of the GLAM Dementia Socials, plus the Dementia Trainer from Age Scotland.

## **DIGITAL RESEARCH METHODS**

As these Dementia Socials were delivered digitally to accommodate Scottish Government guidelines and restrictions on physical social contact, all interviews and focus groups were conducted through online platforms such as Zoom and Microsoft Teams. Although there are undoubtedly benefits to conducting qualitative research in-person, especially with people living with dementia, this was an impossibility due to Covid-19. However, there are several proven advantages to utilising digital methods for interviews and focus groups including:

- Less intrusive for participants
- Greater contributor control in terms of participation
- Increased comfortability of participants, as they are able to contribute from the comforts of their own surroundings
- Reduced costs of travel for in-person interviews
- Increased accessibility and greater geographical reach
- Reduced risk of Covid-19 infection

Organisers and facilitators of each Social series were invited to partake in a semi-structured interview to discuss the challenges associated with moving these established in-person socials to an accessible format online. Points of discussion included training for the delivery of dementia events online, attendance numbers and reach, financial support or budgetary constraints, marketing and accessibility and best practice reflections. Participants provided consent for sessions to be recorded, and video transcripts provided evidence on facilitators' perspectives on delivering digital events for the dementia community.







## ETHICS AND DATA MANAGEMENT

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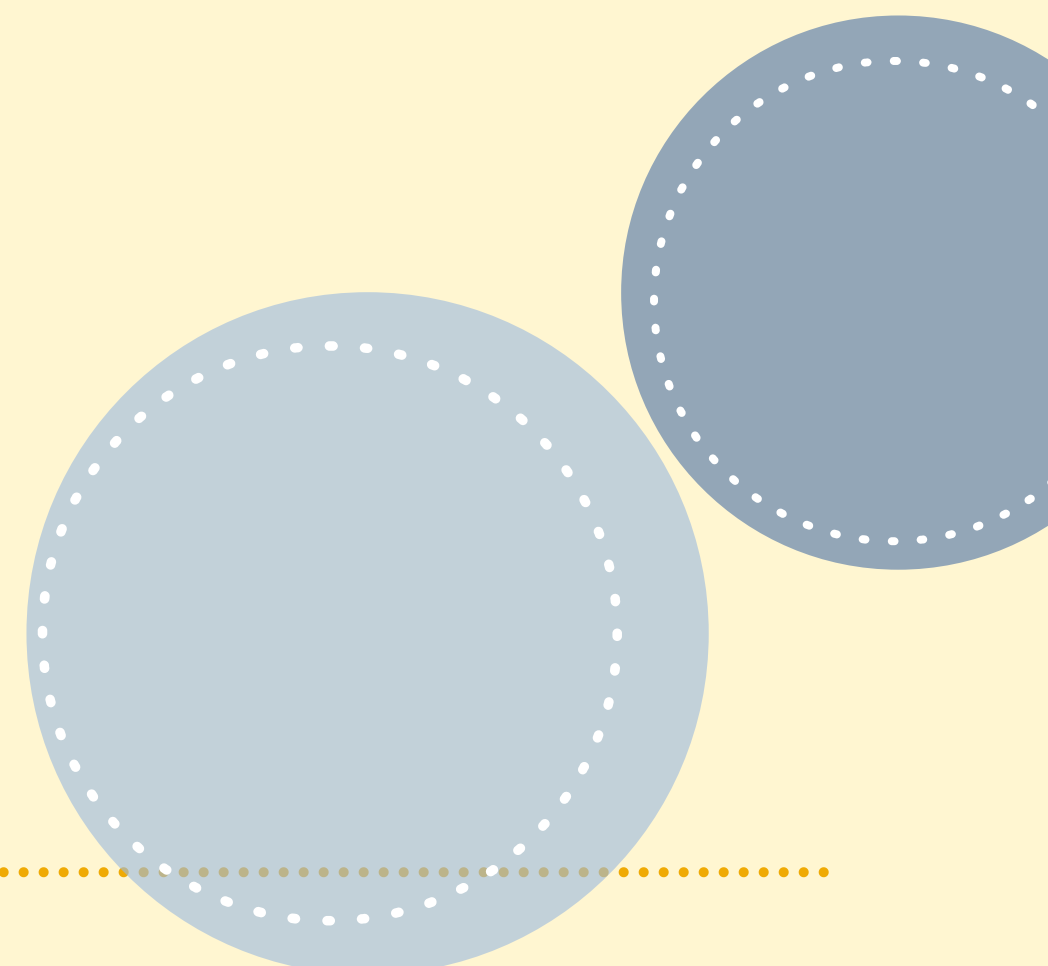
- Data were collected and stored in a manner which is consistent with the ethics and data handling guidelines produced by the British Sociological Association and is consistent with the principles of research ethics in higher education
- Research participants were verbally provided detailed information on the background of the Unlock & Revive action research project and how findings would be shared; on the purpose of the focus group or interview; on what data was being collected; and how data was being analysed, anonymised and stored
- Research participants were asked to verbally consent to their participation in this research for which they agree to data they provide being used in the final report
- All participants were guaranteed anonymity ahead of the interview. Names have been removed wherever necessary and data in this report has been anonymised to protect research participants
- Interviews and focus groups were transcribed verbatim by one of the researchers, adhering to EU and UK regulations on data protection and GDPR
- Audio files were destroyed once transcripts were completed and checked for accuracy by the research team
- Transcribed word documents and other digital data relating to this project are held on a secure digital repository at Edinburgh Napier University and will be destroyed within 24 months of those data being collected

