

Unlock & Revive:

A key to wellbeing for people living with dementia through online heritage sessions

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THE UNIVERSITY of EDINBURGH
Lothian Birth Cohorts

Barbora Skarabela¹, Ruthanne Baxter¹, Zuzana Elliott¹ and Stephen Smith²

¹University of Edinburgh and ²Edinburgh Napier University

Introduction

For people living with dementia, life can become increasingly isolating. Yet, being engaged in regular activities that offer a sense of purpose and connection with the world is a key to their wellbeing.

The restrictions on social contact due COVID-19 have had a significant impact on people with dementia and their carers, with the vast majority of face-to-face services suspended, and many activities that support their mental and physical wellbeing disrupted.

New technology has provided an essential means to staying active and connected. The transition to online engagement has, however, presented challenges for people living with dementia as well as those who organise and create bespoke cultural and heritage events.

The Unlock & Revive programme was created as part of Prescribe Culture at the University of Edinburgh Museums as a flagship heritage-based, non-clinical health, wellbeing and social care initiative, built on cultural and social prescribing.

The aim of the Unlock & Revive pilot project was to bring together an online programme for these communities to test whether and how we can use this technology to provide a sense of connection to the world around us through online cultural engagement activities.

In Spring 2021, the initiative brought together 12 online sessions in order to identify best practice

for delivering **engaging heritage and cultural events** for people living with dementia and similar conditions.

The programme was organised by the **University of Edinburgh Museums**, and the events were delivered by **Heather Macleod** in partnership with **Lothian Birth Cohorts, Historic Environment Scotland**, and the **University of Edinburgh Museums**.

The University of Edinburgh conducted the evaluation on this project, focusing on the needs of people with dementia, carers, and Community Care Partners.

The document offers a set of practical recommendations for accessible and engaging online events, informed by the voices of the programme participants, including people with dementia, their carers, and Community Care professionals as well as Programme Leads.

This resource has been created primarily for heritage and cultural event organisers and Community Care professionals working with people and communities living with dementia and related conditions. It may also be of interest to health care professionals as well as carers and people with dementia.

Links to further information and guidance for event organisers and resources for people with dementia and their carers are also included.



People living with dementia

Dementia is a condition caused by gradual changes and damage in the brain, affecting mental abilities, including memory and language.

The common symptoms include:

Slowness of thought

Difficulty with planning and understanding

Problems with concentration

Changes to mood, personality, or behaviour

Feeling disoriented and confused

Difficulty walking and keeping balance

The condition can affect many aspects of a person's life as well as those around them. In this document, **people living with dementia** refers to the individual diagnosed with dementia as well as family and friends, who often become carers for their loved ones, and also social and health care workers and volunteers.



The Unlock & Revive programme

The insights and recommendations presented in this guide are based on the delivery of three different series:

Sing It Back

A series of six online singing sessions delivered by singer and choir director Heather Macleod and LEOD Music. These sessions were delivered in collaboration with Lothian Birth Cohorts and with the support from the Knowledge Exchange fund in the School of Philosophy, Psychology and Language Sciences at the University of Edinburgh.

The aim of Sing It Back was to build on reported positive effects of music engagement activities and to assess participants' interest and ability to enjoy online singing while learning a new song.

Historic Environment Scotland Archive Talks

A series of three online sessions exploring archive records from Scran, delivered by HES Learning Manager, Jackie Sangster.

The aim of the series was to engage participants in a journey through popular cultural, social events and recognisable destinations, as captured in photography recorded over the past 70 years.

Heritage Share Conversations

A series of three small-group conversational sessions inspired by archives from the University of Edinburgh's heritage collections. The sessions were facilitated by Ruthanne Baxter, the Unlock & Revive Programme Lead and Museums Services Manager at the University of Edinburgh.

The aim of Heritage Share was to set a thematic foundation from which participants could share their stories and opinions, developing opportunities to learn more about each other and increase a sense of connection.





Creating a team: Who is who?

Organising and delivering successful online cultural events requires the involvement and coordination of dedicated people in a range of roles.

