



THE TRUACANTA PROJECT

HELPING EACH OTHER WITH
DEATH, DYING, LOSS & CARE

Evaluation Report August 2023

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The Truacanta Project

Helping each other with
death, dying, loss + care



Executive Summary

The Truacanta Project was set up to support local communities in Scotland who were interested in taking community action to improve people's experiences of death, dying, loss and care, using a community development approach.

Building on the findings of the [Interim Report](#) (published May 2022) the later stages of the Truacanta Project were evaluated by Janet Biggar Research, using a combination of depth interviews with participants, observation, reflective workshops and self-evaluation. Drawing on this and additional evaluation published in the Interim Report (May 2022) this report sets out key findings and reflections from the Truacanta Project as a whole.

Local impact

Four out of five of the local projects had clear positive impact at a local level, despite the challenges of establishing a new project during the COVID-19 pandemic. The evaluation found that progress had been made in all the intended outcome areas set out at the start of the project.

In addition to this, projects have left valuable legacies within their communities and much local work will be sustained beyond the life of the Truacanta Project.

Transferable learning

The Truacanta Project was based on a new model, whereby one community development worker was employed centrally to support work in five local communities. Communities could also access small grants for specified activity and access learning and networking activities with other Truacanta communities.

This model was successful in enabling work to be genuinely led by communities themselves. Communities also reported that they benefited in various ways from being part of a national project and network, and that access to central expertise and resources was beneficial. However, the project also illustrated there are limits to what can be achieved by those doing work such as this as volunteers or on top of existing job roles.

As well as highlighting some of the challenges associated with supporting this type of work, the project has provided important insights into communities and community development, and the potential ways an organisation such as the Scottish Partnership for Palliative Care (SPPC) can support this kind of work in the future.



Truacanta representatives gather for the end of project celebration at the 'Wings' bench in Perth

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1 Introduction

The Truacanta Project was set up to support local communities in Scotland who were interested in taking community action to improve people's experiences of death, dying, loss and care, using a community development approach. The project was funded by Macmillan Cancer Support and run by the Scottish Partnership for Palliative Care.

Janet Biggar Research and Rebecca McFarlane Ltd were commissioned to evaluate the Truacanta project. This final report presents their findings at the end of the evaluation, and reflects on the impact achieved and learning gained from the project overall. This report builds on an interim report published in June 2022.



2 Background: Establishing the Truacanta Project

2.1 Design

In designing the project, the SPPC drew on learning from the National Compassionate Communities Practice Forum, Australia. At the time, this project was working with eight communities of practice for two years, supporting them with mentoring, tools and advice. Key individuals involved in this project informally shared their experiences of this work, and SPPC were able to incorporate key learning points (eg, the need for longer than two years, the importance of sustainability, and the need to focus on a few key communities) into the design of the Truacanta Project.

Other projects of note at the time were Dr Libby Sallnow's research into public health approaches to palliative care at St Joseph's Hospice in London; and Compassionate Inverclyde.

SPPC also sought the advice of the Scottish Community Development Centre, which was integral to shaping an application process that recognised that supporting communities to develop their ideas, plan and apply is an important part of the overall life of the project, and helps to build strong foundations and relationships for future work.

2.2 Preliminary work

Prior to seeking funding for the Truacanta Project, the SPPC undertook some preliminary work which it hoped would create the conditions for future successful community development work. They:

Established the Scottish Compassionate Communities Network

This was launched in October 2018, providing a network where people interested in building local compassionate communities could share learning, ideas, and inspiration.

Launched the Scottish Compassionate Communities Toolkit

The SPPC developed the Scottish Compassionate Communities Toolkit a practical resource providing ideas for individuals and communities wishing to build compassionate communities, and signposting to relevant initiatives taking place in Scotland and beyond. This was launched in May 2019.

2.3 Application stage

The Truacanta Project Manager was recruited in April 2019, and a selection process for participation in the project was undertaken from May to December 2019.



Firstly, expressions of interest were invited from groups who wished to undertake a compassionate community project in their geographical area.

A shortlist of eleven applicants were invited to work with the Project Manager over six months, during which time they developed their vision for change with a view to submitting a more detailed application to be part of the project for two years.

A map showing the locations of the eleven shortlisted applicants



Shortlisted groups get together at a Truacanta networking event

2.4 Selection stage

Five projects, based in Dundee, Perthshire, North Berwick, Ayrshire and Highland, were selected from the applications. Originally it had been intended to support up to four projects, but the panel agreed to stretch to five given the quality of the applications and the potential for communities to drop out later.

2.5 Overview of the project

It was envisioned that local communities would define the aims of local projects and lead on progressing local work. SPPC would give community development advice and support for a period of two years, provided by the Truacanta Project Manager. Communities would also be able to access small grants (initially of £300, rising to £600 in the later years of the project) for specified activity and be able to access learning and networking activities with other Truacanta communities in addition to the Good Life, Good Death, Good Grief (GLGDGG) resources and events already available to all.

The project was scheduled to be officially launched in April 2020, and run until March 2022. However, due to the COVID-19 pandemic none of the projects ran according to plan, and the funding was extended till March 2023 to compensate for time lost.

3 COVID-19: Adapting to the unexpected

The COVID-19 pandemic became apparent just as the project was about to begin. This had a huge impact on the project.

3.1 Impact on the Truacanta communities

A combination of lockdowns, shielding, furlough and the necessity to redeploy resource from planned activity to COVID-19 response meant that the communities could not proceed with the activities they had been planning. Two communities (Truacanta Perthshire and Say Something Dundee) chose to adapt their plans and deliver some activity, whilst the remaining three chose to put their activities on hold until March 2021. However, late in 2020 North Berwick Compassionate Community began developing their ideas and a timeline.

3.2 Impact on the Project Manager/SPPC

With less Truacanta community activity underway in 2020 than envisaged due to the pandemic, the SPPC considered how the time of the Project Manager could alternatively be used to continue to develop compassionate communities in line with the project's stated objectives.