# 4. RESULTS & DISCUSSION

## FOCUS GROUPS WITH EVENT ATTENDEES

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The GLAM Dementia Socials featured 6 of the overall 9 cultural and heritage organisations within the Unlock & Revive action research project. From this programming strand, 3 researchers conducted 5 focus groups with 20 participants. St. Cecilia's Hall Music Social focus group did not have any participants on the day researchers attended the event; unfortunately, due to scheduling conflicts, researchers were unable to facilitate any additional focus groups with these participants. Focus group participation was entirely voluntary and several participants attended multiple focus groups, adding different insights each session. All participants identified as active members of Edinburgh and the Lothian's dementia community and included carers, people with dementia, family members and people affected by dementia or other cognitive degenerative conditions.





## ATTENDEE SATISFACTION

Each focus group began by asking participants to use one word to reflect how the Social they had just attended made them feel. All responses were overwhelmingly positive, with 'happy', 'enthused' and 'informed' being the most frequently used descriptors (see Figure 2).

According to participant feedback, several factors contribute to motivation to attend Dementia Socials, including personal interests in a theme or topic, being made to feel part of a wider community, the delivery format and/or presentation style of an event and individual capabilities.

Several themes arose from the data analysis process, namely challenges surrounding accessibility and digital barriers to participation, the importance of community and connectivity during lockdown, concerns for reintegrating back into a face-to-face environment and expert by experience on what makes an ideal event.

*"The organisers are so pleasant, and the topics that are covered, I can actually understand!"*

*"It's nice to be able to see familiar faces – there's a real sense of community."*

*"As a carer, it's nice to have time to learn something new."*

*"My husband was the person interested in art and we used to attend these Socials together. Although he died two years ago, I'm so grateful that as a carer I've been allowed to stay on because it's been giving me something to look forward to."*

## FIGURE 2: QUANTIFYING THE EXPERIENCE

### Frequency of words used to describe participant experiences from Dementia Socials events held between April-July 2021



## ACCESSIBILITY – DIGITAL BARRIERS

### Navigation

For most participants, Dementia Socials had become a weekly staple of scheduled activities for as many as six years pre-pandemic. Participants described the shift to digital offerings as “a blessing”, stating they were incredibly “grateful for an opportunity to ease feelings of isolation” and “maintain some semblance of connection with friends from the dementia community” during COVID-19. However, many participants expressed a sense of frustration when it came to navigating organisational websites and the wider internet in search of Dementia Socials details.

*“When you go onto the website of one place, you need to type in ‘dementia social’ to find information and then on another website, you have to type in something different—there’s no single access point to tell us which place is which, who’s running [the Social] that month or how we book our tickets.”*

*“We only get to join the Library Social because [the organiser] sends me the link every month. Every time I go on Eventbrite to try and sign up, it’s always ‘sold out’.”*

One participant mentioned she was unable to locate information for the National Galleries Socials for nearly four months, while another participant was surprised to learn St. Cecilia’s Hall Music Socials were not on hiatus, as he had not found any event details in his online searches for three months. One carer suggested that even if people are dextrous enough to locate event sign-up points, it would be a challenge for people living with dementia to book tickets without assistance:

*“It would be nearly impossible for anyone with dementia to try and negotiate their way through getting tickets and links to [these Socials] online. In actual fact, I, too find it very tricky to be able to find a route to get booked up.”*

