



compassionate
INVERCLYDE

VOICES: THE NARRATIVE
FROM A LOCAL PERSPECTIVE

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Overview

“It softened us all. It makes us all kinder. Because you have got a bigger array of, I call them, friends. Ok, we don’t meet every day or whatever but when we do meet, as Daniela said... and I think it has made us all kinder”

(Doreen, group feedback meeting)

One of the most compelling features of Compassionate Inverclyde is its humanity and simplicity. It is fundamentally about ordinary people helping ordinary people, guided by the intrinsic community values of being kind, helpful and neighbourly.

The simplicity of Compassionate Inverclyde’s message, expressed in the language of the local people - and the purposeful avoidance of references to procedures, services or measures - has had profound implications for the way in which it has grown. It also has implications for the way in which Compassionate Inverclyde is evaluated and reported upon.

About this Document

This document presents the learning from the evaluation of Compassionate Inverclyde from the local perspective. When we first connected with the Compassionate Inverclyde community we anticipated producing a traditional evaluation report. Over time, we have learnt more about Compassionate Inverclyde, its origins, the ways in which it has been influenced by the international compassionate communities’ movement and, importantly, the ways in which it is unique. Through *doing* the evaluation and connecting deeply with the people of Inverclyde over several months, we have come to understand how Compassionate Inverclyde works and is experienced, and what it is becoming. We have also come to appreciate the significant contributions of the many individuals involved directly and indirectly and the growth of relationships, networks of support, interconnections within and across Inverclyde and the social functioning of the community. We realised that we needed to take a closer look at the substance of these contributions and relationships, rather than risk reducing ‘making a contribution’ to an outcome to be achieved *for* individuals. We began to think about the purpose of the evaluation differently and how we might report upon it in a human way that stays true to and reflects the essence of Compassionate Inverclyde - so that others might learn from it and be inspired by its possibilities.

This document does not set out to prove, measure or attribute impact and it does not offer a blueprint or recipe for how to become a compassionate community. It describes the approach that we took, our reasons for presenting our learning in narrative form and then tells the story of Compassionate Inverclyde as a living entity, focusing on what is distinctive and using concrete, ordinary yet extraordinary examples to illustrate the enactment of local values, principles and good practices in a way that recognises all contributions.

Approaching the Evaluation: Compassionate Inverclyde as an Assets-Based Approach

Compassionate Inverclyde has taken a new public health approach, drawing upon assets-based thinking. In carrying out this evaluation, we were mindful of some academic critiques of such approaches, including concerns about the shifting of responsibilities onto communities, legitimatising welfare retrenchment, replacing sufficiency with aspiration, and allowing respect for personal and community resilience to obscure the root causes and structural drivers of social inequalitiesⁱ. Other commentators however have argued that to reject assets-based approaches for these reasons would be simplistic and ‘risk throwing the (assets) baby out with the (neoliberal) bathwater’ⁱⁱ.

Social connections are only part of the jigsaw – but a vitally important part. The desire to belong, be appreciated and respected is invisible – but is at the core of our needs as human beings. Actions related to social contexts however need to be integrated with actions to tackle broader inequalities, to address the historical impacts of deindustrialisation, and to mitigate the impact of current economic and poverty challenges.

We approached the evaluation with the above understanding in mind. From the outset, Compassionate Inverclyde has recognised the importance of families and communities working *alongside* formal services. As the Compassionate Inverclyde story illustrates, community assets-based approaches can not only have powerful mitigating effects and significant impact, but can also unleash radical possibilities.

Engagement Methods

Our approach combined 1:1 in-depth interview, conversation and participant observation in meetings and routine activities. Over several months (April - September 2018) three members of the evaluation team (Emma, Karen and Madeleine) spent time enacting and talking about the everyday activities, events and happenings of Compassionate Inverclyde as follows:

- Initial meeting with 5 people from the evaluation team and ten volunteers (10)
- Documentation review and analysis
- Facilitative / reflective session with the Board (8)
- 1:1 in-depth interviews with Board members and organisational leads (15)
- Observing at Board meetings
- Companion circle meeting (20)
- Back Home Box volunteer support group meeting (12)
- Community Hub meeting (12)
- Back Home Visitors introductory meeting (8)
- Individual interviews with people with key roles (7)
- Follow-up telephone conversations with Alison Bunce, the Compassionate Inverclyde Lead (1)
- Admin office visit (2)
- 3 Back Home Box collection points visit (5)
- Back Home Box store visit with primary pupils visiting (7)
- Back Home Box ward round (3)
- High Five: St Michael’s Primary School classroom visit and teacher interview (12)
- High Five: Kilmacolm Primary School visit (1)

- High Five: Interview with teacher from St Columba's High School (1)
- Interviews with NODA companions (13)
- Interviews with Back Home Box volunteers (7)
- Interviews with nurses in Inverclyde Royal Hospital (3)
- Follow-up meeting with the evaluation team and volunteers (8)

While this list totals 143 contacts with children and adults involved in Compassionate Inverclyde, the total number of people we spoke to is around 100, as we met many of the adults involved on two or more occasions.

Informed consent procedures were followed and the 'participant information sheet' and 'participant consent form' are presented in **Appendix 1**.

We were invited to attend various scheduled Compassionate Inverclyde meetings, with site visits arranged especially for us. Evaluation contributors were invited to take part in 1:1 interviews by Doris and Alison A (two of the volunteers with administrative and coordinating roles). The contributors were given the option of being named in the evaluation report and publications or remaining anonymous. All wanted to be named, with many commenting that they were proud to be associated with Compassionate Inverclyde and welcomed the opportunity to contribute. A list of contributors is also provided at **Appendix 1**.

All 1:1 and group sessions were audio recorded and transcribed and detailed field notes were recorded immediately after the more action-oriented observation sessions.

In conducting field work, with the exception of the initial and follow-up meetings, we worked separately, with Madeleine engaging with the Board and strategic partners, Emma and Karen working mostly independently in connecting with the volunteers and those involved with Compassionate Inverclyde located in schools, hospital and back home box collection points. We came back together several times to share our learning and were struck by the parallels.

We were also aware that we were each finding ourselves being gently folded into the Compassionate Inverclyde mix as we experienced its effects – like whisked egg whites being gently incorporated into a souffle. Although we all have extensive experience of working and of research in various contexts in health and social care, we felt there was something special going on in Compassionate Inverclyde. Yet we still maintained a balanced perspective that enabled us to notice where everything was not quite rosy.

Analysis: Coming to Narrative and Metaphor

We spent many hours reading the transcripts and field texts to try to come to some sort of summary account. In contextualising the data socially and theoretically, we were struck by the number of leadership models and policies the data spoke to, bringing popular concepts such as 'authentic leadership', 'collaborative leadership', 'compassionate leadership', 'adaptive leadership' and 'co-production' to life. Concrete examples of local understandings, practices and experiences of ordinary people helping ordinary people were privileged over conceptual labels to try to preserve this liveliness.

We co-created several interim texts and experimented with different structures, but struggled to capture the energy, dynamism and passion that we had witnessed. We concluded that narrative analysis was appropriate and undertook to tell the story in a way that stays true to the essence of Compassionate Inverclyde. In so doing we have found it helpful to use the metaphor of a community woodland. In particular, we were inspired by the book *'The Hidden Life of Trees'* by Peter Wohllebenⁱⁱⁱ and the BBC video *'How trees secretly talk to each other'*. This video is less than three minutes long and we encourage readers to view it at: [<https://www.youtube.com/watch?v=yWQqeyPIVRo>].

We have a great deal to learn from Compassionate Inverclyde. Like trees, its constituent parts are highly adaptable. The woodland functions as a community in which, much like a human community, there are numerous advantages to working together. This metaphor not only speaks to the organic, unforced growth of Compassionate Inverclyde, offering insights into the conditions for growth provided by this particular locality, but importantly also tells us about interconnections between the different parts. It calls attention to the social functioning of the community, its altruistic tendencies and the extensive communication networks beneath the surface that support the exchange of essential nutrients.

The community woodland metaphor also speaks to the intergenerational aspirations of Compassionate Inverclyde:

"We do not plant trees for ourselves, but for the generation after next".

Our confidence in this approach was greatly increased following a feedback session with a subset of Compassionate Inverclyde volunteers, where we shared our findings using this metaphor to see if it made sense to them. The volunteers' enthusiastic and creative response confirmed this was the way to go.

Narratives function as arguments in which we learn something essentially human about the experience under consideration. This function is consistent with 'emphasising humanity', which emerged as one of five provocations for health and social care^{iv} following the recent Think Tank of Scottish leaders to consider what is needed to transform Scottish society so that all citizens can thrive. Our hope is that the Compassionate Inverclyde story, much like the accounts of the 'hidden life' or 'secret language' of trees, holds the potential for revelation of what has previously remained unseen, in this case beneath the surface of the apparent ordinariness of this community, and for transformation, through an invitation to the reader to act differently.

We now use the community woodland metaphor to tell the story of Compassionate Inverclyde, beginning with the import of the initial seeds. We attend closely to prevailing climate and local growing conditions, preparation of the ground, fresh tree plantings and crucially, their interconnections, through to the harvesting of the fruits, ongoing growth and factors that may limit such growth. We conclude by considering the moral of this story, distilling the essential nutrients, notably the 'super-nutrient' of kindness and offer key messages for others.

The Compassionate Inverclyde Narrative

Importing the initial seeds to Inverclyde (source of inspiration)

Compassionate Inverclyde was first conceived ten years ago, when in 2008 Alison Bunce heard Professor Allan Kellehear, an Australian public health academic, speak at a conference in Scotland about his work on engaging communities in conversation about death and dying. Kellehear^v argues that health is everyone's responsibility, including death, dying and end of life care and the concept of compassionate communities has grown from his earlier focus on compassionate cities. Compassionate cities are broadly organised according to the principles of Kellehear's Compassionate City charter which outlines 13 changes required, mainly centring on bringing death, dying and caring to the surface of public consciousness in organisations. Though often linked to hospices or palliative services, activists in compassionate cities are ordinary local citizens.