Programme Lead	Programme Host	Community Care Partner Lead	Session Facilitator	Participants
<p>This is a person who overviews and manages the programme and its events.</p>	<p>This is a person who develops the relationship with the Community Care Partner Leads and is present at all sessions, a familiar face who connects with the participants and consults the communities about the activities, timing of sessions and platforms, and coordinates with Programme Lead and Session Facilitators.</p>	<p>These are the Activity or Lifestyle Coordinators in care homes and Development Officers or Programme Coordinators at local support and community groups. They represent the interests of the residents or community group members and act as a point of contact and gatekeepers for the activities.</p>	<p>This is a person who delivers the event to the participants (e.g., choir directors, musicians, story-tellers, presenters, or performers). They typically communicate with the Programme Host, to confirm timing and content and to respond to the participants' feedback.</p>	<p>People living with dementia, including people diagnosed with dementia and their carers as well as other members of the community and support groups.</p>



Key Findings



1.

Online events for Community Care Partners offer opportunities for creating shared experiences and maintaining social contact, including new friendships, across diverse groups and distant locations.

2.

Online sessions provide a sense of purpose and connection to the world from a safe home environment and promote active and positive interaction and stimulation, which can aid participants' wellbeing.

3.

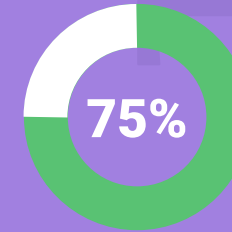
Growing participant numbers and engagement takes time and effort and requires building a relationship with Community Care Partners: It is important to plan ahead and aim for a long-term engagement with a series of regularly scheduled events and sessions.

4.

Creating beneficial engaging events requires understanding the needs and interests of your participants.*

5.

Programme Leads and Session Facilitators benefit from bespoke training aimed at raising awareness of dementia and related conditions.



*75% of the focus group participants joined the sessions primarily to engage and socialise, not to learn.



100% of the focus group participants prefer regular weekly sessions between 10.30 am and 3 pm, avoiding lunchtime, that are no longer than 30-45 minutes.



“Who would have believed that two years ago our members would be meeting online? Zoom has been an invaluable tool and we’ll continue connecting online for cultural engagement events even now that some of us can meet in person!”

**Community Care Partner,
Headway East Lothian**

Planning effective cultural events online



Before you start: Training

The pilot project included two levels of training for different groups of people working within the partner cultural organisations, to raise their awareness of dementia and facilitate their event planning and delivery.

The first session was aimed at senior leadership level, to raise awareness of the value and impact of cultural events for those living with dementia, delivered by the Project Lead, Ruthanne Baxter, and Age Scotland's Dementia Training Co-ordinator, Sandra Brown.

A second, more operationally detailed training session, was provided for the facilitators who would deliver sessions, reviewing the most effective ways to present, both verbally and visually, their content. It was led by Scotland's leading charity for older people, Age Scotland.

Planning the event

Before you start, learn about your participants and how their condition may affect your online event.

Plan well in advance and focus on building a team and a relationship with everyone involved.

Invest time to really get to know the Community Care Partner Leads. They are key to pre-event consultation on themes and content of activities and ensuring the experience is as effective as possible. They are gatekeepers for the community and their input makes an enormous difference for the success of your programme.

Be accommodating and schedule a regular set day and time for your activity so that it fits the participants' routine.

For the purposes of marketing your programme, use national / regional 'gatekeepers' to the Community Care Partners you are seeking to engage with the programme. Consider an advert in a relevant e-newsletter such as Age Scotland or Dementia Society as well as directly contacting local care homes and local community dementia hubs.

Keep your marketing material for the programme simple and easy to follow. Choose transparent names for your activities (e.g., Sing It Back), supported by clear images and simple descriptions that highlight the nature of the engagement. Consider using short videos that the Community Care Partner Leads can share with their members via email and text messages in order to pique the members' interest in the programme.



We consistently found that participants prefer to avoid scheduling events first thing in the morning or later in the afternoon. **Aim for scheduling activities somewhere between 10.30-3 pm, avoiding lunchtime.**



Think quality, not quantity: Choose a group size based on the type of activity on offer. Our focus group participants were comfortable in larger groups for singing but expressed preference for small groups with familiar faces for sessions relying on discussion.



Using technology

- Use a platform like Zoom: It is the most commonly used platform by Community Care Partners for online interactions with their members. It is freely available and accessible on most devices.
- If your organisation has security passcodes for using Zoom, make sure to use the same transparent and easy to type passcode for every session to facilitate participants' access to the session. Passcodes are challenging and can discourage some members from joining the session.
- Coordinate your event reminders with the Community Care Partner Leads. We recommend sending two reminders: the first reminder a week in advance of the session and also on the morning of the session. Reminders should be short and easy to read and share via text messages by the Community Care Partner Leads.
- Be familiar with the tools available in Zoom, such as sharing screens and presentations and using the spotlight function to highlight the speaker. The tools are effective in enhancing your connection with the participants and will help to reduce confusion.
- We recommend you 'rehearse' your event if engaging a variety of facilitators or, as a minimum, have a 'tech check' in advance of the live session. It may also be helpful, if available, to use a two-screen set-up to see participants whilst presenting.