### Technology

100% of focus group participants prefer Zoom to any other digital meeting platform, as it is the platform most often used by event organisers and they find it more user-friendly. Four participants highlighted the benefit of Zoom’s ‘mute all’ function, as it helps attendees to focus on a single speaker and provides an opportunity for carers and/or family members to explain and/or discuss content:

*“Event organisers should mute everybody because it’s difficult with people with dementia, that you’re sitting for an hour and then you think ‘oh! I have to explain to them!’ or you realise something that’s been mentioned triggers a memory of theirs so you have the chance to discuss with them without disrupting others.”*

With the initial shift to digital events, participants expressed extreme gratitude for the time several event organisers took to offer instructional phone calls and online tutorials to ensure everyone was comfortable using digital meeting platforms. However, research highlights that attendance numbers have dwindled since the event digitisation. One participant observes:

*“There are very few cared-for’s attending the online meetings, which I think is evidence that they’re struggling to navigate and participate.”*

Additionally, several participants shared feelings of “digital fatigue”, stating that they were “Zoomed out” because of the abundance of online events. One attendee conceded, stating:

*“For me, it’s a lot of time in front of a screen considering I didn’t really use my computer before lockdown. It can be a bit exhausting at times, but it’s my way of life now.”*

Participants offered that the level of participation and engagement of each attendee is largely affected by the screen size of the at-home device being used, as computer screens provide greater visual detail than a tablet or mobile phone. However, the majority of participants in a caring role fed back that the complexity of digital screens adds a layer to the challenge of cognitive engagement for people with dementia:

*“It is very, very difficult for people certainly with advanced dementia – like my wife – to engage with 12 or 14 or 20 small screens on a computer at the same time; it’s like a matrix of little screens and it’s really difficult for her to engage with.”*

Evidence suggests certain Dementia Socials translate better into a digital format than others. As one participant suggested, this is entirely dependent on each attendees’ physical and cognitive capabilities. Upon reflection, one carer shared that although his wife is no longer able to directly engage in ‘normal’ conversation, she has the capacity to actively participate in music Socials and virtual choirs because “she can lock into the audio better than the visual, can recognise songs she’s listened to in the past and can sing along with them.”

Art Socials were mentioned as being better suited to an in-person format, as participants felt certain subtleties including texture, mood, colour and brush strokes were being missed by viewing artwork digitally:

*“This is a lot better than nothing, but we’re missing a lot by not actually seeing the paintings.”*

*“I’m sure technology would allow [the presenter] to point at things in the painting to say ‘notice this’ or ‘notice that’ that would allow us to pick things up on the screen.”*

### Engagement

Collectively, participants agreed that in-person Dementia Socials are of more benefit to those attending with dementia than ones conducted online.

*“I don’t think that if [my husband] had still been alive he would have been able to connect to a computer. I think for people with dementia, these Socials have to be physical.”*

*“For my wife who has dementia, journeying somewhere on a Thursday or Friday and physically going into an environment where you met with other friends in a similar situation and just had a chat used to be almost a weekly highlight. Online Socials don’t seem to provide the same level of engagement or sense of wellbeing for people with advanced dementia. It’s a real shame [my wife] can’t share her perspective with you because your research would really benefit from feedback from people with dementia, but that’s just how I see it.”*



*"We came along to today's session for me. Although it's meant [my wife] and I have been able to do something together, the long lecture-style format hasn't contributed anything to her... it's just been an alternative to sitting staring at a television."*

*"I enjoy these Socials because I find them to be mentally stimulating. Generally, we probably attend these types of events more for my enjoyment than [my husband's]— they make it interesting for the carers."*

## COMMUNITY AND CONNECTIVITY

*"The biggest challenge around these online Socials is that it's been very difficult to keep in touch."*

Although the digitisation of these Socials expanded audience reach to remote areas like Isle of Skye, Shetland, Germany and the United States of America – audiences who would have otherwise been unable to attend pre-pandemic– it has arguably come at the expense of regular attendee satisfaction.

Originally, Dementia Socials were created to cater to the needs and capabilities of Edinburgh's dementia community. Eight participants expressed concern that the basis of why these events were created and ethos surrounding why people regularly attend has been compromised by external groups and/or people digitally attending.