At the time, Alison was the Director of Care at Ardgowan Hospice and shortly after hearing Professor Kellehear's talk, she was able to implement her first schools' project working with children to think about their experiences of caring. The schools undertook a creative project and came into the hospice to present, establishing the link of visiting and hearing about the hospice, but not particularly talking about death and dying. The small seeds sown at this time resulted in a firm commitment to further explore public health approaches to palliative care and also international approaches to 'compassionate communities.'

Compassionate Inverclyde did not start from scratch, and was able to draw upon ideas from compassionate communities and cities internationally¹. While the initial seeds have been imported from elsewhere, as discussed below Compassionate Inverclyde has its own story and has grown in distinct ways. Indeed, international approaches underscore the need to adapt to the local context. Discussions locally reinforce both the particular challenges and the assets and advantages of the Inverclyde terrain.

The Local Terrain (the geographical and socio-economic context)

Inverclyde is named in Scots according to its geographic location: *Inbhir Chluaidh* or 'mouth of the Clyde.' Inverclyde is situated in an area of outstanding beauty, along the broad coastal reaches of the River Clyde with breath-taking views to the Argyll Hills and Scottish Highlands. Inverclyde has a population of 78,800^{vi} with 3 main towns and several smaller villages. The population structure of Inverclyde has fewer younger people, more older people and fewer people of working age than the national average and the percentage of single occupancy households at 38.5% is higher than the Scottish average by 3.8%^{vii}.

Overall, in common with other former shipbuilding areas, there are challenges with the local economy and associated health indicators. The percentage of people on out of work benefits stands at 5.5% compared to 2.7% of the Scottish population in general^{viii}. In the 2011 census, Inverclyde had the highest prevalence of long-term activity-limiting health problems or disability (24%) compared to Aberdeenshire as the lowest (16%)^{ix}. As a former shipbuilding area, Inverclyde has had to work hard in recent years to attract alternative industries which include electronics, banking and leisure.

¹ Alison later successfully applied for a Florence Nightingale Foundation (FNF) Travel Scholarship which allowed her to study examples of compassionate communities in Australia, the US and other parts of the UK

While the overall picture highlights income and health challenges, there is significant variation in income levels within Inverclyde. Intermediate zones, which are statistically defined areas smaller than local authorities (16 in Inverclyde) represent a wide diversity of income deprivation. At the lower end of the scale, Greenock has one zone which is 35% income deprived and Port Glasgow's poorest zone is 33% income deprived.^x At the wealthier end, two zones in Inverkip are categorised at 4 and 6% income deprived and Kilmacolm and Gourrock are at 8% and 9%.

Inverclyde presents certain opportunities for any initiative which seeks to work alongside health and social care organisations. There is one hospital covering the population, Inverclyde Royal, and it and the health and social care partnership serve three wellbeing communities with similar population sizes but very different geographies. There is also the cultural heritage, the generosity and friendliness of its people, which was repeatedly referred to in our local conversations and which we were fortunate to experience first-hand. In addition, the local and national policy climate surrounding death and dying was conducive to nurturing the seedling ideas.

The Climate (the policy context)

The national policies on palliative and end of life care at the time were Living and Dying Well; Building on Progress^{xi}, to be followed by the Scottish Government's Strategic Framework for Action on Palliative and End of Life Care, and Good Life, Good Death, Good Grief^{xii}. These documents all talked about the importance of engaging with communities to work alongside professionals.

The policy climate was thus favourable for cultivating these ideas, inspired by Kellehear's^{xiii} work, which sought to bring communities together in a way that was natural in the places where community meet to promote compassionate citizenship and care. The wider Scottish policy context was also conducive, with the report of the Christie Commission^{xiv} grounded in a commitment to assets-based approaches, co-production and a greater role for communities, progressed through the Community Empowerment Bill^{xv}. Rather than being policy-driven, for these ideas to germinate and take root, it was essential that were planted on fertile land, populated by people with passion, a strong sense of possibility and a desire to make a difference.

Understanding the Local Terrain, Preparing the Ground

Ardgowan Hospice has been a symbol and source of compassion and caring for over 30 years. In 2012, a conference was held celebrating 30 years of Ardgowan hospice and acknowledging decades of a Compassionate Community in Inverclyde. It involved the local community from Inverclyde and showcased local partnership working. At that event around 150 people signed a statement to say that 'compassionate community' was something that they would like in Inverclyde.

The Hospice Board endorsed the aspiration to promote compassionate care and citizenship across Inverclyde and approved funding for Alison Bunce to be seconded to lead Compassionate Inverclyde for three years. Critical elements for taking on this role included Alison being well known and respected locally, having the expertise and authority to act in this area, and being at the heart of established, vibrant social networks. Knowing her own patch, living and working in Inverclyde for many years, she understood the local context.

At the time, there was growing local awareness (supported by evidence from public engagement exercises) that lack of understanding was contributing to the suffering associated with potentially

life-limiting illness, survivorship, dying, death and bereavement. Public engagement initiatives suggested that there was considerable scope for addressing this significant area of suffering. The initial aim was to begin to transform societal, institutional and individual attitudes about death and dying in a natural, locally relevant way.

With fixed term funding for Alison's post secured, the first thing she did was reach into the community to find out what mattered locally, what they would like to see grow within Inverclyde and what the local soil could support. She went out to meet and talk with local groups, thus ensuring that efforts were community-driven. Once again it was not a case of starting from scratch. The organisation "Your Voice" was a key entry point, providing ready access to established community networks and actively supporting Alison in making connections. It was important not to dilute or plunder the soil, but to understand what was already there and find ways to bring it together that spoke to the needs of all groups.

Alison held a series of community meetings to find out what it was like to live in Inverclyde. The Inverclyde soil was found to be rich and full of nutrients. Drilling down into the information about what it was like to live in Inverclyde, there were three words that encapsulated what the local people were saying and they were **compassionate, helpful and neighbourly**. These became Compassionate Inverclyde's guiding values². This initial step was invaluable in ensuring a robust understanding of the intrinsic values of the community. [More information on the responses is in the section on **Community Engagement**]. The next step was to think about the type of governance that would be needed to transform this fertile land into a community woodland and oversee its development.

Overseeing the Community Woodland (Establishing the Compassionate Inverclyde Board)

In establishing the Board to oversee the growth of Compassionate Inverclyde, once again local knowledge and relationships were critical. This included Alison's knowledge of local people as people – not simply their roles or status, but their earned reputations based on their personalities, skills, values and passions. The core focus was all about relationship building and social purpose, with Alison saying "we can do this together" and asking "what can we do together to make this work"? [Individual interviews]

The task was finding people who could work together; people who care, who represent a wide range of community interests, who had the capability and authority to act, who would be not only willing but eager to help. The Board was established to encourage all members to get involved in different and very action-centred ways, rather than pre-determining contributions based on organisational role and position alone. Indeed, the engagement of the Board and its representation from the community and across the diversity of third sector, independent sector, education, commercial and statutory bodies has influenced the shape, focus and impact of Compassionate Inverclyde on the local community.

(See **Reflections on Leadership** for conclusions regarding Board specification and guiding principles for effective Board engagement as described in the Deep Dive report available at www.ardgowanhospice.org.uk/compassionate-inverclyde).

² As the language of Compassionate Inverclyde continues to evolve to reflect the talk of local people there has been an increased emphasis on **kindness**, and the importance of preserving a place for **friendliness** alongside neighbourliness has also emerged

Enabling Organic Growth (freedom to act in response to intrinsic community values)

There are a number of factors that have enabled organic growth. Alison is the only paid member of staff for Compassionate Inverclyde. Apart from this investment by the Hospice and, more recently, by the HSCP, everything that Compassionate Inverclyde has achieved has been community resourced and community driven. Applications to local community funds provided some funding for to cover essentials such as PVGs and training for volunteers.

While this resource constraint presented its own challenges, in many respects it could be considered as liberating, and cleared the way for all local actions to be based on the intrinsic community values identified at the outset, with strategic objectives aligned with these values. Importantly, it enabled Compassionate Inverclyde to be attentive and truly responsive to community ideas as they developed, working flexibly with community initiative and readiness, rather than sticking to a predefined path based on predicting the future and tracking predetermined indicators. This freedom to evolve in a model of social leadership^{xvi} has been a critical factor in Compassionate Inverclyde's success.

With the community values understood, the various trees that would later be planted were given sufficient space and light to grow organically rather than being planted within a predefined box or restrained against a wall. There are some first drafts of traditional project documentation such as PIDs, but the driving force was the strapline, as Alison put it: *"This is all about ordinary people helping ordinary people, being neighbourly, friendly and kind. It's not about a health service and so ordinary people wouldn't be interested in milestones or indicators or outcomes"* [individual interview].

Alison reflected: *"While there were a few conversations and a bit of discussion about how we might work without the sorts of indicators and measures that people are used to working with, but no resistance."*

The time burden of performance reporting represents an important but often overlooked opportunity cost for community projects. Freedom from this burden has helped Compassionate Inverclyde to be agile, to adapt and evolve.

The Board was nevertheless accountable to the community and adopted a set of strategic objectives for Compassionate Inverclyde. These four strategic objectives derived from the community values of being compassionate/kind, helpful and neighbourly, were:

- Patients and their families facing the challenges of palliative and end of life care in Inverclyde will know how to help and support each other compassionately at times of increased health need and in bereavement;
- Local workplaces and other bodies will have compassionate, supportive, life-limiting illness and bereavement policies in place;
- Public engagement/involvement will promote compassion, celebrate life and commemorate the dead and will be an integral part of the local, civic calendar ;
- People facing the challenges of bereavement, loneliness, survivorship in Inverclyde receive compassionate group support that improves their wellbeing,

The strategic objectives, which later loosened to embrace the community concern with loneliness more broadly, and expressed in the everyday language of the community, became the four arms underpinning all of Compassionate Inverclyde's 'projects' or initiatives.