The majority of participants in our sessions didn't connect via a laptop or desktop computer, relying instead on smartphones. Aim to create events that will be accessible and enjoyable on the smartphone, with limited use of screens and the chat function.



For group singing, use "muted mics" feature so the attendees will only hear the singing leader. For heritage presentations you should encourage muted mics while the presentation section is live, to reduce background noise, which can be distracting.



Making sessions engaging and beneficial

Session management

- The success of your programme and how it is received depends on your host and facilitator. Having passionate, enthusiastic people delivering the sessions, who are focused on supporting wellbeing of the attendees, makes or breaks your event.
- A key task of the host is to build a relationship with the participants. We recommend creating opportunities to learn about attendees: hosts should welcome the participants into the session on an individual basis and encourage interactions between the attendees. All focus group participants expressed they wanted to engage and socialise with others.
- Ensure there is a designated host in charge of the Zoom session, supporting the facilitator’s delivery of the event. The host admits, welcomes and builds relationships with the participants, monitors the chat function, and attends to muting and unmuting participants in a discussion as well as keeping an eye on the wellbeing of all attendees.
- Make sure that the host and facilitator are situated in non-busy settings (e.g., plain walls in the background or a block-colour Zoom virtual background) when they are on screen. This will make it easier for the participant to focus on the session content.

Session format and content

- Sessions should last no longer than 45 minutes.*
- Engage, don’t teach: Although sessions included opportunities to learn, this was not the priority for our participants and should be reflected in the programme’s structure and session content.
- Use simple, accessible language - and make sure you speak slowly and clearly.
- Create engaging narratives around familiar and meaningful themes, places and locations which use multi-sensory triggers to help evoke memories.
- Support your words with visual aids (photos or videos) to help contextualise themes.
- Keep any slides simple (i.e., avoid lists with bullet points, focus on a single image and one line of text).
- Encourage interaction by presenting in short bursts to allow for questions and discussion at intervals, not keeping all participant interaction until the end of the full presentation.

*The length of the session may vary depending on the activity and the form and nature of the engagement. Listening to a 15-minute presentation could be draining but singing or dancing of the same length may be rejuvenating! Our focus group participants agreed that 45-minute sessions worked for singing but would be too long for narratives and discussions.

Three benefits of online cultural engagement for those living with dementia!

1. Bringing together people from remote locations
2. Giving access to social interactions and stimulation for those with mobility or transport barriers
3. Engaging in a group activity from a familiar home environment, which supports participants’ involvement and sense of wellbeing



“It’s very nice that we can meet even though we are in different places.”

Heritage Share Participant

Sing It Back

Sing It Back aimed to build on reported positive effects of music events for people living with dementia and to assess participants' interest and ability to enjoy online singing while learning a new song.

Each session involved the session facilitator and host, research observers, Community Care Partner Leads, and people diagnosed with dementia and acquired brain injuries and their carers.

The sessions were attended by four to fourteen participants and they consistently included at least one Community Care Partner Lead who actively promoted the event to their members and engaged the members in the activity during the session.

The session facilitator selected a new song for each session, focusing on one aspect of learning (e.g., melody, lyrics, rhythm). Most songs were not well-known. Song recordings were given in advance of each session to support the workshop and to be enjoyed at leisure afterwards.

On the day of each session, the host and the facilitator met briefly to review their plans before the session commenced and both welcomed attendees to the Zoom meeting at the scheduled time, with music playing in the background.

The sessions were delivered with energy and humour. The facilitator made sure that each session was relaxed and delivered at a gentle speed, and that discussions about the new song were upbeat and positive, individually addressing each attendee for full inclusion.

The host kept an eye on the administrative demands of online engagement, and the Community Care Lead played a key role in monitoring the participants' wellbeing.