The wider GLGDGG network was consulted on what support would be helpful during these pandemic times, and the SPPC adapted the project

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plan to incorporate new activities whilst continuing to support the two ongoing community projects. Additional activities included:

- The creation of *An Introduction to End-of-Life Issues*, a short online module designed to be of use to people seeking information about death and dying during the early stages of the covid pandemic.
- The development of an online version of the End-of-Life Aid Skills for Everyone (EASE) public education course.
- The exploration and development of a 'train the trainers' approach to enable communities to deliver EASE online courses themselves.
- The development of *Hoping for the Best, Preparing for the Worst*, information about caring, dying and grieving during the specific circumstances of the COVID-19 pandemic.
- Running a Compassionate Communities Week in May 2020.
- Holding a series of open-access arts-based discussion groups ('death clubs') and three online Truacanta workshops (*Bringing death, dying and bereavement work online*; *A community development approach*; and *Creating inclusive, accessible spaces*) for people looking to build on or interested in finding out more about compassionate communities activity and work around death, dying and bereavement in Scotland.

4 Evaluating the impact of the Truacanta Project

4.1 Intended outcomes of the Truacanta Project

The Truacanta Project was grounded in a community development approach, where local projects are led by local communities, and participating communities set out their own desired outcomes for their local projects.

However, at an overall project level, the SPPC set out the following intended outcomes for the Truacanta project:

- 1.** People have improved knowledge of how to respond to declining health, death, dying and bereavement themselves.
- 2.** People have improved confidence/knowledge/skills relating to supporting others through declining health, death, dying and bereavement.
- 3.** People have improved access to relevant local information relating to declining health, death, dying and bereavement.
- 4.** Different organisations/groups undertaking relevant activity have strengthened relationships/mutual understanding in their activities to support people with declining health, death, dying and bereavement.
- 5.** People have more opportunities to plan for declining health, death, dying and bereavement.

6. People have more opportunities to offer support in the face of declining health, death, dying and bereavement.
7. More people offer support to others during times of declining health, dying, loss and care.
8. People receive more support relating to declining health, death, dying and bereavement from community members.
9. SPPC has a better understanding of how to build community/ individual capacity to respond to death, dying and bereavement.

The SPPC did not have an expectation that each community project would achieve, or even aim to achieve, all these outcomes. Rather, the outcomes provided a guide for SPPC in setting up the project and selecting communities whose objectives seemed compatible with the objectives of the wider project.

4.2 Objectives of the evaluation

Janet Biggar Research and Rebecca McFarlane Ltd were commissioned to evaluate the project in ways that would enable the SPPC to:

- Understand the impact of the five local projects.
- Learn about the effectiveness of the model (one community development practitioner supporting five local communities).
- Share the learning gained from the project with other communities and stakeholders in Scotland.
- Inform how future 'compassionate communities' work in Scotland is undertaken.
- Contribute to international literature relating to public health palliative care.

Janet Biggar Research also offered Truacanta groups support to undertake local level evaluation if they wished. However, none of the local groups took up the offer of support with local evaluation as each group felt that their priority for their limited community capacity, time and resource was delivery of activities.

4.3 Stage 1: Interim Report

An Interim Report. was produced in May 2022 presenting the findings of the evaluation of activities to that point in the project. This included a focus on activities undertaken by the Project Manager and GLGDGG in response to the pandemic (these activities are outlined in section 3.2 above).

The Interim Report found that despite the disruption of the pandemic and changes to focus of activity, good progress had been made towards the intended outcomes set out at the start of the project. Community projects were beginning to revive their plans and there was already evidence of a lot of learning about the effectiveness of the model and what could be achieved.

4.4 Stage 2 evaluation and overall conclusions

This final report builds on the [Interim Report](#), presenting the evaluation findings from between April 2022 and March 2023 (Stage 2), and drawing overall conclusions from the lifespan of the project.

The Ayrshire project was being led by NHS staff, who suddenly faced additional pandemic-related priorities which made it extremely difficult for them to find capacity to work on the project, and to participate fully in evaluation activities. This evaluation therefore focuses mainly on the other four communities — Dundee, Perth, North Berwick and Highland.

4.5 Stage 2 Evaluation Methods

Research tools were designed to focus on progress towards the intended outcomes, reflect on the effectiveness of the model and explore the learning and legacy from the work undertaken and how this could be effectively shared.

Activity	Approach
Consultation with community projects	<ul style="list-style-type: none"> • Depth interviews with community leads • Quarterly catch-up meetings with community teams • Offer of input and support with self-evaluation activities • Attendance at all Truacanta networking events • Reflective workshop with local community teams • Final project summary for each team
Consultation with stakeholders	<ul style="list-style-type: none"> • Depth interviews with the Project Manager, Director of GLGDGG and SPPC Chief Executive • Depth interviews with members of the Truacanta Steering Group • Depth interview with the funder (Macmillan Cancer Support)

It is important to note that the second phase of the evaluation was entirely qualitative and did not include quantitative approaches. A key requirement of evaluation was that it should not overburden community capacity with demands. Each group contributed to the qualitative data gathering.

5 Sharing the stories of the 'Truacanta Communities'

The stories of the five community projects are presented here. They give a flavour of the range and extent of activities undertaken in communities and summarise the teams' thoughts on legacy, sustainability and sharing learning.



Say Something Dundee used Truacanta grants to invest in promotional items such as a pop-up banner

5.1 Say Something Dundee

Who was involved?

Say Something Dundee (SSD) involved a mix of third sector and academic organisations: initially Funeral Link; Dundee Volunteer and Voluntary Action and the University of Dundee, joined by Marie Curie, Making Recovery Real and Just Bee.

Why be part of the Truacanta Project?

The motivation to be a part of Truacanta was a desire to make conversations around death, dying, loss and care easier to initiate.

What were the aims of the project? (Pre-pandemic)

Originally, the project team planned to develop, implement, and evaluate an awareness-raising campaign focusing on the importance of 'saying something' as a means of helping each other with death, dying, loss and care.

What did the project do?

The project delivered three face-to-face conversation café sessions, vicarious trauma training for over 30 members of the community, six planning ahead information sessions and three bereavement workshops. In addition a YouTube channel with six information videos (to date), an information leaflet, pull up banners and a *What to Say* mini guide were created. Two EASE facilitators have been trained.

What partnerships have been created?

SSD is itself a partnership of individuals from different organisations. In addition, the SSD team has worked with:

- Thorntons Law, the University of Dundee body donation department and NHS staff to create content for online information sessions and videos.
- The University of Dundee Botanic Gardens for *National Day of Reflection* and *To Absent Friends* events.
- Dundee Deaf Hub to run conversation cafes with BSL interpreters.
- Wellgate Library and Dundee & Angus College to present information stands.