With the objectives agreed, the Board was prepared to place their trust in the grower and to wait. As each of a series of trees were planted, the Board members were prepared to wait until they could see the growth, observe small green shoots appearing, and appreciate that good things were blossoming.

The First Tree Planting: No one dies alone (NODA)

NODA was the first initiative in Compassionate Inverclyde, based on the approach developed in Oregon, US. Sandra Clark was a nurse at the Peaceheart^{xvii} centre in Eugene, Oregon, where in 2001 she found herself through pressures on the ward to be unable to fulfil her promise to return to a dying man who had asked her to stay with him. Consequently through NODA she envisioned a program where volunteers would sit at the bedside of dying patients to provide comfort and compassionate care.

The Comfort Care Bag carried by volunteers contains a CD player, a variety of genres of CDs, a NODA



vigil journal that documents the present vigil for the oncoming volunteer, a notebook to record the volunteer's thoughts/experiences, NODA cards and envelopes to leave a note for the patient or family, a Bible or rosary if applicable, insightful readings, and evaluation forms that the volunteer completes at the end of the vigil.^{xviii} The model as implemented in Inverclyde remains faithful to the original in some ways. Key differences include the fact that volunteers are recruited from the community (though many nurses are amongst

them) and as we explore in the section 'Bearing Fruit,' NODA in Inverclyde also provides support to families struggling at the end stage of life of their relative.

After a period of planning, negotiation, recruitment and training, NODA was implemented in December 2017. When the hospital gets in touch to advise that a patient is approaching the end of life, companions are alerted and rotas organised through the NODA companions "what's app" group. Updates are communicated through what's app and notes about the person's condition and any changes or interactions are recorded in a journal which can be shared with the family. While we were conducting the evaluation, 70 NODA companions have been trained to support people in their last hours of life, and another 25 recruited. To date, 30 patients, their, families and care staff have benefited from NODA support at Inverclyde Royal Hospital and work is underway to spread NODA into 12 local care homes.

A Second Planting - High Five

High Five is based on an established programme intended primarily to *improve wellbeing* but also linked to *awareness and education*. It addresses the five ways to wellbeing^{xix}: connection, activity, taking notice, learning and giving. Consistent with the community values, it has been adapted to the local conditions, where the emphasis is on *kindness*. It is delivered over five weeks and is highly

transferable to different settings and life stages. After successful delivery in West College, variants have been seeded in diverse schools, bereavement groups, community groups and Amazon management. High Five can evolve in distinct ways in different settings. In St Michael's primary they have developed 'kindness Jenga' and a kindness post-box for pupils to nominate peers for acts of kindness, with recognition given at assembly.



Work with St Columba's high school last year resulted in a kindness project connecting a group of female pupils to a local care home, which they are now visiting on a three weekly basis. In Notre Dame high school a group of seven pupils are being trained to present high five to primary two pupils in three cluster primary schools.

Alison is beginning to deliver the High Five Programme with a group of men in Greenock prison. Once again, local networks proved critical in securing permission; one NODA companion is a prison officer and made the connection.

At the time of the evaluation, 360 people have completed a wellbeing programme. **Improving Wellbeing through High Five** has more information on participants and the High Five outcomes.

Planting a Tree of the Home Grown Variety - Back Home Boxes

After a year, Alison looked around and asked *are we missing anything?* By this time 'NODA' had increased local awareness of how many people of different ages and from difficult walks of life were alone in the world at the time of their deaths, and also therefore in life. High-Five had also firmly established the link between kindness and wellbeing. Their roots were connected by the nutrients of helpfulness and neighbourliness, and the **kindness** super-nutrient. Local people began to talk about loneliness more broadly, spontaneously shifting the conversation upstream. Like the classic double diamond of design^{xx}, the discussion opened and then closed, moving from the general to specific situations, and they started to focus on how it must be terrible to come home from hospital alone and not even have a pint of milk to make a cup of tea with.

Although not tied tightly to the original palliative and end of life care focus of Compassionate Inverclyde, "**loneliness**" was clearly a source of suffering that the community wanted to do something about and that could be addressed through compassionate citizenship. Alison listened, was prepared to hear, and thought: "*we could do something with this*". The Board also listened, agreed and more room for growth was created, loosening the support strap.

The four strategic objectives broadened, in response to community concerns, and were reframed as:

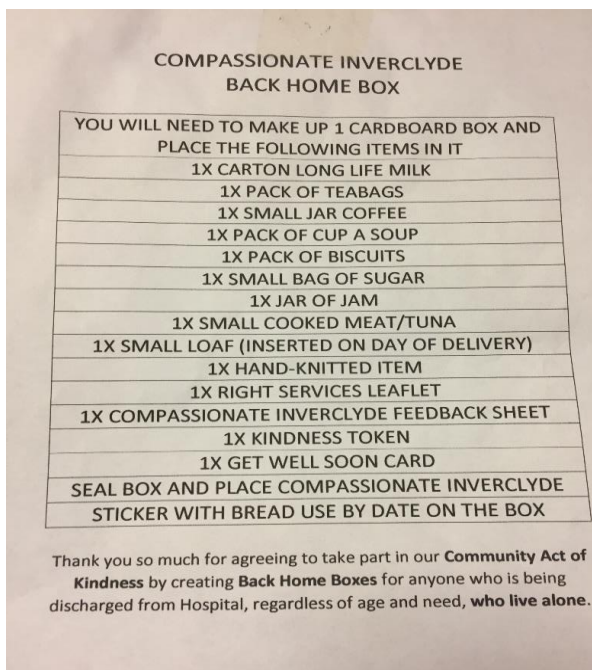
- improve wellbeing
- promote compassionate citizenship
- raise awareness and education
- promote compassionate organisations



Ensuring a diverse and inclusive coalition so that all voices within the community are heard, and to better understand those issues causing pain and suffering to individuals or groups or the entire community which can be addressed and relieved through compassionate action was vital. This aspiration is consistent with the international compassionate communities approach. It requires humility and a genuine preparedness to listen and learn from the community.

The Back Home Boxes tree was planted, and has been prolific in its growth. Like death and dying, loneliness is a cross-cutting concern that can impact upon people of all ages and from all walks of life. This focus has been an important factor in the way in which Compassionate Inverclyde has brought

the whole community together and in its success. The very first person Alison spoke to was employed by Amazon - a contact established through an existing social network. This seemed like an essential first step to Alison, in that if they could find a source the boxes, the rest could follow. She then approached key contacts including the ambulance service, infection control, the hospital and nursing services, and brought those groups together with the same message: *"This is a new idea, from the people, we're in this together, at the very beginning – can we make it work"?*



Alison B: *"People said you'll never, ever get the ambulance service on board, not in a million years. They have to support people upstairs, sometimes with walking aids and bags. But I very nicely sat with the head of the service and said I*

know it's a big ask, but I think we can make this work and it will make a big difference. What can we do? Let's keep the weight manageable? Can we try it? [Individual interview].

At the same time, Alison began asking those same groups: *who should get the boxes?* At first she had thought it would be for people over 70, but the group members had different ideas. They argued and she agreed that this is really important for anyone of any age going home alone, young people could be in the same position.

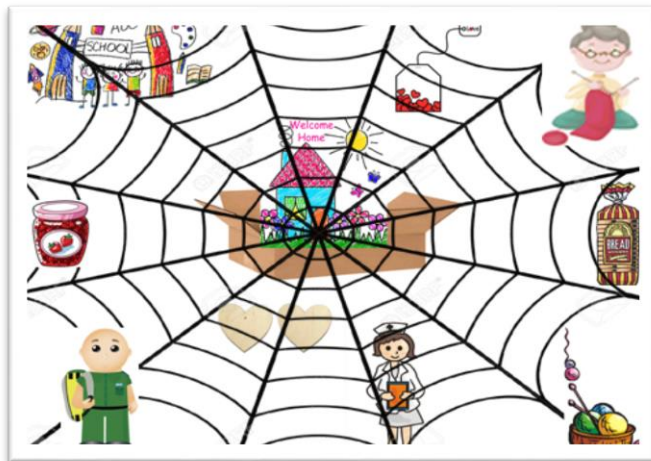
The next decision concerned what should go in the box. The list of contents came from local people and their careful thinking in this respect and ongoing revisions have been critical. The boxes now include items such as tea, milk, bread and snacks (see pictures) allowing recipients to make a hot drink

and light snack for the first few days on return home. They also include a get-well card made by local school children and other citizens, and a blanket knitted by local people. Finally they include a hand-made kindness token and, as initiated by volunteers, information about local services.

Initially the back home box 'store' was located in the community, but space was later secured within the hospital, despite space being at a premium. This presence and the delivery of the boxes within the hospital has been invaluable in increasing the visibility of the volunteers with staff and visitors.

Of all of the trees planted in Inverclyde, it is the home-grown, community-derived 'Back Home Box' variety that has had the greatest reach. Its branches have grown quickly, spreading high and wide across the community, contributing strongly to intergenerational working and community cohesion between people from different walks of life, including many who have been isolated in different ways; work is underway with a second group of prisoners to make cards and kindness tokens for back home boxes and female prisoners have knitted blankets.

The growth has been likened to spinning a web of *kindness*, with this box in the middle; simply by asking: Who else can add to this box? What can individuals, groups and organisations do to help? What



other talents do the people in our community have to share? And it has just grown. The success of this initiative is down to an extensive array of partners; Amazon, the ambulance service, the nurses, infection control, the volunteers up at the hospital, and the foot soldiers in the local community handing out leaflets, manning stalls outside supermarkets, visiting collection points, churches, shops, supermarkets, other local businesses and other organisations, knitting groups,

brownies, guides, cubs, individuals donating tins of soup, Facebook, social media, school children decorating boxes and making welcome home cards, prisoners making kindness tokens. As Alison noted: *"A big web has spun itself all around this one box – a web bringing together a whole host of people of all ages and from all walks of life, all having a can do attitude, all saying yes"* [interview]

Soon after the back home boxes were implemented, it was identified that some patients were coming into hospital without toiletries. The volunteers themselves proposed an expansion of the project to make up miniature toilet bags incorporating toothbrush and toothpaste, soap and so on.