*"When [organisers] advertise [the socials], it shouldn't just be as a 'Social'. During the Patrick Geddes event at the National Library, an academic from Germany joined in...there was an archaeologist from Glasgow and only one other dementia person out of maybe a dozen; it becomes more of an academic discussion rather than an open and relaxed conversation for the dementia community... It's not ending up being a Social for the people who want that sort of contact."*

*"The whole idea behind whatever it is each Social is offering is being diluted by the fact that it's so easy for other people to join in."*

## THE IDEAL EVENT

Based on feedback, the ideal event will always be an in-person one, but if it has to be delivered online, Zoom is preferred, as all participants expressed experiencing unnecessary challenges while using other digital meeting platforms.

In terms of format and best practices, feedback suggests the most effective digital delivery model would be similar to that of the pre-pandemic, tri-part approach:

- 1/3 of the time allocated to tea, coffee, cake and chat
- 1/3 of the time allocated to presentation
- 1/3 of the time for a hands-on activity

Participants acknowledged the logistical challenges associated with implementing hands-on activities for digital sessions but expressed that it would be effective for people with dementia. Activities could be as simple as posting a pre-event care package to attendees that includes dried herbs with instructions on how to make tea.

As a baseline, Socials should facilitate a participant-centred

approach to thematic content, presentations and discussions. PowerPoints should only be used as visual aids to encourage talking points, share images, videos or audio clips and should avoid using excessive text. Presenters should involve participants in the presentation and discussion, allowing ample opportunity for attendee-driven conversation and sharing.

As such, delivery styles must be flexible and adaptable, and presenters should be able to deviate discussions based on memory recall and participant input; event delivery should be informed (and, if necessary redirected) by the perceived level of audience engagement. As a 'Dementia Social', content should be curated with the lowest functioning participants in mind, catering to people with dementia; carers and family members should be enhancing the overall experience, not dictating it.

*"The Socials we've participated in most and have worked the best, particularly for my wife who has dementia, have been groups where the presentation is able to combine visual with discussion in a short form."*

People with dementia may have a limited attention span and ability to contribute or hold on to triggered talking points. Based on feedback, Socials should adhere to a format that offers mini presentations, simple visuals and ample opportunity for participant-led discussions surrounding the subject matter.

As Dementia Socials begin moving back into a physical setting, the majority of participants would like to see some semblance of online delivery maintained, whether that be through live streaming, pre-recording or the facilitation of separate digital events altogether. This could address absenteeism due to inclement weather, poor physical and/or mental health, parking challenges for blue badge holders in the city centre, etc.

## CONCERNS FOR REINTEGRATION

Although in-person events are preferable to most participants, 5 individuals expressed concerns surrounding parking, now that cycle lanes have replaced blue badge spaces in Edinburgh's city centre:

*"[My partner] uses a wheelchair so parking has become impossible outside the National Library because of the cycle lane. Around the National Museum—only two disabled parking spaces, and with Court going on, there's never a parking space. With the National Gallery – where up the Mound was a single line – there's now a cycle lane making it impossible to park. And I can't park behind because it's a hill and I can't push him up it. As things deteriorate with dementia, mobility gets worse and it's not feasible for us to constantly rely on taxis."*

Conversely, concerns mount for newly integrated members of Edinburgh and the Lothian's dementia community who joined in on the Socials during lockdown. A live-in carer residing on the Isle of Skye shared:

*"Attending digital events has enabled me to join in activities of all sorts from anywhere in the world and from that point of view, lockdown has been great. I feel a bit sad that I might be cut off from this as things begin to open up and Socials start to happen in person."*

## INTERVIEWS WITH EVENT MANAGERS

Event organisers and facilitators were selected as a key stakeholder in Edinburgh and the Lothian's Dementia Socials for the Unlock & Revive project. 8 interviews were conducted with 8 different event organisers and 1 dementia training coordinator.

All specialists in their own field, these individuals held managerial titles relating to 'outreach and access', 'learning' and 'community engagement'. All participants were positive in their feedback regarding the perceived benefits of online Dementia Socials but acknowledged that the shift to a digital platform was not without its own challenges and required additional training, research and preparation.

*"Everyone with dementia is unique—it's about understanding what could be causing some of the issues people are having whether it's about participation, reluctance to give it a go or not being able to engage with the technology."*

## TRAINING

All the event managers confirmed their attendance at the Unlock & Revive dementia training session facilitated by Age Scotland ahead of the events that took place for the Unlock & Revive action project, with a further 2 of the event managers sharing they had attended additional training sessions facilitated by the University of Stirling. Only 3 organisations reported having volunteers who had also undergone dementia training for events.