**Say Something Dundee
at Dundee Botanic Gardens**

"Our community's key priority is to make conversations around death, dying, loss and care easier to initiate. We view this as a fundamental step in positively impacting on how support and information, for all, can be rolled out across Dundee. Whether it's about initiating a conversation with your neighbour who has been recently bereaved (rather than crossing the street) or taking an opportunity to speak to someone about identifying a Power of Attorney, people often don't know what to say and end up saying nothing. Our vision is to help people feel more confident about starting those conversations."

What was the impact/legacy of the project?

All this activity has built partnerships and information sources within the community and the team feel that their activity has gained momentum and visibility, with groups and organisations now approaching them rather than them reaching out.

SSD have created a YouTube channel with 6 information videos to date, an information leaflet, pull up banners and a *What to Say* mini guide.

The group were successful in applying for funding for a paid development worker. The development worker has been recruited and is now working in the community to deliver information sessions, encourage conversations, and create a legacy of information that can be accessed online.

"It was great to work with the other Truacanta groups to share our story of compassionate communities at Bruges and in the Glasgow conference, allowing us to build on ideas and develop an ongoing network of support."

"We are a source of information and collaboration for the community to tap into. Our partnership has also enabled us to get news coverage."

Was being part of a wider, Scotland-wide project of help?

Local project group members have enjoyed being part of Truacanta and being involved in the Truacanta network events has added to their sense of momentum and support. Their connections and collaborations are strong and will continue.

"Each member of the steering group has learned a lot from each other, and the connections made feel strong even in the changing environment we work in."



Planning Ahead Conversations - Body Donation

42 views May 4, 2022 A #SaySomethingDundee conversation about body donation with Vivienne McGuire MBE, Bequeathal Manager, Centre for Anatomy Research

Say Something Dundee set up a YouTube channel



Say Something Dundee in the local press

5.2 Highland Truacanta

Who was involved?

Highland Truacanta was a partnership between the Highland Senior Citizens Network (HSCN), Creativity in Care (CIC) and Highland Hospice, all third sector organisations.

Why be part of the Truacanta Project?

Highland Truacanta wanted to enable the communities themselves to set their priorities and to plan their own systems of support, based on local needs and local skills and experience, building on work the partner organisations had already been doing.

What were the aims of the project? (Pre-pandemic)

They originally planned to facilitate a range of get-togethers to generate creative engagement through community conversations, building safe spaces, sharing stories, and identifying what works, what doesn't work and what is most important for the community and then to support communities to decide how best to implement personal or community changes, and evaluate.

"We will be facilitating local conversations about life, death, dying and caring communities. Events, combining sharing practical end-of-life skills and gathering experiences through creative conversations, will enable communities to explore their own ways of supporting each other through death and dying."

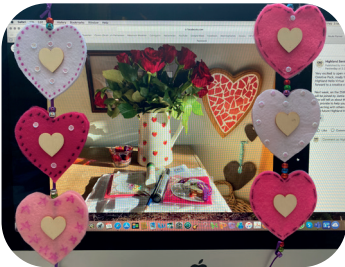


The EASE course was delivered to an intergenerational group in Cromarty

What did the project do?

The project delivered Last Aid Courses (a public education course) in Cromarty (intergenerational) and Kinlochleven, an online EASE course and an in-person intergenerational EASE course in Cromarty, creative conversations (using a simple creative activity to start a chat) in

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**Creative workshops with
Highland Truacanta**

Cromarty and Kinlochleven and four online conversations at weekly HSCN tea-breaks and some public events, for example, two Remembrance Ceilidhs. In addition, thirty-one creative workshops, which can use a variety of pre-prepared arts materials to explore death, dying and grief as a group activity, were run with Creativity in Care both online and face to face.

What partnerships were formed?

The team formed new partnerships and collaborations with End-of-Life Care Together Partnership (EOLCT) who provide end-of-life care in Highland and invited the Highland Health and Social Care Network as a partner. There are ongoing conversations about end-of-life, celebrating and remembering - through partnership between Creativity in Care and Cromarty Youth Café.

What was the impact/legacy of the project?

The team report more willingness and openness to talk about end-of-life and greater awareness of resources and support available.

The community has one trained EASE facilitator who can run further courses within the community. There is now a remembrance bench in Cromarty, established annual remembrance ceilidhs (when people bring a story, photo, poem or song to share about

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loved ones [pets or people]), and resources such as a community booklet and creative Life, Death and Grief toolkit for community groups and schools as well as What-to-say cards designed by community members. An ongoing community-based partnership between CIC and the Highland Hospice - *Life, Death and Me* - explores topics raised in the community about end-of-life care, death, dying and grief.

The team are planning a printed *Guide to Death and Dying in Highland* and a Highland-wide event to share Highland Truacanta learning. Creativity in Care will continue work around Death, Dying and Grief as part of the Windows of Reality Project and HSCN will continue to focus on death, dying and grief through attending Grief Matters Network meetings, facilitating EASE courses, and participating in Good Life, Good Death, Good Grief events.



The remembrance bench in Cromarty, designed by local community members

5.3 North Berwick Compassionate Community

Who was involved?

North Berwick Compassionate Community (NBCC) involved local people from North Berwick Wellbeing Association, a GP surgery, local churches, a Youth Project and a Day Centre. The project was led by volunteer members of the community.

Why be involved in the Truacanta Project?

The NBCC Project Group felt to be a part of Truacanta would provide opportunities to learn and gain experience of other local areas and the national project. To enable the project group to amend the project to facilitate and develop further the support for local people to become more comfortable talking about death, dying, loss and grief.

What were the aims of the project? (Pre-pandemic)

The project group originally planned a programme of awareness raising events and engagement through creative community events. Running alongside was the development of practical support through training and supporting volunteers to become 'compassionate neighbours. The project was to be overseen by a local network of interested organisations and local people including local members from the Health Centre, Churches, Youth Group, Day Care Centre etc.

"North Berwick Compassionate Community aim to provide opportunities for local people to become more comfortable talking about death, dying, loss and grief through creative events and big conversation activities; while also providing more practical support for local people experiencing death, dying, loss and grief."

What partnerships were formed?