The volunteers have to ensure that the box is something that everyone can help with, that stock is used wisely and that the initiative is sustainable. A volunteer with a significant role in organising the boxes commented on the challenges associated with donations being overly generous, sometimes donating luxury brands:

"For people looking at it who might want to contribute back, they're looking at it saying, 'oh that must have cost a pretty penny, there's no way I could contribute that, I'm only on a pension', it might stop them and it is important for a lot of people to feel they can give something back. This is something we are working to manage" [Myra: individual interview].



In trying to account for this 'can do' attitude, it has undoubtedly helped that Alison herself had a positive attitude and said "*listen this could really work, can we do it?*"

But just as importantly, as volunteers have articulated: "*it has been responsive to what we as a community can do*" / "*it's evolving all the time and all ideas are listened to, it's a case of that's not working, let's try this; we tried that before but why don't we give this a go*" [William and Myra, paired interview]

As discussed under impacts, the home-grown 'Back Home Box tree' has also proved instrumental in strengthening the interconnections between the different trees, with its roots growing deep and wide, touching the other trees, sharing the kindness super-nutrient.

At the time of the evaluation, 45 helpers are involved in sourcing food and well-wishes from the community, filling and delivering Back Home Boxes - 1300 people living alone have returned home from hospital with a Back Home Box.

Other tree varieties

A variety of other initiatives have seeded or been implemented in the Compassionate Inverclyde community woodland, all growing organically, responsively and at different rates.

What began as a bereavement café in 2017, consistent with the original focus on death, dying and bereavement, has developed in response to local concerns about loneliness more broadly, transforming into a vibrant volunteer-led hub at St John's Episcopal church hall in Greenock. This welcomes all local people, particularly people who are lonely, socially isolated or bereaved. Charlie, one of the original beneficiaries of the bereavement café has played a key role within this development. He is delighted by the growth and proud of his contribution:

Charlie: I felt wanted and understood thanks to the two Alisons. It was just that they were always there for me but unfortunately I was the only one attending (the bereavement café) for quite a long while.... The community café is open to anyone but if you're having a bad day there's always someone there that you can speak to Karen, and the turnout has been fantastic from day one. The first Tuesday, maybe 15 or 20 people there.... I feel quit emotional about it. I feel proud to be part of it, to be part of this" (individual interview)

This initiative has been nurtured by interconnections with neighbouring initiatives. Information about the Community hub is now included in the back home boxes and made available through the growing number of back home box collection points and by word-of-mouth. For instance, the owner of a nearby hair salon who previously received a back home box is now actively promoting it to clients she knows to be socially isolated. Many of the people who attend the hub do so as a result of becoming socially isolated through caring for a family member until death and are also supported with loss and grief, in line with the original objectives.

The local concern with loneliness has also resulted in the seedling idea of Back Home Visitors, extending kind, helpful and neighbourly connections to people who may be socially isolated and unable to attend the hub. This initiative was undergoing rapid germination at the time of evaluation, with recourse to the notion of 'neighbourliness' and repeatedly asking 'what would a neighbour do' helping things to progress swiftly, ensuring essential safeguards are in place but without getting bogged down by bureaucracy.

The nationally imported 'Absent Friends' seedling took the form of an annual 'Absent Friends' Festival comprising a series of public events whereby promoting compassion, celebrating life and commemorating deceased loved ones were an integral part of the civic calendar. This too has evolved more recently in response to local conditions, notably community understandings of 'absence', requiring outreach to people who are absent from the lives of significant others through imprisonment.

The original objective of promoting compassionate organisations has been evidenced through the generosity of local businesses in supporting the back home boxes, and the reciprocal running of high-five programmes within organisations such as Amazon and West College. Work to support organisations to adopt compassionate illness / bereavement policies is an area for further development. A community education university student is currently exploring the introduction of an award scheme for local organisations participating in Compassionate Inverclyde.

Creating the conditions for successful growth

Nurturing leadership

Nurturing leadership has been key to successful growth. Leadership across all aspects of Compassionate Inverclyde is not driven by position or power but is reflective of a shared community desire to see Inverclyde thrive. It is framed around shared values and lived through attitudes, behaviours and actions which are authentic, transparent and concerned about how we relate to others.

When thinking about leadership from an organisational or positional perspective, there is a deep emotional connection amongst those tasked with leading Compassionate Inverclyde, and a rare spirit of camaraderie and kindness within and across the Board. Alison Bunce has been the driving force behind Compassionate Inverclyde and has taken it forward with commitment, humility and passion. She serves as an excellent leadership role model who encourages engagement, commitment, and meaningful contribution and is a positive influence on others. This, blended with Alison's wisdom, experience and reputation for fairness and kindness is the foundation of the trust that others have in her. She serves as a valuable cornerstone for enabling Board and inter-agency decisions and actions to be taken in a timely, non-bureaucratic manner. She is consistently authentic regardless of whom she is engaging with. Her ability to engender a spirit of kindness, neighbourliness and helpfulness is based around her compelling communication of community stories and ability to adapt to constant change with a resilient, innovative mind-set.

Although inspirational, Alison is not a hero leader, but more of a host leader. She demonstrates a rare preparedness to listen to others and to hear when working within both formal and informal spaces. She has invited community members, as full contributors, to articulate what they intrinsically value, what they need/want, to take initiative and to be part of creating the solution. Her belief and confidence in the skills and capacities of the community – as a collective and as individuals is genuine and clear to see, as is her capacity to discern the hidden talents and strengths of others as unique and particular persons. She invests in authentic and meaningful conversations across many parts of the community and has created substantial change by placing her trust in the community's creativity, commitment and generosity, acknowledging and valuing that people willingly support things they have been instrumental in creating.

When thinking about leadership as practice, the leadership within Compassionate Inverclyde is collaborative and distributed. Volunteers universally speak about feeling of equal worth, that no suggestion or observation is silly and also recognise their own freedom and permission to take initiative and to act. Leadership in this sense is a shared, social endeavour – indeed the volunteers communicate that they, the young people in the schools, the nurses, ambulance crews, knitters and a host of other people who comprise Inverclyde are all leaders.

Pacing and taking time to listen and reflect

The Compassionate Inverclyde community woodland responds to natural, circular rhythms, like day and night and the seasons. Periods of stillness and quiet are required to listen to what the community is saying it needs and recognising and valuing all that it has to contribute. This authentic, social, collective leadership is helping to solidify the existing culture of kindness in Inverclyde. It is harnessing the capacity of this community to co-create change, unblocking potential barriers and fostering effective partnerships, achieved not through persuasion but by a clear shared purpose and by leaving any potential power dominance, egos and bureaucracy at the door. [Refer to **Reflections on Leadership** for more details about the key elements of the multiple leadership philosophies that Compassionate Inverclyde embodies].

Compassionate Inverclyde is also characterised by a collective ‘mindfulness’, with mindfulness techniques incorporated into its regular meetings. Many of the volunteers have taken part in the High-Five programme which includes mindfulness, resulting in increased noticing and awareness of others, and indeed participation in Compassionate Inverclyde itself has a similar affect:

BHB volunteer: *It opens your eyes. You realise how many people in Inverclyde actually live on their own.* (BHB meeting)

Good air quality and a nurturing environment (attention to language and making it simple)

Use of clean, jargon-free language and compelling messaging has been key to Compassionate Inverclyde’s success. This relates directly to the emphasis on the ordinary doings of ordinary people. Often it is discernible in the small things. For instance, the term “stakeholders” is not used – rather the focus is placed on creating, nurturing and sustaining human relationships with and between people who care and who can help. Language plays a huge part in that.

The language is continuing to evolve too, softening in response to community alternatives to some service-oriented legacies. For instance, the use of the term ‘volunteer’ is not overly popular. While the NODA volunteers have long been called companions, it has been suggested that ‘helper’ would be a more appropriate alternative for the remaining volunteers.



Starting small and taking an incremental approach has been part of the mind set, but without explicit use of the language of Improvement Science. For instance, in essence, the Back Home Box initiative was a ‘pilot’ that started out with one box, then two – but there is no mention of small tests of change or Plan Do Study Act cycles. Equally, there is an ongoing commitment to ‘identifying strengths’ and working in a manner recognisable as ‘co-production’. However, locally this is articulated as finding a way of approaching ordinary people and talking in ordinary language, asking *‘in what ways are you willing to share your talents, what can we do together?’*



Making things easy to do has also been critical. Alison B: *"If people fancy helping out with the Back Home Boxes, when they hear what's involved they straight away think, yes, I can do that. It's a case of come up next Monday afternoon and go round with the folk that are doing it and let us know how you get on. Having a way of getting people involved that doesn't have a great big rigmarole of things round about it is key. It's also important to make everything easy for nurses because they will not fill out any more forms"* [individual interview].

In addition to sustained attention to language and making things easy, positive behaviours are not only modelled but have become the norm, notably kindness, acceptance and equality. Volunteers are made to feel that they belong, are equal and have something positive to contribute from the outset. These are important outcomes in their own right and are discussed further under impacts, but 'modelling kindness' is a key generative 'mechanism', contributing to the senses of belonging, purpose, achievement and significance.

Social recognition is vital for self-identity^{xxi}. Valuing and caring about the person for who they are, appreciating his or her potential and realised contributions to the community and being treated as an equal contribute respectively to self-confidence, self-esteem and self-respect. All three are necessary if a person is to have an integrated sense of self-worth and all three are actively supported through the established ways of relating to each other within Compassionate Inverclyde.

Actively supporting growth (risk enabling governance)

In order to grow, trees need some sort of support until they are established. There are many supports in the Inverclyde community woodland, but they have purposefully been kept loose to avoid restriction. This is specifically so in terms of the Board, its representation and unique way of operating.