*"It's very important for people who are working with people living with dementia to have a general understanding of the many different types of dementia and the many different ways that can impede someone's participation in something."*

There were 2 training sessions for cultural and heritage partners participating in the Unlock & Revive action research programme:

1. Breakfast Briefing for senior managers of the cultural and heritage partners facilitated by Ruthanne Baxter, to provide them with an overview of the action research programme
2. Dementia-specific training provided by Sandra Brown, Dementia Training Coordinator at Age Scotland. This session was for event managers and also the staff and volunteers at the cultural & heritage partner organisations who would be involved in the delivery of the online events

## CHALLENGES

### Digitising Events

Originally established as in-person events, all GLAM Dementia Socials event managers stated the approach to online event delivery had to be adapted to maximise online engagement and participation.

*"Our in-person events ran around 90 minutes, but we found that was a bit too long to expect event attendees to sit in front of a screen,*

*especially without the same level of physical and tangible engagement they're used to... we could see they were losing interest by the end. Now we run our events so that they're between 45 and 60 minutes long."*

*"Our organisation usually uses [Microsoft] Teams but we run our socials through Zoom. We've done lots of research and we've found that Zoom has so many more settings that make it easier for our intended audience to use."*

Only one event organisation reported using Microsoft Teams as their online Social platform, expressing they were bound to doing so because of stipulations set out by their wider organisation.

All event managers acknowledged the challenges associated with maintaining (or creating for the HES and University of Edinburgh series) a sense of community, support and intimacy with the provision of digital events. An event organiser from the GLAM Dementia Social series shares:

*"In a way, I think the carers had formed their own support network because they knew they'd see each other every week. Virtually, I think it's much more challenging to create the same level of intimacy we had with the live events."*

### Attendance

Pre-pandemic, GLAM event organisers reported hosting approximately 35 people each session. Due to the nature of online events, all organisers felt it necessary to cap participation numbers to anywhere between 12-20 people, event-depending. However, all organisers conceded the near impossibility of a full house, even at a reduced capacity. All event managers from the GLAM series reported a severe decline in digital attendance numbers, sometimes hosting as little as 1 attendee. All event organisers expressed an awareness of attendee apprehensions and fears surrounding the reliance on technology to participate in events.

*"There's quite a lot of fear from the participants that they don't feel comfortable online because only a third of our pre-pandemic audiences are showing up online. We need to try to make it a more comfortable situation for people with dementia."*

One event organiser facilitates a 'closed group' approach to event ticketing where interested parties must contact her directly to reserve a space in the Social. Another organiser shared that booking can only be done through their organisational website. While attendance to all GLAM Socials are exclusively facilitated through Eventbrite, several organisers expressed frustration with the ticketing platform.

*"The challenge with a limited event capacity and using Eventbrite to book these free slots is that the platform is open to anyone and anyone is able to book them, not necessarily from the dementia community. The event could be listed as 'Sold Out' online, but in reality, I only have 3 people out of an assumed 20 joining in the event. That's why I've resorted to reaching out to some individuals myself—I send them the event link to every session so that I know they can attend."*

*"I would not recommend Eventbrite; it's too much of a headache for our attendees who are already struggling to adapt to an online Social and learn Zoom or TEAMS and emails. I would prefer there to be a large database where people can contact me and/or I can contact*



*“them with event-specific details and then send the event link through myself.”*

One organiser bypassed online ticketing reservations altogether and has seen positive results:

*“[Our Social] is a closed group in that people have to contact me to get added to the mailing list. That’s just so that we know a bit more about peoples’ needs. People can’t just drop in. I’ve found that this method yields higher attendance numbers. I think asking people to book puts unnecessary pressure on people who are worried about taking up spaces and not being able to attend for whatever reason.”*

This event manager adds that because the organisation’s Socials are advertised as being ‘for people affected by dementia’ instead of as ‘dementia-friendly’, they have more control over the demographic that attends and know more about the specificity of attendee’s needs. The 7 other organisations advertise their Social series as ‘dementia friendly’ and have found this to attract not only people affected by dementia but others who are simply interested in the topic.

## EXPANDING HORIZONS

All event organisers were asked if and how they would adapt their Socials if resources were limitless. 3 organisers reported they would only minorly – if at all – change their current format.

*“Our approach is simple and our attendees like that. I don’t think increased production value would have any great impact.”*

The other 5 event managers suggested that with infinite resources, they would experiment with posting monthly activity boxes and/or care packages to attendees, increase marketing and communication efforts to the wider dementia community and hire technical expertise.