New partnerships were formed with a wide range of local organisations:

- North Berwick Trust were local funders of the post for the worker and collaborated to create and purchase a memory tree.
- National Lottery funded local voluntary project North Berwick Community Connections to employ a worker.
- Fringe by the Sea festival hosted a large public event & two smaller events.
- A Compassionate Neighbour cared for a resident in the in the Abbey Nursing Homes and provided feedback on the experience. The care home have requested to access the locally run EASE courses for staff.
- St Columba's Hospice Care collaborated and supported the development of local Compassionate Neighbour Scheme
- Tippecanoe, a local bookshop, provided books and displayed the selected book for book club at the Fringe by the Sea event in their window.
- Local art group pARTicipate created an inspiring art display to absent friends in the old telephone exchange phone box.



NBCC hosts Richard Holloway and Kathryn Mannix at Fringe by the Sea

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- North Berwick Coastal Connections project were key partners in seeking funding for the paid worker post and employing and managing the paid worker. The local volunteer advisors continued to steer the project.
- The Youth Project helped to run the 2022 Absent Friends event.
- NBCC liaised with East Lothian Community Hospital for a feedback session on local hospice care, after being asked to provide feedback on the use of the new palliative care beds at the local nursing home. This involved identification of the learning needs of the staff and the provision of a relatives' room. The feedback was used to enhance palliative care service provision. They have been asked to provide EASE training to the staff and the new volunteers who work at the new palliative care ward at the Community Hospital. The collaboration with the Nursing home generated positive comments in their Care Inspectorate report.

What did the project do?

Overall the project has delivered four online Armchair Chats (Jan-March 2021) during lockdown; a public Big Conversation event (130 attendees)



Pebbles were collected and decorated with names of people who had died, then placed on a cairn by the sea, organised by NBCC.

BSL interpreters were present to allow members of deaf community to attend; a book club to discuss Kathryn Mannix book 'With the End in Mind' (10 attendees); an Emotional and Wellbeing event for young people (20 attendees) during *Fringe by The Sea* (Aug 2021); an art display in old telephone exchange phone box where over 120 people have added the names of loved ones who have

died (Nov 2021); a '*To Absent Friends*' memorial event (Nov 2022) where stones were decorated with names of people who had died and placed on a cairn by the sea. A Memory Tree planted in the new Community Orchard (May 2023).

Four EASE facilitators have been trained and have run six courses with a total of fifty-three people trained, twenty-seven of whom are from North Berwick community.

NBCC has worked with St Columba's Hospice Care to establish the pilot Compassionate Neighbours project, which has recruited and trained (using both St Columba's and EASE training) eight volunteers who will visit people in their own homes. One of these Compassionate Neighbours supports the local care home, providing advice about the palliative care room. There is ongoing three monthly networking for local trained Compassionate Neighbours. NBCC has worked with North Berwick Coastal Community Connections to seek lottery funding, resulting in an employed paid worker for aspects of this work.

North Berwick Compassionate Community has had some positive publicity locally and been shortlisted for a National Award through GLGDGG.

North Berwick Compassionate Community project was initially based on a community development approach by volunteers with a small amount of funding through local Health and Wellbeing Association. It transitioned to a more sustainable model in partnership with a local organisation. There is now part-time employed worker funded by the North Berwick Trust and the National Lottery.

What is the legacy of the project?

The project team feel their voluntary effort has seeded a sustainable approach within the community with established events and local collaborations that allow local people to be aware and more comfortable about talking about death and dying. Four members of local community have experienced support from local Compassionate Neighbours. There is a Network of Compassionate Neighbours, a rolling programme of local EASE training courses (two per year), now established *To Absent Friends* events, and a formal link with a local nursing home to provide training courses for new hospice beds.

"Local partnerships with organisations have enabled us to move from a model of only volunteers to a sustainable model embedded in a local health and wellbeing organisation."

5.4 Truacanta Perthshire

Who was involved?

Truacanta Perthshire originally involved individuals from a mix of public and third sector organisations: Perth & Kinross Council; Tayside Managed Care Network for Palliative and End-of-life Care; Perth and Kinross Association of Voluntary Service Ltd (PKAVS) (a local wellbeing charity); Carers Hub; and Dalween Residential Home. The pandemic led to most partners being unable to continue participation and from 2020 the activity was taken forward largely by one individual.

Why be involved in the Truacanta Project?

The original partnership wanted to be a part of Truacanta so they could improve the local experience of loss, grief and bereavement and support ways and means to connect and care for each other in a community through practical kindness.

What were the aims of the project? (Pre-pandemic)

The group planned to deliver some practical kindness offers through a range of activities, awareness raising and collaborations.

"Our vision is that Perthshire is known as a place where practical kindness, support and openness of dialogue is present and accessible for those who have experienced loss, death, bereavement or grief and will be developing a number of different activities to achieve this."

What did the project do?

- Give or Take boxes containing food and other essentials were put up in partnership with the North Inch and Muirton Community Council Compassionate Communities initiative. The boxes were constructed by volunteers using repurposed wood with one of the boxes being supported by Zero Waste (P & K Council).
- Three EASE facilitators were trained.
- A QR code remembrance trail was organised through the city centre for the To Absent Friends Festival 2020. It included works by the Scottish poet Jim Mackintosh and was featured on STV news.
- A Crossing Over remembrance event with lanterns was held by the River Tay for the To Absent Friends festival in 2022.
- A 'Selfie Wings' listening bench was built in North Inch Park.
- 'Selfie wings' – a huge set of colourful wings painted on the doors of a rugby club in the city centre – were designed by local young carers, painted by a local artist and promoted via social media.



Truacanta Perthshire Selfie Wings



A remembrance trail using QR codes for To Absent Friends in Perth



Give or Take boxes put up in Perth during lockdown

The Truacanta selfie wings became a symbol of community connection during lockdown and created an online narrative around loss, grief and bereavement. It became an adopted 'bumping space' for people to meet, and a talking point.

When the wings were painted over (by the rugby club) there was a big sense of loss, and it became evident that the wings should continue the legacy somewhere else. A portable set of 'selfie wings' have been created (based on the original community-led design) that can be used as a conversation starter in different contexts (for example, they have been used by Tayside neighbours Say Something Dundee), and a listening bench – with the wings painted on the back - has been built in North Inch Park to encourage conversation and kindness. Another listening bench is planned for elsewhere in the city.

What was the impact/legacy of the project?

As the project progressed the activity was being driven forward by one person who has since moved on to work in a different area. So, after a lot of innovative activity during the timespan of the project this work in Perthshire has come to an end.

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The Give or Take boxes remain in place, the Wings Listening Bench is a permanent feature to encourage listening and space sharing in a well-used park. Another bench will be built outside a mental health hub for young people, creating more of these important spaces and encouraging conversation, reflection and kindness.