Enshrined in the Board Terms of Reference is a requirement to ensure Compassionate Inverclyde is community led and informed by what matters to local people, community initiative and feedback. Volunteers from each of the initiatives are now represented on the Board. The Board meetings are characterised by strong governance and overview of actions and what difference they are making. Reports are dealt with efficiently, but process does not drive the agenda. Rather there is a more informal, friendly conversational feel to the meetings, which requires a strong but distinctive type of chairing role. Initially chaired by successive Chief Officers of Inverclyde HSCP, the Board now has an independent chair appointed to the role as described in the person specification:

- motivated to support and contribute to the strategic direction of Compassionate Inverclyde
- sound knowledge of the community of Inverclyde
- demonstrates a passion and commitment that matches the key values: Compassionate, Helpful and Neighbourly

Processes are in place to ensure that the day to day running of the initiatives continue without undue risks. These processes are proportionate and risk enabling, avoiding the introduction of delays and barriers from undue professionalisation, over regulation and performance management, which are significant barriers to kindness. However prerequisite mechanisms are adhered to, such as the requirement for disclosure checks for all NODA companions. Steps have also been taken to ensure adherence with health and safety requirements that emerged during the development of the back home box initiative. For example, the weight of the boxes monitored to ensure they are not too heavy

for ambulance staff. There were also infection control stipulations: Alison B: *“For infection control, we can’t store anything that is temperature sensitive or perishable, so we can’t have butter. We accepted that – people can still have toast and jam. We followed their guidance and kept them happy but were still able to deliver a box”* [individual interview].

From the outset, Compassionate Inverclyde has recognised a need to gauge success, learn and refine. Evaluations of the training for NODA companions and of the high five groups were included assessing differences in wellbeing scores alongside feedback on the quality and impact of the training. Formative feedback is also taken on the spot, as happened following the initial high-five session with older pupils in St Columba High. The approach to working with secondary pupils was adapted successfully in response to this feedback.

The early growth of each initiative has been checked without unnecessary form filling. In the case of the back home boxes, Alison monitored the initial implementation herself by phoning the people who received the first ten boxes, asking for feedback and recording it on paper. Positive learning included an appreciation that the nurses were on board and felt able to use their discretion to determine who might benefit from a box upon going home from hospital, for instance extending this to an older woman who did not live alone but cared for her husband.

The requisite governance mechanisms and procedures surrounding the everyday workings of Compassionate Inverclyde are also in place, and requirements are met, but they sit very much in the background, don’t drive things and are embraced with good humour by the volunteers. This again can be illustrated through the back home box initiative. For the volunteers who deliver the boxes, hand hygiene is factored in seamlessly, with one person pushing the trolley, while the other presses the buttons to open the doors.

Importantly, there are also numerous support mechanisms for the volunteers, from being able to pick up the phone, the regular support circles for the NODA companions through to the camaraderie and genuine friendship between the volunteers:

Sarah: I was thinking about it on the way up here. Everything is very low key. I use the term gentle. That means that people like myself feel supported, secure and able to pick up a phone and it won’t matter how silly or whatever there will be somebody there if you’re not sure (individual interview)

Social media have played an important role in this respect, through the combination of Facebook, what’s app and messenger. Giving everyone a platform to have their say about Compassionate Inverclyde was part of the appeal, but the applications were increasingly used for entirely social reasons, and the recommendation never to *‘underestimate the power of banter’*:

The ongoing sense of connectedness was vitally important, particularly for people who have previously been isolated:

Myra: “I put my phone on first thing in the morning and I’m working across to the bathroom it’s like a disco, beep, be beep beep beep [laughs]. But it’s great – there’s so many people up before me and they’ve already had their say” [interview].

Social media have also played a critical role in making the woodland visible to the community.

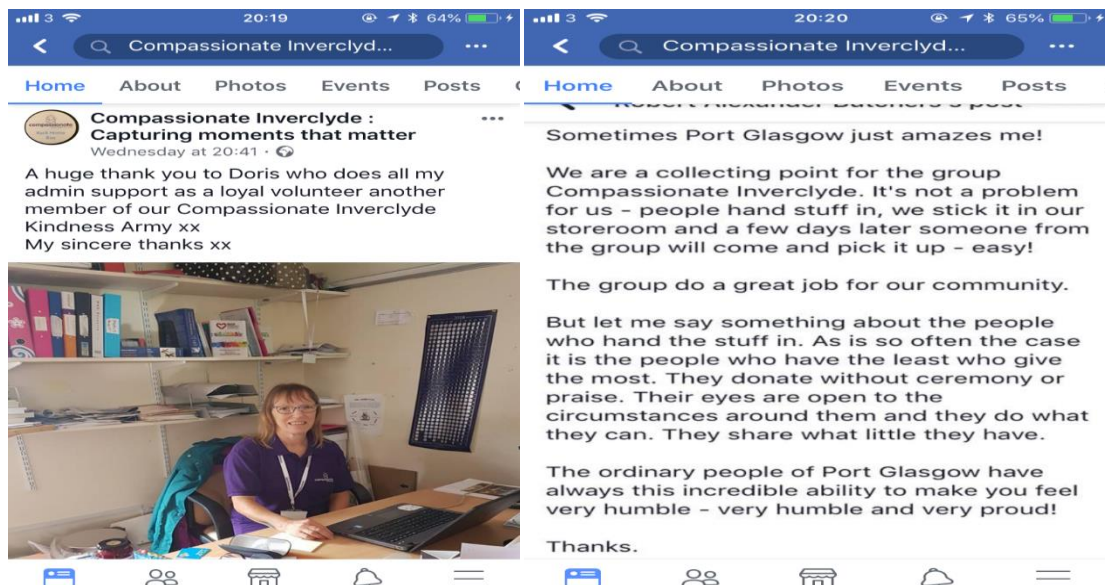
Raising Awareness of the Community Woodland (Communication)

Earlier recruits to Compassionate Inverclyde report that they were drawn in through specific events from early 2016, such as a visit by Alison to the hospital to speak to staff about NODA, through adverts in the paper about the bereavement café or through word of mouth from colleagues. As time has gone on, Compassionate Inverclyde has found diverse routes into the day-to-day communications of the community, including holding stalls at local events, posting leaflets in lots of shops and amenities, and engaging with local faith groups and community organisations.

The Greenock Telegraph is a local newspaper with offices in the main town. It covers news in the wider area and regularly reports on Compassionate Inverclyde. We interviewed Rosie, a Telegraph journalist who informed us that while the 'Tele' as it is known locally helps to raise the profile, social media have had a bigger influence. Several people told us that they had heard about it through the Compassionate Inverclyde Facebook page, which is updated daily. And as Rosie commented, it is through constant grassroots activity that many people come directly into contact with it.

Rosie, Greenock Telegraph journalist: *Some of that is down to the paper and nearly everyone talks about the 'Tele', but a lot of it is through social media and the Facebook page. It is well managed and then every week they are out and about, visible and actually doing things in and across the community, in the nurseries, schools and involving people from all walks of life on an equal footing (individual interview)*

The Facebook page is used for diverse purposes, including recruitment, appeals for materials, publicity about events, spreading messages about kindness and as a means of publicly acknowledging *all* contributions including the less visible roles which are essential to keeping Compassionate Inverclyde going. It is also increasingly being used by members of the public to express thanks, and acknowledge benefits from the back home boxes in particular.



Making space for the stories about people whose lives have been touched by Compassionate Inverclyde has been a critical element, with stories purposefully selected to illustrate that it is reaching people of all ages and all walks of life to increase community cohesion.

William: *“Basically we’re getting the stories about very different people, it’s the stories that touch people and encouraging the sharing, it’s the sharing as well”.*

William monitors Compassionate Inverclyde’s reach closely, and offered the following example to illustrate the scale of this amplification:

“I remember one particular story, it was a NODA story and Alison Bunce was at an awards night and the call came in to say that someone was needing someone and she went away and sat with the person who was dying... and at half past five in the morning I think the person passed on and she just looked out and saw the sun coming up through the hospital window and took a beautiful photo of it and put it up and explained what she’d done and within something like 5 hours that post had 9’000 hits and within the week it was something like 49,000, just by sharing and capturing people’s imagination [interview].

Other ways in which Compassionate Inverclyde has become visible to the local community and beyond include the national media, visitors to Inverclyde, presentations at conferences, articles and awards.

Nurturing and supporting continued growth

There is now a shared sense of community responsibility to continue and to grow, making use of everyone’s talents, motivation and time to allow it to really prosper. The volunteers and hub attendees keep coming back because of the enjoyment obtained through being out, being connected and feeling useful [as discussed in the next section, including people who have been seriously unwell and are now in recovery].

There has also been a concerted effort to keep the bugs off. The recourse to being kind, helpful and neighbourly also helped to move things forward at times when more bureaucratic or service-oriented objections and obstacles emerged. For instance, when concerns about cover arrangements for the back home visitors began to surface, the discussion took the form of, this is about being neighbourly – so what would a neighbour do if she went on holiday? – Just say I’ll not be in for a couple of weeks – it’s not a befriending service. It’s about ordinary people doing ordinary things to help ordinary people.

Within Compassionate Inverclyde the emphasis is generally on ‘growth’ and where reference is made to ‘spread’ it is in a rather distinctive way. As the following quote illustrates, this is understood as happening by ‘touching’ everyone, through reciprocity and perhaps by making people braver through lessening the fear of rebuke and spreading permission to act.

Myra: It touches everyone, one girl contacted us and said my granny got one of the boxes and I’d like to help. She said she’s going to speak to her area manager to see about putting a wee sticker on the edge of some of the shelves saying why not buy another one for the BHB ... I think it is making people a bit braver about doing things, just off the bat. [Individual interview]

Over time there has been a discernible shift upstream. For many volunteers, the vision for Compassionate Inverclyde is a return to the old days of neighbourliness. While some might dismiss this as utopian thinking, we found many examples where this was already taking place, inching closer to tackle the root causes of loneliness within modern society. Examples include increased attentiveness to the plight of others by people who have busy lives, and reducing the tendency to allow concern for people’s privacy to prevent offers of help by countering the fear of rebuke.