Six 45-minute sessions during April to June 2021



Things we learnt

1. Participants enjoyed the sessions but generally preferred singing songs they knew as some found it hard to cope with new lyrics, especially when presented on screen. We recommend that you support your activities with additional resources (such as song sheets) in a format that can work well alongside technology.
2. The mute button is important! Our participants highlighted the unexpected benefit of the 'mute all' function for singing as it reduced undesirable noise, given varying internet connections, and made it easier to sing with the facilitator, overall helping promote enjoyment and reducing stress and inhibitions.
3. Looking for those who may need support and encouragement based on visual clues on video calls can be extremely difficult. Facilitators, Community Care Leads and the host all play an active role in supporting the session and keeping an eye on participants' wellbeing, responding to subtle shifts in body language, such as leaning close to the screen or furrowed brows.
4. Every person's circumstances are different. High-functioning people with dementia may be able to join the session and participate straightaway. It is important to secure in-person support for those who are more strongly affected.

“Singing with muted mics is good. Too much noise affects you, and it's too much. Hearing just one person helps.”

Sing It Back Participant



THE UNIVERSITY of EDINBURGH
Lothian Birth Cohorts

Historic Environment Scotland Archive Talks

Three 30-minute sessions, monthly from April to June 2021

Part of Historic Environment Scotland



SCRAN
LEARNING CULTURE HERITAGE

As the lead public body set up to investigate, care for, and promote Scotland's historic environment, this Historic Environment Scotland (HES) series was designed to share and celebrate Scotland's rich past, explore social history and intangible cultural heritage.

Each session was a 15-minute narrative around a single event, enhanced with the archive photographs of historic locations pertinent to participants.

One of the events delivered a virtual "bus tour" of familiar areas around the East Coast of Scotland.

The narration aimed to engage, educate, and entertain.

The session facilitated some participants' access to memories of their visits to these locations in the past, or, for others, had them remember similar experiences in other locations, and engaged the participants' senses.

Discussions were as much about the sensory or tactile experiences (e.g., sand and water, holding a thermos, visualising food, feeling heat and sunshine) as they were about the locations themselves.

Things we learnt

1. Narratives presented as a journey around familiar locations, people and themes made participants engaged and excited.
2. Visuals help bring memories to life, especially when presented in a clear and engaging way, which may liberate participants with speech and memory difficulties and facilitate their contribution.
3. Talking about settings which are familiar, even after many years, triggers emotional responses, taking people back to a place in time that isn't easy to get to now.
4. Sessions would work more effectively when questions and discussions can be threaded through the presentation, rather than held until the end.



“I know I had questions I wanted to ask. But by the end I'd forgotten them.”

Historic Environment Scotland
Archive Talks Participant

Heritage Share Conversations

One single
30-minute
session

Heritage Share had the fewest attendees as the series was intended to be a small-group focus discussion between one session lead and up to five participants.

Its aim was to stimulate conversation around objects and archives from heritage collections.

The session aimed to prompt sharing participants' thoughts on gardens and greenspaces. There was a brief presentation on Scottish sociologist, Patrick Geddes, and his work on greenspaces and gardens in Edwardian Edinburgh.

The session facilitator employed prompt questions throughout the presentation, and she encouraged and was receptive to the participants' sharing personal reflections and experiences.

Following the presentation, the session seamlessly transitioned to an intimate conversation, with the participants sharing their passion for flowers, parks, and gardens, with reflections on themes covered in the presentation.

Things we learnt

1. The session was engaging and interactive and created a comfortable and safe platform for sharing personal views and stories, contributing to the overall collective experience.
2. By focusing on relatable topics, using accessible language, the facilitator was able to respond to participants' interests and maintain their attention, making them feel heard and valued.
3. The intimate and casual nature of the conversation offered a welcomed connection to another person and insight into someone else's life and contributed to the participants' wellbeing and happiness.
4. While the sessions had intended to be for about 4-5 people, the group felt that one or two additional participants would have helped the conversation.



Our methodology



The evaluation of the project focused on capturing the needs of people with dementia, carers or community professionals involved in the online engagement sessions.

Using a qualitative approach of focus groups with people with dementia, carers and community care leads and semi-structured interviews with the facilitators, the researchers sought to capture the participants' experience and the events' impact on their wellbeing. To contextualise each session, the report also builds on direct session observations.



Direct observation

Researcher(s) participating in the events attended individual sessions to collect notes to provide first-hand accounts of the session's format, content, and dynamics. The notes provide insight into the effectiveness of the series, the interest in the themes covered, and interactions between participants and the session facilitator. **The observations are based on eight out of the total of 12 sessions: six sessions of the Sing It Back series, one Historic Environment Scotland talk, and one Heritage Share conversation.**



Focus groups

For each series, all attendees were invited to join at least one post-session focus group to share their views and experiences. Participants provided consent to the focus group being video recorded, and recording transcripts were used as evidence to evaluate the participants' experiences and perspectives on the delivered online events.