*“I’m really inspired by what they do at the Festival Theatre for dementia engagement events. It’d be amazing to be able to offer care packages and live stream events, but that requires you to have a budget for that sort of stuff.”*

*“It wouldn’t be online. I’d get an adapted bus and take the Social to them, to the communities.”*

*“I would like to make our online resources more dementia-friendly—every video that our organisation produces would have accessibility standards in place like subtitles and closed captioning.”*

## WORDS OF WISDOM AND GOOD PRACTICES

Event organisers were asked to share words of wisdom and further insights on lessons learned throughout the shift to delivering Dementia Socials online, highlighting key advice for other organisations planning to produce events for people with dementia. Most event managers stressed the importance of event simplicity and creating a relaxed environment for attendees and stated that IT and tech support both internally and externally is paramount to the event’s success.

*“I post [event attendees] a schedule of the session so that they can look*

*at it and know exactly what’s happening on the day. I keep track of what we said we’d be doing so that [participants] can build confidence in that we’re able to deliver on what we said we would.”*

Considering the demographic, one event organiser highlighted the importance of ensuring all participants are comfortable engaging with the various digital meeting platforms:

*“Make sure people know how to use the technology and provide support to those who don’t.”*

Several event organisers echoed this sentiment, stating they, too, had offered support to participants outside of regular Social programming to ensure maximum digital comfortability. One manager expanded on the notion of support, suggesting that trial and error practice sessions are paramount to event success:

*“Think about all the facets of the experience for the end user. Try and take yourself out of your own head and put yourself in their place and test it with colleagues. Perhaps have a small Review Board of volunteers – the practice is invaluable because there was just so much I didn’t know wouldn’t work; [the volunteers] were telling me what they could see from their end [of the computer] and what was and wasn’t working.”*

There was a majority consensus surrounding the importance of utilising accessible resources to enhance delivery methods and encourage wider audience participation. Organisers shared:

*“Change your marketing strategy to try and reach as many people as possible.”*

*“Work with other in-house departments if you can and take on as much advice as you can find.”*

*“Be prepared to adjust and adapt your plan accordingly and commit to outputs! If you’re going to film something, get the subtitling done. It might be a higher initial cost, but the long-term benefit will be priceless.”*

Above all, audience members must feel comfortable and be made to feel an integral part of the delivery structure and paramount to the overall success of the event:

*“Make sure it’s not too large a group, use humour, encourage interactivity, be flexible in your delivery and ask probing questions in a conversational manner so that you can learn more about attendees’ lives outside of the Social. Just make them comfortable.”*





# 5. CONCLUSION

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This report identifies the key findings and learnings from action-based research with event managers and people from within the dementia community and evaluates their engagement with the Unlock & Revive project. The findings provide a valuable insight into how to effectively plan and deliver online events to the people with dementia community and their carer's. It is hoped that this is the first step of wider research to examine effective engagement at cultural and heritage events whether they are delivered online, face-to-face or blended.





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# 7. RESOURCES & FURTHER READING



## ALLIANCE SCOTLAND

The ALLIANCE is a strategic partner of the Scottish Government and has close working relationships, several of which are underpinned by Memorandum of Understanding, with many national NHS Boards, academic institutions and key organisations spanning health, social care, housing and digital technology.

<https://www.alliance-scotland.org.uk>

## COMMUNITY MAKERS

Community Makers is a network of community groups supporting people affected by dementia to reconnect during the COVID-19 related isolation and beyond by exploring the role of technology in helping groups get connected and creating a knowledge exchange network to share experiences and advice.

<https://communitymakers.co/>





## **ALZHEIMER SCOTLAND**

Alzheimer Scotland is Scotland's national dementia charity. Their aim is to make sure nobody faces dementia alone through the provision of support and information to people with dementia, their carers and families, campaigning for the rights of people with dementia and funding vital dementia research.

<https://www.alzscot.org/>



## **DEMENTIA SERVICES DEVELOPMENT CENTRE (DSDC) - UNIVERSITY OF STIRLING**

DSDC is an international centre of knowledge and expertise dedicated to improving the lives of people with dementia.

<https://dementia.stir.ac.uk/>



## **FESTIVAL THEATRE**

Edinburgh's Festival Theatre is committed to creating a warm, welcoming and adapted environment that enables people affected by dementia to flourish, enjoy the arts and stay connected with the community around them through Tea and 'Jam' sessions, tea parties with live music and drop-in cafés.

<https://www.capitaltheatres.com/take-part/dementia-friendly-work>





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