Utopian thinking may well have a place after all:

“There are always limitations on purposive action — of leadership, power, resources, knowledge. But if we begin with these limitations rather than with images of the desirable future, we may never arrive at utopian constructs with the power to generate the passion necessary for a social movement that might bring us a few steps closer to the vision they embody”^{xxii}

We now consider the impacts of Compassionate Inverclyde ‘social movement’ in detail.

Bearing fruit (outcomes)

This section sets out the impacts of Compassionate Inverclyde as revealed to us through direct contact with more than a hundred local people including volunteers, companions, Board members, teachers, nurses, children and other contributors to the ‘movement’. Our observations are also informed by reviewing project documentation and monitoring social media output including Facebook posts, as well as keeping an eye on the Greenock Telegraph.

To support the analysis of impact, we adopt a three tiered approach to assessing wellbeing, including individual, relational and community wellbeing.^{xxiii} This framework is based on the understanding that the wellbeing of any one person is highly dependent on the well-being of her/ his relationships and on the community in which she/he resides. As such, wellbeing is understood as a positive state of affairs in which the personal, relational, and collective needs and aspirations of individuals and communities are fulfilled. Each one of these entities is unique and dependent on the others at the same time. The voices of local people show clearly how all of these interconnected, that equally important forms of wellbeing are in evidence in Inverclyde, and that what has been achieved is something richer than the sum of individual parts.

The planning of Compassionate Inverclyde lasted many years. While it is a comparatively short time since work began in earnest two and a half years ago, it appears that the preparation and patience involved until that point has resulted in abundant and nourishing fruit which is being enjoyed by the many people who come into contact with Compassionate Inverclyde.

Interdependencies

While we were engaged in interviews and group activities during the evaluation period it became clear that the different initiatives under the banner of Compassionate Inverclyde don’t separate out neatly. Rather, they are linked through intertwined roots under the surface, sharing nutrients, particularly the kindness super-nutrient, and information to their mutual benefit. For example, a significant number of NODA companions are also involved in back home boxes. Many people who have been through the high five programme with its emphasis on kindness, also donate to or volunteer for back home boxes. And a combination of all of these people attend the hub meetings to support newcomers.

The ‘Back Home Box’, with its extensive reach into and across the community, has proved instrumental in strengthening the interconnections. It has done so by raising awareness about Compassionate Inverclyde as a whole and its various interconnected parts, and contributing to everyday conversations about kindness, death, dying and loneliness. This underscores the vital but often overlooked

contribution of the complex arrays of relationships and networks that permeate the social fabric of our communities.

So while it is not always possible (nor desirable) to attribute specific impacts to individual projects, inferences can be drawn by the stories we heard on the ground. There were also as many references to the benefits enjoyed by volunteers or helpers themselves as there were to the benefits for people receiving support, companionship or boxes.

A distinctive feature of Compassionate Inverclyde is the range of people whom it touches. This extends from the very young to the very old as well as people from all walks of life coming together, as explained by the journalist on the local newspaper:

Rosie (Telegraph) – That’s something that Inverclyde has needed... *[T]his is a project where the entire community is involved rather than just specific groups or a few key individuals and that’s quite rare. One week I could be reporting in a school, then there are very different local people who are donating, people of all ages and from all walks of life raising funds in different ways and then there is the new drop-in facility that’s opened up and you can actually see that everyone is coming together. It really is about the whole community* (individual interview)

In this, the longest section of the Compassionate Inverclyde story, we explore its multi-layered impacts. We cannot cover everything here and we can’t say exactly how many people have experienced some kind of positive outcome associated with Compassionate Inverclyde. However, at the time of writing 1300 boxes have gone out to people going home alone from hospital, influencing both direct recipients and their family members; hundreds of people are contributing through knitting, making cards and donating goods for these boxes; hundreds more people have been through the high five programme and have attended the bereavement cafés or the new community hub drop in centre.

It is therefore safe to say that thousands of individual residents of Inverclyde have been directly influenced by it, relationships have flourished and the community as a whole has benefited.

Given the anonymity of recipients of the boxes and people supported by NODA, most of this section is based on volunteer perspectives. We have also included limited but powerful examples of anonymous feedback from direct beneficiaries.

While we can’t make direct claims of attribution with regard to national and local performance outcomes and data illustrated in *Realising Outcomes and Value* in the Deep Dive report (available at www.ardgowanhospice.org.uk/compassionate-inverclyde), the reader can draw their own inferences based on what is reported here about people’s experiences and individual outcomes.

What is reflected here are the very significant benefits being enjoyed by diverse members of the community across Inverclyde.

Individual Wellbeing

The fruits of individual wellbeing enjoyed by adults

Summary of Individual outcomes for adult volunteers

- Sense of belonging (to a specific initiative, CI in general and/or the community)
- Sense of achievement
- Sense of purpose
- Sense of significance / feeling valued
- Feeling listened to
- Improved confidence and self-esteem
- Improved physical health
- Improved mental health
- Feeling less alone
- Getting out and about
- Improved social connections
- Giving and receiving kindness
- Giving something back
- More able to think and talk about dying, death and bereavement

Summary of Individual outcomes for people receiving boxes, attending the hub and using NODA

- Feeling less afraid of dying (especially patients and families using NODA)
- Feeling reassured that a dying patient is being cared for (nurses/families connected to NODA)
- Feeling less alone (BHB recipients and families)
- Being better equipped to manage on return home from hospital (BHB recipients)
- Sense of belonging
- Sense of significance – that you matter and people care

One of the most notable features of Compassionate Inverclyde's response to potential volunteers or helpers is the underlying principle that everyone has something to offer. So nobody who wants to help is turned away, although on occasion people end up taking on a different task according to the needs on the ground and their skill match. This open door policy means that even people who have not had any kind of active role in their community for some time can be folded in:

Alison A - It's picking up people who all through life there are issues that have held them back. We make it work (individual interview)

There was continual emphasis on the less visible roles being acknowledged. People knitting the blankets were mentioned by many back home volunteers, and their efforts seen as essential:

Alison A: One lady does 15 crocheted blankets a fortnight. She had bereavements and now has a focus for her knitting. She got her whole group involved (initial group meeting)

For some volunteers who had experienced setbacks, bereavements and/or illness, the opportunity to be more active and engaged had provided immediate health and wellbeing benefits. These included getting out of the house on a regular basis, getting exercise through walking around the wards with boxes, improved social opportunities and having a sense of purpose and belonging. For some these

opportunities represented steps out of long term dormancy as experienced by trees in winter. While one volunteer had her first day out in nine years, another felt she was blossoming through having something interesting to talk to her friends and family about for the first time in many years.

Some people identified themselves as having been very unwell and/or depressed and described the varying extents to which they were in recovery. In the following example Charlie describes significant improvements in his wellbeing from attending the bereavement café, with involvement continuing through back home box volunteering:

Charlie: The more I went [to the bereavement café], the more fruitful and the more help I was getting and even my psychiatrist said he's seen a big, big change in me for the better... I felt wanted and understood thanks to the two Alisons... I feel I've got a purpose in my life now Karen, I've got that extra get up and go and I feel motivated.

Doris, who plays a major role in managing the administration of Compassionate Inverclyde, describes how a sense of purpose and belonging has significantly improved her wellbeing:

Doris - It's helped me... I wasn't in a place to do paid work. I was very low and then a friend told me about this and said there would be something I could do. I contacted Alison and we met up... That's been since last May... But what it did for me is helped me feel I belong somewhere and it has helped me feel useful – it has helped my wellbeing a lot. (initial group meeting)

Some volunteers emphasised that being kind was necessary to individual wellbeing, and that a lack of kindness could have negative effects:

Daniela: When we are not kind we get sick (group feedback session)

Outcomes for back home box recipients

Back Home Boxes were repeatedly described by volunteers as meaning that a person going home alone would have enough provisions to have snacks and drinks to last up to a few days, but at least equally important, that they contain human touches to bring hope and a sense that people care.

Doris - It's a sense of belonging which it also gives to people who are receiving the service... Going home knowing that they have bread and milk. They know they are not completely on their own. The family who can maybe be busy – they have a sense of belonging too. They belong to this community. (individual interview).

The following feedback was left as a voicemail by an older gentleman who had opened his box up when he got home from hospital. This voicemail was replayed at a back home box meeting, where volunteers noted that the man, who sounded breathless and frail, had made considerable effort to leave the message:

Back home box recipient voicemail: Good morning Alison... I have just been discharged from Inverclyde hospital and I am phoning you to really thank you for the, for the box. It made a big difference and it eased me because I had no food in the fridge and I was very, very concerned and it put me back on my feet. I would just like to thank you again, once more, because it made me feel better and I'm certainly more on my feet. And if there is anything I can do for you in the future please give me a ring and let me know. Once again thank you very much for your kindness, care and attention. Thank you.

In another example, a younger woman who had returned home after leg surgery, explained that because she lived alone in an upper story flat, she really needed the box to help her through the first few days:

When I got home I opened the box up and couldn't believe what was in it. I loved the blanket and the idea that someone had sat and knitted it for me. The box had everything needed to keep me going for a few days, and I particularly enjoyed the 'piece and jam' with a cup of tea when I got settled. My favourite thing was the 'welcome home' card from the kids and especially loved that it opened backwards so the 'welcome home' picture was on the back and I've kept it. The pack also contained information with Alison's phone number and when I phoned Alison to thank her, I promised that as soon as I was back on my feet I would start a collection box in my salon, and that's what I did.

In both of these examples, recipients were so touched by the gesture, that they wanted to give something back, a response that we encountered dozens of times in our interactions with Compassionate Inverclyde. Such reciprocity is a key characteristic of relational wellbeing.