The report is based on conversations with a total of 20 participants and included views of community care partners, carers and people diagnosed with dementia and head injuries.

At the onset of the interview we first invited participants to provide one-word feedback on how they felt about the session, to facilitate and encourage their engagement, and then asked to respond to a series of questions about the format and content of the sessions and to share any recommendations.

Two of the sessions and focus groups were attended by Dr Stephen Smith, Associate Professor, School of Health and Social Care, Edinburgh Napier University and Honorary Consultant Nurse in Compassionate Care, NHS Lothian, who monitored the participants' wellbeing.



Interviews

For each series, Session Facilitators were invited to join at least one post-session interview to comment on specific questions about the event and the series. Interviewees provided consent to being video recorded, and video transcripts provided evidence on their perspectives on delivering digital events for people living with dementia. **The report is based on three 15- to 20-minute interviews with the Sing It Back facilitator, one 45-minute interview with the Historic Environment Scotland facilitator, and one 60-minute interview with the Heritage Share facilitator.**

Going forward

The Unlock & Revive programme and its sessions have brought together people from diverse and remote locations, offering wider access to activities and community.

The pilot has shown that online cultural and heritage engagement provides beneficial access to social interactions and stimulation for people living with dementia.

These are the main reasons why the Unlock & Revive participants and Community Care Partners would like to see this service continue.

As a result, the University of Edinburgh Museums have committed to embedding the Unlock & Revive programme in the Prescribe Culture initiative. The Autumn Unlock & Revive programme has just concluded, and the Spring Unlock & Revive programme will be on offer from February to April 2022, with plans for this seasonal programme cycle to run annually.



“A lot of other online activities are going to start to slow down on Zoom. But we’ll be carrying on doing things online because it adds to our activities. We’ll take our gadgets to our in-person group meetings so that we can all connect and take part. Onwards with online cultural engagement!”

Community Care Partner, Headway East Lothian

How to get involved

The Unlock & Revive programme is part of Prescribe Culture, the University of Edinburgh Museums flagship heritage-based, non-clinical health, wellbeing and social care initiative, built on cultural and social prescribing.



Are you a Community Care Partner who would like to register for Unlock & Revive to receive the Spring Programme and weekly session invitations?

Are you a heritage organisation who would like to connect with the Unlock & Revive programme for Community Care Partners?



Please email:
PrescribeCulture@ed.ac.uk



“I am aware many people living with dementia may be returning to a more open world again, as lockdown restrictions lift. However, there are still and will always be people who may remain to be housebound or prefer to connect with the world from their home. We will continue to seek and support online opportunities that will allow them to enjoy heritage engagement, stimulation and connection with others in the post-lockdown world.”

Ruthanne Baxter,
Unlock & Revive Programme Lead,
University of Edinburgh

Acknowledgements

The Unlock & Revive evaluation was delivered by the Lothian Birth Cohorts with the support from the Knowledge Exchange and Impact fund of the College of Arts, Humanities and Social Sciences at the University of Edinburgh.

We'd like to thank our local Community Care Partners who played an active role in the structure, content, marketing of and access to the sessions:



- **Kirrie Connections**, representing a community of people living with dementia



the brain injury association
SCIO 035535



Cramond
RESIDENCE

- **Headway East Lothian** and **Headway Dundee and Angus**, representing a community of people with acquired brain injuries, some of whom suffer from vascular dementia and other conditions with similar symptoms
- **Cramond Residence Care Home**, representing a nursing home specialising in residents with dementia

In addition to providing recommendations and feedback for the sessions, the community partners acted as gatekeepers, with multiple responsibilities in this role. Gatekeepers were the main contact for the event facilitators and community members, assisted with marketing of the Unlock & Revive sessions, and ensured that all participants were able to attend the sessions in safe and comfortable environments.



We'd also like to acknowledge Sandra Brown, Dementia Training Coordinator at **Age Scotland**, for delivering dementia awareness training for the Unlock & Revive facilitators and cultural partners and for her input and advice on various aspects of the Unlock & Revive pilot and evaluation.



With thanks to *Electrify* for creating the design.

 PrescribeCulture@ed.ac.uk



**Unlock
& Revive**