The project lead has described gaining a lot from being part of the Truacanta network and being proud of all they've achieved, and are now supporting compassionate community activity in a different area (Angus).



The Truacanta Perthshire listening 'wings' bench in North Inch Park, Perth

5.5 Ayrshire

The Ayrshire Project was led by NHS staff, who understandably found themselves with new priorities due to the COVID-19 pandemic, and have been unable to fully participate in evaluation activities. Below are the Project Manager's reflections on the project.

Who was involved?

The original application from Ayrshire was from a partnership of four people who worked for the local North, South and East Ayrshire Health and Social Care Partnerships.

While it was clear this project was not based in the community, rather at a strategic local authority level, SPPC was impressed by both the community engagement demonstrated during the shortlisting period and the final application and felt there was a clear desire to make connections at a grassroots level and build up from there.

What were the aims of the project? (Pre-pandemic)

This partnership was “seeking to increase knowledge and skills and understanding of palliative and end of life care and ‘death and dying’ processes ...[and to] recapture nearly forgotten traditions relating to death and bereavement and seek to root any linked programmes on long term cultural change.”

What did the project do?

Pressures arising from the pandemic, plus redeployment and retirement, affected capacity to such an extent that it became almost impossible to move forward with plans in a meaningful way. Ayrshire representatives attended Truacanta networking meetings and there was clear enthusiasm to make connections and effect change. An in-person community engagement event was held post-lockdown and was well attended. However, with no respite from the pressures it became clear that — outwith scheduled strategic level meetings — the project would be unable to gain momentum within the Truacanta timeframe.

5.6 Truacanta Project Communities coming together with each other

The community groups regularly took part in network activities supported by the Truacanta Project Manager and SPPC. These included:

- Network meetings for peer support, knowledge sharing and learning (with input from external speakers and experts)
- Delivering a workshop at the *Democratizing Caring, Dying and Grieving: Participation, Action, Understanding and Evaluation* conference in Bruges in September 2022
- A plenary and workshop at the Good Life, Good Death, Good Grief Winter Get-together in December 2022 on the theme of *Caring, Dying and Grieving: encouraging and supporting action in communities*.

There is further information about these and other activities in the project blog.

"I was really proud of the global presence at the Truacanta workshop at Bruges. It was amazing! Really lovely to be part of the Truacanta team."



Truacanta representatives present to an international audience at the PHPCI conference in Bruges

6 Did the project achieve its intended outcomes?

The intended outcomes

Below is assessment of the extent to which the Truacanta project has progressed the intended outcomes. It is important to recognise that the outcomes overlap and interact. For example, it is likely that 'increased knowledge and confidence' will lead to 'more people offering support', and that 'more opportunities to offer support' will lead to 'more people offering support', which will lead to 'more knowledge and confidence'.

It was also recognised at the outset that some outcomes would potentially take longer to achieve than others. For example, 'increased knowledge' could be seen as being simpler to achieve and measure than 'increased opportunities to offer support' and 'more people offering support to people facing death, dying and bereavement'.

Intended outcome	Assessment
People have improved knowledge of how to respond to declining health, death, dying and bereavement themselves	Several of the local projects have been involved delivering EASE courses. Pre- and post-course surveys show that the course improved participants' knowledge of how to respond to declining health, death, dying and bereavement.

Several communities now have community members with the skills to deliver EASE courses themselves and are running courses to further increase knowledge and skills within communities.

In response to the pandemic, GLGDGG produced an online module on 'end of life issues' and public facing information about care, support and grief in times of covid. Several evaluation participants commented on the quality of the GLGDGG website, finding it to contain a wealth of information and useful resources.

Projects reported growing levels of knowledge in their communities resulting from their various activities and events such as conversation cafes; creative community workshops; online armchair chats; online information sessions; and book groups.

People have improved confidence/knowledge/skills relating to supporting others through declining health, death, dying and bereavement

Several of the local projects have been involved delivering EASE courses. SPPC's ongoing evaluation of the EASE course clearly shows that participants feel more confident and knowledgeable around declining health, death, dying and bereavement once they have completed the course.

As outlined in the Interim Report, information on the GLGDGG website provided information to increase people's knowledge in this area.

Projects have been receiving feedback from community members that they feel more able to discuss death, dying and bereavement with others; their confidence and knowledge are improved; and skills continue to be developed through EASE and the local in person and online community events. The various resources such as What to Say, You Tube videos, planning ahead and other information resources also help to improve knowledge and confidence.

People have improved access to relevant local information relating to declining health, death, dying and bereavement

The work of the projects involved a lot of direct local information sharing and signposting activity: for example, Say Something Dundee's You Tube videos and What to Say information cards and Highland's community booklet and toolkit. Project teams report take-up and feedback that suggests that community members are accessing relevant local information. Now that there is an employed project worker in Dundee, community members are approaching them for information.

**Different organisations/
groups undertaking
relevant activity
have strengthened
relationships/mutual
understanding in their
activities to support
people with declining
health, death, dying and
bereavement**

The process of applying for the Truacanta project brought together new or fortified existing partnerships. Learning, networking and information sharing sessions for the Truacanta groups and wider GLGDGG community took place throughout the pandemic and beyond, providing many opportunities for strengthened relationships and partnerships.

The projects cited a wide range of new and stronger ongoing relationships developed through collaboration and connection, directly attributable to the Truacanta project including with local churches, care homes, hospices and hospitals, community groups and others.

**People have more
opportunities to plan for
declining health, death,
dying and bereavement**

Several projects undertook work to support and inform planning, for example through planning ahead information sessions in Dundee and conversation cafes/armchair chats in North Berwick and workshops in Highland. The EASE course also covers planning ahead, and signposts to GLGDGG resources on the topic.

**People have more
opportunities to offer
support in the face of
declining health, death,
dying and bereavement**

In Perth, members of the community came together in the creation of the Selfie Wings, which provided an opportunity for people to connect at a time when many were experiencing isolation, and the

listening bench continues this legacy. Arts workshops and online events in Highland provided opportunities for people to come together, as did online discussion events in Dundee. In North Berwick *Fringe by the Sea* events and Armchair Chats allowed the community to come together in a supportive environment and the Compassionate Neighbours initiative provided a structured opportunity to offer support.