Outcomes for hub attendees

The hub was also playing a crucial role in bringing the different concerns of Compassionate Inverclyde together, notably death and dying, loneliness and kindness. One volunteer spoke about the number of people attending the hub who had cared for relatives until death, had become isolated as a result and whose whole demeanour could be transformed through simple acts of kindness:

Michelle: You see so many people, it has become their only focus and they stop seeing friends and then when the person dies they are lost. One man, he had been so isolated, he didn't want to be there initially, he didn't know how to be around people any more... just being kind, you can see it, after two weeks, he's like a different person... and he's now coming every week. (Individual interview]

Outcomes for NODA companions

Motivations for becoming a NODA companion varied. One common concept was that they viewed the opportunity to be a companion to someone at the end of life as a 'privilege.' While there was a spiritual aspect to the way many people spoke about NODA, companions represented different faiths and no faith. Many talked about their family values, with several talking about the importance of not allowing people to die alone as having been passed down by their parents.

In keeping with the original purpose of compassionate communities in general, there was also a concern that death and dying should be less of a taboo subject, with many people emphasising that it was a necessary part of life that should not be hidden, and several referring to the 'circle of life.' One volunteer talked about seeing how people avoided her mother-in-law as she got closer to death and attributed this to people's fears:

Daniela: [people don't talk] so much about the NODA. It's still a bit stigma. But I think it's important to open it up. We are all going to die.... Cathy (my mother-in-law) was 85 when she died and she got frail and people couldn't cope any more, seeing her changing.... [people don't want to think] If she dies, I can die. (Individual interview NODA)

There was also often a sense of uncertainty about whether the person who was dying was fully aware that the companion was with them. Despite this uncertainty, for most companions, the concern was

that for those people at the end of life who were experiencing at least some level of consciousness, they should have a sense of being cared for:

Mary - *I'm almost sure she knew somebody was there. I was reading and I started singing. I don't know why I started singing but she just seemed to be at peace then when you were holding her hand... So that first time, it was lovely* (individual interview NODA)

Another NODA companion acknowledged that sometimes you could not be sure what benefit companionship would have for an individual who was non-responsive. She described an exception to this:

Anne C: *The first gentleman had an elderly aunt who came from England. She didn't want to leave him but she had been sitting all night after travelling. It let her get a rest and she didn't need to feel guilt. That was one of the times I felt it did make a difference because you had feedback* (individual interview)

In other situations however, the benefits to a person at the very end of life were clearer. In an interview with a member of nursing staff, she spoke about how having a companion could give relief to a dying person who wanted their family to have a break:

Claire: - *And I've seen it on the other side where it is the patient who is relieved that someone is sitting there with them, and it's taking pressure off their family, long periods of time sitting waiting.* (Individual interview)

Outcomes of NODA for family members and friends

In the early days there were instances where NODA companions arrived at hospital and family or friends had turned up in the meantime. Alison Bunce in interview acknowledged that NODA had evolved, so that support to family and friends of the dying person was quite common and recognised as valuable in its own right:

Alison B - *I think that's been used more than I first thought. I was thinking that they would have no family or friends, but the service has been used a lot for family support* (individual interview)

In a companion circle meeting Alison described the new criteria for NODA involvement as follows:

Alison - *The 3 reasons or criteria for requests to NODA are*

- *If they have no family or friends visiting*
- *If the family are there and are exhausted and want a break*
- *Also if family are frightened and want support* (NODA companion circle)

NODA companions variously described the support to family and friends as resulting in 'that bit of reassurance,' 'relief', and 'being less afraid.' The benefits of support for family members described by companions was often quite striking:

Mary - *I would say in that situation it was the aunt that needed more support than the patient.... She was so glad somebody was there. At the time when I went in, the first day was quiet and when I went in the second day, [the man who was dying] was very, very restless. She hadn't seen that side and she was getting really quite distraught. So I was more or less holding onto her...just trying to reassure her...*

She said she was glad somebody was holding her because she couldn't have done it on her own (individual interview NODA)

Continuing or extending a professional caring role through NODA

We were struck by the number of NODA companions who currently or had previously worked in nursing or related caring roles:

Gillian - You need to give something back. Believe it or not sitting with someone when they are dying, I don't know the words, but I feel I am doing something, I'm being helpful. Now I've retired I don't have that nursing input and after 38 years you miss that. NODA gives me that (individual interview NODA)

The more we encountered people from caring professions the more it seemed that they were 'filling a gap' that they had not been able to address in their working lives, with several identifying that they had struggled because they had not been able to be with a patient who was dying:

NODA companions: I'm a nurse and I first heard in fundraising for the hospice and there was a meeting in the Beacon and I thought – that would be worthwhile because as a nurse you don't have that time (individual interview NODA)

This feedback chimes with literature on NODA in the United States, and indeed the lack of time available to spend with dying patients was what prompted nurse Sandra Clark to start the initiative at the outset in Oregon in 2002.^{xxiv}

Outcomes of NODA for nursing staff

In parallel with the feedback above from nurses and ex-nurses who became NODA companions because they did not have time to be with people at the end of life in their professional roles, current nursing staff on the wards described the relief they felt from having access to NODA support:

Claire Hynes - It's a great support mechanism for us as nurses. I think in this current climate where it is really acute settings that people are dying in. (Individual interview)

Nursing staff also liked that there was support for families of dying people through NODA, including the journal where companions kept notes of the last hours of the dying person:

Ward nurse: there's this journal that the family can look through and they say "Oh right, did that happen that night with my mum." It's a great thing. (Individual interview)

Although NODA companions don't necessarily have a lot of contact with nursing staff, there were examples where they described support they had provided to staff:

Gillian - The nurse started to cry and that will be the same in the care homes as they will know the people. Then I was comforting her to make sure she was ok. That nurse asked me to wait until the doctor had been so I did wait and when he went and I said my cheerios to the lady and checked if the nurse was ok (individual interview NODA)

Outcomes of NODA for the wider community

The interconnections between the various initiatives, all located within the one Compassionate Inverclyde community woodland has also resulted in indirect impacts from the NODA programme. There are small signs that it may be opening up conversations about death and dying in gentler ways.

For instance one volunteer at the hub and Back Home Boxes indicated that her involvement had resulted in opening up dialogue with her twenty-three year old son and a group his friends who have all been affected by another friend's suicide two years earlier:

Michelle: I was talking about it [Compassionate Inverclyde] and I mentioned the NODA and they started to talk about death. They've all been affected by it and they said we've not really thought about death and what it would be like to die. And they all said, everyone single one of them, the worst thing would be to be alone, not even how they might die, but they wouldn't want to be on their own... So I think in our communities we are starting to have more conversations about death... and if we can be open, we can be compassionate. [Interview]

Wellbeing outcomes for children and young people

Individual outcomes for children summary

- Sense of achievement
- Giving and receiving kindness (nurtured)(responsible)
- Improved wellbeing through understanding emotions (healthy)
- Increased activity (through high five programme)
- Mutual respect
- Included (in community initiatives and by peers at school)

Most of our connection to children involved in Compassionate Inverclyde was indirect through interviews with teachers representing two primary schools and one secondary school, and with volunteers working in another secondary school. We also attended one kindness assembly in a primary school and sat in a class with primary two pupils who talked about the high five programme. We met three primary seven girls who volunteered in the back home box store room, and went back to their school to tell other pupils about it. We observed the pride of primary school children who went up to receive their kindness badges and balloons in school and also heard primary two children talking about their increased understanding of emotions through taking part in high five:

Primary two pupil: When I used to fall out with my pals I didn't speak to them again. But now we can talk about it if we argue and me and my pal talked yesterday and we fell back in (discussion group St Michael's primary)

It was emphasised by many helpers that there was often no immediate or even long-term feedback from people who received support or goods from Compassionate Inverclyde, which means that people were acting altruistically with no expectation of further reward. As Doris put it with regard to children making cards and tokens for the back home boxes:

Doris - They are doing a kindness not expecting anything back.... They can still feel the value of it. If they know they are doing something for an elderly person they are getting that feeling that they are doing something good (Individual interview)

The involvement of children in the high five programme and in contributing to back home boxes was seen as valuable by adult volunteers not only as encouraging kindness in children, but in building capacity and sustainability for the future and the continuation of the values of Compassionate Inverclyde:

Myra: *And to get kids involved and get them making wee cards, kids from age 5 are getting involved and they are learning how to be compassionate – no one goes home alone without a wee get well card and that's the next generation and that's so important, to get them involved.* (BHB interview)

All three teachers we spoke to identified that their involvement in Compassionate Inverclyde added to existing wellbeing and volunteering initiatives in their schools. However, there were added benefits from the specific focus on kindness and in the case of the secondary school, through involvement in community-led initiatives, which were viewed as being more meaningful and as having direct benefits for fellow citizens of Inverclyde.

St Columba teacher: *This is the next step of volunteering in the community...It's good for the pupils to work with people in their community* (individual interview)

In particular, it was identified that sixth year pupils had joined the organising group for the planned back home visitors initiative. They contributed to monthly discussions to plan the new project and had visited a local care home, making a commitment to maintain regular contact and had already attended a social evening where they danced with residents. The secondary teacher also identified that the intergenerational work was breaking down assumptions and stigma:

St Columba teacher: *I think there is huge benefits. First there is a perception that young people are all bad and they are not. I understand why older people think that so you can break down barriers.... The connection and closing the gap of stereotypes.* (individual interview)

At the beginning of this section we quoted the local journalist who talked about the unique aspects of Compassionate Inverclyde as being its intergenerational and 'people from all walks of life' aspects. The following two examples show how one aspect of Compassionate Inverclyde is being implemented in two similar and yet contrasting settings. In both primary schools we visited, the primary two children take a kindness bear home with them, respectively Koby and Cuddles, and record an act of kindness in a journal. The stories show both similarities but also differences reflecting contrasting social-economic settings:

Miss Donnelly, St Michael's: *There is Koby the kindness bear. It was to make it as easy as possible for the families. A lot of our children might not have the facilities needed....So I put in my camera and they have taken very good care of it. We gave them batteries. So they got the camera, the kindness book and an information thing about what the bear is, what it's about and why we are doing it...We made it clear they didn't have to print the pictures. If they left a space we would print the pictures... Koby went fundraising, he was hanging out the washing, doing the dishes* (individual interview)

Wendy, Kilmalcolm teacher: *We started off with Cuddles, our kindness bear, he spreads cuddles wherever he goes and the children that came up with the name. And then there's a diary that goes with him and every night somebody took Cuddles home with them and filled in what they did. And you can see the different things, there's photographs and drawings and I should actually have brought my phone because we put it on the school twitter account, so the parents would tweet at night what they were doing. Let me show you some of the things* (individual interview)

Although Compassionate Inverclyde did not set out with preconceived ideas about achieving SHANARRI outcomes for children in the area, it is not too much of a stretch to see how many of the indicators are in evidence here, including relational, wellbeing and achievement outcomes. We now turn to consider how Compassionate Inverclyde is impacting on relational wellbeing.