More people offer support to others during times of declining health, dying, loss and care

Phase 1 evaluation indicated some early evidence of this a few specific examples of participants offering new or qualitatively different support as a result of increased knowledge or confidence.

Without imposing a burden of evaluation on communities themselves, it was difficult to measure progress on this objective. However, progress on this has definitely been made for example the Compassionate Neighbours Initiative enables volunteers to provide neighbourly support. There are also plans to evaluate EASE to assess the extent to which people who have done the course have offered support to others. Indirectly, it is likely that increased knowledge and confidence reported

elsewhere in this report will result in more people offering support to others. Anecdotally, activities such as conversation cafes or EASE discussions have left people feeling better able to offer support.

People receive more support relating to declining health, death, dying and bereavement from community members

In phase 1 there was evidence of interest from people already involved in the project (such as volunteers) wanting to become more capable of supporting others. As projects gained momentum and more people participated in EASE, people grew in confidence and knowledge, making it more likely that support would be offered. New initiatives and collaborations are also directly delivering more support, for example: the North Berwick project worked with St Columba's Hospice Care on the Compassionate Neighbours project, which provides direct support to people; several of the projects provided supportive spaces for people to talk about death, dying and bereavement.

SPPC has a better understanding of how to build community/ individual capacity to respond to death, dying and bereavement

SPPC staff report that this objective has been met in many ways:

The collaborative process of designing the project model with advice from Australian and Scottish community

development practitioners enabled SPPC to learn from those with significant experience of working with communities.

When changes in plans were required during COVID, the wider SPPC team was involved in problem-solving, re-prioritising and innovating new activities.

SPPC staff participated in online workshops and Truacanta networking meetings, learning from experts in community development and hearing first-hand about how the different Truacanta communities were operating and the challenges they faced.

SPPC staff have worked with Truacanta communities to develop joint workshops at conferences, and to reflect on the outcomes of the projects, giving them unique insights into the practicalities of building community/individual capacity to respond to death, dying and bereavement.

All of this led to a better understanding of how to build community/individual capacity to respond to death, dying and bereavement, with some more specific learning points outlined in the section on learning later in this report.

7 Key Findings

7.1 Understanding the impact of the five local projects

Local projects had an impact despite the challenges of the pandemic

The pandemic led to massive, instantaneous changes in the ways people could live their lives and resulted in all kinds of individual and community responses, and changes in attitudes and behaviours. In this environment, it is difficult to separate out the impact of the Truacanta Project from the impact of changes brought by the pandemic.

The Interim Report concluded that, despite the disruption of COVID-19, good progress had been made towards the intended outcomes and that some of this progress was clearly and directly attributable to the work undertaken under the banner of the Truacanta project. Further evaluation work reinforces the finding that four of the projects made an impact locally, as outlined in Section 5 and Section 6.

"People told us they have more knowledge and ability to talk with family, friends, neighbours about death, dying, grief."

"In the communities where we have had Highland Truacanta activities people are more comfortable talking about end-of-life issues."

"I supported a community member with the end-of-life stages for their mother."

During the pandemic the Project Manager was not able to travel to the communities to connect with the local groups and had to find different ways to support the projects. The project themselves had to reconsider their planned activities, innovate and learn new skills as they looked to take their activities online.

Project teams have widened their skills and networks and, partly through having to adapt plans during the pandemic have found new ways to engage with communities. Adapting to an online approach, whilst not anticipated at the start of the project has been very successful, particularly in delivering EASE training, but also delivering support at local level in communities. Digital inclusion is likely to remain an important consideration in these and other similar projects in future.

Different groups have different challenges and strengths

Delivering these projects during **the pandemic** has been challenging. All have had to adapt and be creative. For the Ayrshire community, where the project team was primarily NHS staff who naturally had other calls on their time, the obstacles presented by the pandemic proved particularly challenging. In Perth, the pandemic led to most partners being unable to continue participation, with work being taken forward largely by one individual.

Community and third sector-based projects seemed able to be more agile, more responsive and less bureaucratic than statutory organisations. They were often able to attract additional community resource or small-scale funding opportunities.

Where teams were led by community volunteers it was necessary to be realistic about the input in terms of time and resource that could be expected when people were dealing with all the pandemic meant for daily life.

Several challenges were identified at a local level. A key challenge faced by local project teams was the pandemic and their frustration at not

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being able to carry out their intended activities in person, particularly when some of those they would like to have supported were not able to engage with online activity. In addition, lack of support, time or resource locally was an issue for some, and some found specific groups or organisations difficult to engage with.

"The stop/start of opening up post-COVID didn't allow for good big in-person community conversations."

"Engaging the Youth Project and schools — a key aim was to be intergenerational, and this hasn't happened ...YET!"

"Not enough time/energy to start over with new community key contacts post-COVID."

"There was some tension with the initial representative of a partner organisation that felt uncomfortable for quite a while. These conversations take a while, and that's ok."

"The support thread of the project has been the most challenging. The regulations concerned with disclosure and safe-guarding and data protection has made it difficult to run a local service as volunteers. The ability of volunteers to set up appropriate systems was too daunting."

Measuring impact isn't straightforward and can be time-consuming

A key requirement of evaluation was that it should not overburden community capacity with further demands on their time, and the evaluation methods outlined within this report and the Interim Report were chosen with this in mind.

The evaluation team were available to provide any support and advice needed to any of the community projects wishing to evaluate their own activities. None of the communities took this offer up, preferring to spend the limited time and resource they had on planning and delivering community activities.

"I think impact is difficult to measure. The projects I was involved in, we didn't really think about how we would measure impact to inform future projects."

"We did have lots of anecdotal and observed impact, which was positive, but hard to measure."

Truacanta enabled partnerships which increased impact

Across these four communities, a wide range of different activities were delivered, often in collaboration with other organisations. This collaborative approach was felt to achieve more impact than working alone.

"The collaborative event (people with good contacts) gave us a big media piece in the newspaper — 2-page coverage at the weekend!"

"It has opened up broader networks and potential partnerships."

Work will be sustained beyond the life of the Truacanta Project

Although the capacity and resource needed to sustain work can be a challenge for hard-pressed third sector organisations or community volunteers, indications are that three of the projects will manage a level of sustainability following the end of the Truacanta project. They still have ambitions to continue and build on what they have achieved through their involvement with the Truacanta work:

"To complete a Community Creative Kit to support groups talking about death, dying and grief."

"Develop awareness raising strategy as early as possible to gain maximum coverage for EASE."

"To complete the (online) community booklet full of stories, tips, ideas re death, dying and grief."

Where communities have trained EASE facilitators they are keen to continue running EASE courses, drawing on the partnerships they have built to reach new people. Two of the projects have successfully obtained funding to employ people to continue aspects of the project's work.

All the projects leave legacies within their communities

Community members who have been involved in the local projects report that they have increased levels of awareness and confidence and feel better equipped to support people with death dying and bereavement. Physical reminders of the project, such as the remembrance bench and selfie wings pop-up banner and bench remain to provide prompts to think and reflect on death and dying, and where information resources have been produced these continue to provide useful information on

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relevant subjects. In North Berwick and Dundee, the paid posts will now build on the legacy of the projects.

Those involved in the project teams feel more knowledgeable and confident to continue the work Truacanta started in their communities. Four of the Truacanta communities have developed relationships with each other and are likely to remain in touch and continue to share experience, practice, and knowledge. They also report ongoing connection, collaboration, and influence in their own areas.

"The Truacanta Project has been one of my favourite pieces of partnership working and I have gained a lot personally and professionally from it."

"HSCN has greater involvement at a strategic level in end-of-life conversations and planning in Highland."

"It has opened up broader networks and potential partnerships."

Though the Truacanta Project itself is coming to a close, the project has brought more depth of experience and involvement to the Scottish Compassionate Communities Network, which has recently been relaunched as Truacanta: Scotland's Compassionate Communities Network.

The EASE course leaves a legacy of skills, knowledge and confidence within the Truacanta communities where it has been delivered. The approach taken means that community members are empowered with the skills to continue to run courses themselves rather than needing to rely on trainers from outwith the community.

The work put into development and delivery of the EASE course as part of the Truacanta Project has brought long-term value to the wider EASE project. For example, Highland Truacanta piloted the face-to-face

course with an inter-generational community generating fresh insights for future use of the course, and facilitators from North Berwick have contributed to the training for new EASE facilitators. These are long-term legacies that will have an impact more widely than the local community areas, as the EASE course widens in reach and continues to be delivered in new communities. The number of EASE facilitators continues to grow, and the face-to-face course which had been put on hold due to the pandemic has relaunched.

7.2 The effectiveness of the model

The Truacanta Project was based on a community development approach, with one central project manager supporting five projects. SPPC were keen to understand more about the effectiveness of this new model of working.

Work was led by communities

A community asset-based approach has allowed for projects to grow naturally in a bottom-up way that addresses community need and interest. The projects were genuinely community-led and non-prescriptive, allowing community leads to develop projects directed towards local needs and at a pace reflecting local capacity.

Local leadership was a key success factor — the successful projects were led locally, and importantly were led by (and collaborated with) people who were highly motivated and passionate about making a difference in their own community, whether this was on a voluntary basis or as part of a paid role.

Communities benefited from being part of a national project

Being part of the Truacanta project gave community-based groups and third sector organisations some 'authority' or credibility that they might not otherwise be able to command when engaging with other organisations. For example, helping them to justify with trustees the work they planned and helping them to engage with much larger public or health sector organisations and partnerships in a strategic way.

Although there was only a small amount of financial support available,

this was useful to groups, and small grants were put to a variety of uses.

The fact that they had committed to run a project provided impetus and motivation for project leads and organisations to deliver, and this was particularly important during the pandemic when people were more isolated and had new difficulties to contend with.

The idea of 'competition' was motivating for some of the community projects, driving a desire to progress activities, and not be left behind in comparison to the other teams.

National work benefited from the input of communities

SPPC as an organisation has learned much of value that will influence its future work to support communities to grow confidence, knowledge, opportunities, and skills relating to death, dying and bereavement. Specifically, SPPC staff have developed relationships and links with the project leads in Perth, Dundee, North Berwick, and Highland that will help inform future community-oriented work. Both the SPPC and Macmillan Cancer Support have gained valuable learning about community asset building and community development approaches.

This learning is explored in more depth in Section 8.

Communities found the Truacanta Network helpful

This was an innovative model, and the national network has been important to support local activity, with the projects benefitting from being part of a bigger group or community of practice, peer learning/sharing and acknowledging some sense of **credibility and pride** associated with being part of a national project.

The Truacanta networking events were helpful in bringing people together to share experience and to discuss and develop ideas and creative approaches, tools etc. in a way that wouldn't be happening, working solely as individual local projects.

Access to central expertise and resources was beneficial

There is no doubt that the Project Manager facilitated the successful delivery of the model, bringing new skills and expertise to the SPPC, along with a solid understanding of the community asset-based approach

and relationship building.

The central support from SPPC provided projects with ideas and suggestions, signposting to resources they might not otherwise have known about and connecting them with other, wider networks. Access to expert advice and to tools and resources that could be adapted to suit local projects and communities was generally thought to be useful and helpful.

There are limits to what can be achieved without extra people and money

Community-based groups brought much to the work in terms of skills, energy, enthusiasm, versatility and networks. However, the work itself still required a lot of time and energy, and reliance on expanded job roles and/or dedicated volunteers brought limitations in terms of the time and energy people were able to put into the project.

The model was also limited by having just one centrally based community development resource supporting five communities who had varying degrees of local community development experience. Whilst the model brought many benefits, it could be argued that a local, dedicated, paid community development resource might have resulted in more tangible local activities and outcomes. Financial resources weren't available to fund this level of paid resource as part of the Truacanta Project. However, two of the communities, having identified this challenge, were supported by the Truacanta Project to secure funding for salaried posts to sustain this work going forward.

"Resource and time is difficult, but all willing and keen and full of ideas!"

"There was community interest, but no key community leaders able to take things forward."

8 Reflections and Learning

The project illustrated some of the ways that different communities approach the issue of improving experiences of death, dying and bereavement. Though it is often said that people do not want to talk about death, this project reinforced the premise that GLGDGG is built on — that many people value being given the opportunities and supportive environments in which to learn, discuss and plan for death.

As a result of the projects, SPPC report an increased understanding of communities and community development, and the potential ways an organisation such as SPPC can support this kind of work. The Truacanta Project has given the SPPC a better understanding of the practicalities involved in working with communities, and SPPC staff highlighted the following learning points from the project:

- A heightened awareness of power dynamics — a community development approach would advocate for control/agency to reside within communities, yet money/influence tends to reside outside communities. Bringing money to community projects without exerting control over planning/priorities/actions is against current norms, requires a shift in thinking and a visionary funder.
- Volunteers/community members aren't a 'free resource' — community members' time and energy is valuable, and theirs to choose how to give. Volunteer activities can't be planned in a top-down fashion — volunteers need to be engaged and interested to give their time.

Working with a community development approach is time consuming, doesn't lend itself to planning, and progress can feel intangible. While it brings benefits in terms of grass-roots insights and connections, the need for ongoing collaboration and compromise can also bring challenges in terms of decision-making, relationships, and action.

- It is possible to make progress towards defined outcomes while managing a degree of uncertainty, and iterative approaches can be useful and productive. Some of the benefits to this approach might be described as 'intangible', yet this project illustrates that increasing confidence and skills within communities and building relationships and networks has real benefits in relation to the pre-defined outcomes.
- Community development can feel unintuitive for those accustomed to working within structured/hierarchical systems — many people unconsciously revert back to service-centred models, the conceptualisation of volunteers as there to enhance the delivery of models devised by 'professionals', or of the public as people to be educated rather than people with assets to share.
- Organisations often talk about "rolling out", "implementing" or "scaling up" initiatives. This makes sense in the context of projects delivered by paid staff and where power/control resides and remains with the organisation. However, these approaches and this language doesn't reflect the philosophy and practical realities of a community development approach.
- A national organisation can add value to local work by making available resources that can be used and adapted locally, and by providing networking and learning opportunities. Communities will only use what is useful to them, so such resources and opportunities must be developed in a sympathetic and adaptable way. For example, many

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communities took advantage of the national Demystifying Death Week and To Absent Friends Festival as hooks for local work; the EASE course has been very valuable in North Berwick, and Highland and Dundee are looking to run more courses too.

- No two community development projects will ever be the same. Given that the success/progress of this type of work can't be controlled in a top-down fashion, this approach will always be dependent on the individuals and organisations involved. Communities/organisations vary in their ability to deliver this sort of initiative — for example statutory organisations can find it difficult because of the pull of all their other responsibilities, community organisations because of their reliance on time and resource voluntarily given.
- Money is an important factor, particularly because it can pay for dedicated administrative or project-management time towards achieving a community's goals. This is illustrated by the fact that two of the communities prioritised applying for funding for a paid role.
- Money is not the only factor that is important — networks, supportive peers, institutional support, motivation, and a sense of purpose can also help communities to take action.
- The project reinforced the SPPC's belief that communities are integral to improving people's experiences of death, dying, loss and care. However, it also highlighted the fact that communities themselves have limited capacity and interest, so the complementary supportive role (and potentially financial input) of third sector, statutory and private sector remains integral to achieving improvements.

9 Next steps: building on the work of the Truacanta Project

SPPC

The SPPC has secured some funding to employ the Project Manager in the new role of Community Development Lead. This will include leading on SPPC's work to relaunch/rebrand the Scottish Compassionate Communities network as *Truacanta: Scotland's Compassionate Communities Network* which will create opportunities for people with an interest to come together and work together. The learning from Truacanta will enable this to be done with more insight about how a national network can support and facilitate local activities.

This ongoing work will also inform the work SPPC does in terms of accessibility, inclusion and community, and identifying ways of the SPPC becoming more inclusive in all aspects of its work. It will also inform SPPC's input to the Scottish Government strategy on palliative care that is currently being developed.

The Truacanta Project has given SPPC important practical experience of community development work which complements what was previously a strong theoretical knowledge. This will influence future work of the organisation, for example informing decisions about the role SPPC can most helpfully play and what kind of resources and events communities are likely to find useful.

Community projects

The community projects report seeing others using some of the work they've done and adapting and applying it elsewhere in the local community or more

widely. They have also been making their own efforts to share what they have learned, for example Highland Truacanta's plans for a printed Guide to Death and Dying in Highland and an area-wide event. The Truacanta Perthshire lead has moved roles and is bringing the Truacanta learning to a new community and workplace. North Berwick have shared their learning through local press and through community conversations with local nursing homes and art groups; and Dundee have produced leaflets based on their learning through the project and now offer local workshops.

Macmillan Cancer Support

From Macmillan Cancer Support's point of view, as funder, this model is central to developing more community asset based (rather than clinically based) approaches in which people can be supported to deal with death, dying and bereavement. The learning from it is likely to have implications in other aspects of their work (for example providing support to people with a cancer diagnosis).

The Macmillan Cancer Support lead will share learning across the organisation and specifically through some of their workstreams on their strategic priorities such as improving people's experiences after active treatment for cancer and during palliative and end of life care. She will also be sharing with partnership colleagues across Scotland. A session on the Truacanta Project will be part of the Macmillan Professionals UK-Wide conference in November 2023.

Sharing the learning

Learning has already been shared through the Truacanta blog, website, posters in the Hospice UK Conference 2022, a workshop at the *Democratizing Caring, Dying and Grieving: Participation, Action, Understanding and Evaluation* conference in Bruges in September 2022 and a plenary and workshop at *Caring, Dying and Grieving: encouraging and supporting action in communities* in December 2022, and at IFIC Scotland's *Celebrating Kind, Caring, Connected Communities Virtual Café* in April 2023.

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The knowledge gained from the Truacanta Project can also be shared with those working in the field of Public Health Palliative Care both nationally and internationally. For example, there are plans to write papers for journals and to share work at conferences, including the *3rd International Research Seminar on Public Health Palliative Care* in November 2023, and the *2023 Global Ageing Network's biennial conference* in Glasgow in 2023.

10 Conclusion

The Truacanta project was a new approach, developed drawing on learning from initiatives in Australia and Scotland.

Despite significant disruption due to the COVID-19 pandemic, it is clear that the project has had an impact at local level, and has contributed to progress and learning at a national level.

There is evidence of progress on all the intended outcomes to different degrees across the different community projects. The project delivered real opportunities for communities themselves to decide what was needed and to shape action.

The model of embedding local projects within an overarching project had benefits, giving communities access to motivation, support, advice, small grants, networks and peer support.

However, the project also illustrated that there are limitations to what can realistically be achieved through time given by volunteers or as addition to existing job roles.

The project has left a legacy in all the communities it has touched, and there are plans for many aspects of the project's work to be sustained going forward. Learning from this project will inform the work of SPPC and Macmillan Cancer Support in the future.

Much learning has already been shared, and there are plans to share the learning from the project with those interested in this field internationally.

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