Relational Wellbeing

Relational outcomes / signs of relational wellbeing in evidence across groups include:

- affirming and enduring friendships
- nurturance and affection
- respect for diversity
- reciprocity
- norms of mutual support, caring and affection
- networks of support
- collaboration
- democratic participation in decision making processes

As indicated above, the impact of Compassionate Inverclyde represents much more than the sum of individual wellbeing outcomes. Individuals frequently emphasised the importance of the new and often deep social connections they had developed, using words like ‘camaraderie’, ‘special bond’. ‘like-mindedness’ and ‘love.’ This was partly facilitated by the group meetings including the NODA companion circle, Back Home Box meetings, hub meetings, joint working on the ground and more recently social events bringing together people from all of the initiatives. While helpers emphasised the feel good factor of helping other people as satisfying in itself, many also mentioned that the new connections and friendships involved were a benefit they enjoyed too:

Daniela - I look around, Margaret, Jenny, all the people I worked with, when I met them in Tesco’s we go for coffee and a chat. I’ve been involved with other charities but they are very different. I never had the feeling that there was anything I couldn’t ask or could not be involved. I’m not a nurse I’m just a mother. Alison was saying you can do it, I trust you. It’s amazing (group feedback meeting).

This comment, made at the group feedback session where we shared our initial thoughts about the evaluation with a mixed group of volunteers, was followed by another comment from a volunteer who described how the collaborative and friendship aspects of Compassionate Inverclyde had made them kinder, consistent with the relational wellbeing notion of caring norms:

Doreen: ...Sorry, also, it has made us all kinder. It softened us all. It makes us all kinder. Because you have got a bigger array of, I call them, friends. Ok, we don’t meet every day or whatever but when we do meet, as Daniela said... and I think it has made us all kinder (group feedback meeting).

There was also emphasis on the importance of shared values and the importance of everyone involved ‘having a compassionate nature:’

Mary - Another thing, there is a real bond between everybody. Obviously it’s to do with the fact of what we are doing it for. I’m sure there is a kind of love in it... real friendship and I think that’s lovely... everybody is singing from the same hymn sheet (individual interview NODA)

Relational wellbeing was also evident in the first local branch of a business to have engaged with Compassionate Inverclyde. While not claiming, as a multinational business, to have become a compassionate business, local benefits were identified by a manager from Amazon in Greenock:

Gillian - Alison volunteered to do the high five with our management team... with Alison’s help and the work with doing gratitude diaries at work – it changes the culture. We are more compassionate. We

have a what's app group – we all bought in to it – eleven of us over several weeks – and every few days we capture a moment that matters – walking a dog - a sunset... We've gone from a good to great management team (initial group meeting).

Alongside the principle that everyone who wants to volunteer has something to contribute, a linked principle of Compassionate Inverclyde, is that everybody is treated as equal, which was highly valued:

Sarah: There is no I'm wonderful, there's none of that, whoever is available does it... nobody has an inflated sense of their own importance. And that is important for me (individual interview NODA)

While there was recognition amongst volunteers that Alison Bunce had initiated Compassionate Inverclyde and had maintained a co-ordinating and facilitating role, the sense of shared leadership is reflected by the following comment:

Doreen – nobody is the boss – we are all equal and I think that makes a big difference to everybody (individual interview)

The ripple effects of wellbeing stories generated through Compassionate Inverclyde are spread by the sharing of feedback at group meetings as well as through social media. In the following example, Alison Bunce shared a message with volunteers at the back home box meeting which she received in the form of a written telephone message for a back home box:

Alison B: I had a message from a 92 year old – I'll just read it. Just so you can have a dose of greetin' (laughter). His name is Jim. This was what he said in his telephone call

"Jim got home today, he is 92 and he said that in all of his years he has never received kindness like this. He has given all his life and has never asked for anything in return (God I'm going to greet). And he was so surprised and thrilled with the box he said it touched him so deeply and he thanked us from the bottom of his heart. Very and truly grateful" (BHB meeting)

Alison read this message to the meeting in the expectation that there would be an emotional response from the volunteers, and as often happens at the meetings there were indeed tears at this touching human story. We observed how the use of stories at meetings helped to build a sense of cohesion amongst the volunteers, as well as letting them see the benefits of their efforts.

Community Wellbeing

Consistent with understandings of the structural and social determinants of ill-health and inequality, factors adversely impacting on community wellbeing include poor housing, low wages, poverty, lack of jobs or meaningful employment opportunities, poor quality education, limited access to healthcare and welfare. As discussed in the overview of this report, it is recognised that assets-based approaches such as Compassionate Inverclyde must be integrated with actions to tackle broader inequalities, to address the historical impacts of deindustrialisation, and to mitigate the impact of current economic and poverty challenges. The social functioning of a community is however important in its own right and we heard numerous account of community wellbeing outcomes being generated through Compassionate Inverclyde.

Community wellbeing outcomes summary:

- Community voice
- Increased community cohesion (intergenerational and class)
- Heightened attentiveness to the situations of others
- Restored community values and neighbourliness
- Community hope for the next generation and resilience
- Active youth participation in decision-making and community action
- Renewed community pride

Rosie (Telegraph) *Anything that will help people in the community, that's another thing that has been key to its success, they have asked real people – nurses, social workers, school teachers, older people – what is needed - and responded to that. It really has been community-led* (individual interview)

The view of local journalist Rosie above emphasises the importance of the community-led nature of Compassionate Inverclyde.

This was echoed by the volunteers:

Daniela - *I think a key part is Alison asked the community what do you need and I think that's the most important so people could feel a part of it* (individual interview)

There was a strong sense, particularly amongst older adults involved in Compassionate Inverclyde, that it presented opportunities for restoring community values and neighbourliness:

Anne C: *When I was a wee girl I don't remember elderly people on their own – you would go and see Mrs McMillan on the way home from school. People looked after one another* (individual interview)

We referred already to intergenerational aspects of Inverclyde as being seen as breaking down assumptions by older people about younger people in particular. There was also a strong sense that different generations were getting involved through family connections, resulting in significant ripple effects into the community:

Doreen – *my grandchildren all want to be involved and I think that's great* (group feedback meeting)

Carolyn: *A lot of schools are involved too which is really nice. And I've spoken to my kids too – talking about this is reality and some people live like this. It's nice to have something positive to focus on* (individual interview NODA)

We have described how social media are used effectively by Compassionate Inverclyde to generate interest and recruit volunteers. There is also a community building aspect to the promotion of the brand on Facebook in particular, which was referred to frequently as promoting positivity and goodness:

Carolyn: *The social media side. I see on social media every day there is another nursery group or school group – just groups of people going along to the BHB. Even I live in Inverkip, the community centre down there was collecting items to go to the BHB... It's nice to have something positive to focus on.* (individual interview NODA)

The extent of the community pride and ownership of Compassionate Inverclyde was summed up by one volunteer at the group feedback session with the evaluators as follows:

Gillian - *For me it's that renewed spirit within the community that maybe everybody has been searching for and that renewal of spirit and pride that I think will ensure that Compassionate Inverclyde really is sustainable.... None of the personalities in this room are going to let it be anything other than growing* (group feedback meeting)

The Health Foundation infographic below illustrates the interplay between people's immediate circle of relationships, community cohesion, social participation, shared identity and shared ownership and capacity to influence positive change:



Sustainability

Compassionate Inverclyde has become a safe haven where the contributions of people of all ages and from all walks of life are valued. The trees have strong roots, they are deep and far-reaching below the surface, interconnected but not entangled. The growth until now has been organic, it has gone and is going in the direction it needs to go in, upstream, unforced.

The potential to grow in different directions in future is vast. By cutting across generations, forging social connections and cohesion, combating loneliness, enhancing the wellbeing and future capabilities of children, maintaining a gentle connection with death and dying, and a unique manifestation of integration, Compassionate Inverclyde speaks to a great many policy initiatives (See ***Deep Dive report: Policy in Action***). This should assist with embedding and sustaining the initiative beyond this early development stage. But, as with all initiatives, Compassionate Inverclyde has vulnerabilities. One is a perceived dependency on Alison as the nurturing leader of the social movement, albeit this is being mitigated as the capabilities of volunteer leaders are increasingly recognised and their participation at Board level facilitated.

Competing for resource under conditions of scarcity

The Compassionate Inverclyde trees have deep roots and share nutrients and information which can help all to thrive. However, under conditions of scarcity, competition can emerge and associated tensions require attention to avoid healthy trees being stifled.

Another vulnerability is the risk of Compassionate Inverclyde competing for resources (financial and people) within a relatively small system and in a climate of austerity. We came across three examples of such competition while we were undertaking the evaluation.

The first example was a concern raised about competition between food banks and the back home boxes for community donations of groceries. Our own notes from visiting the back home box operation in Inverclyde hospital highlight this:

“During tea-break for the BHB volunteers there was a discussion about the fact that some people who previously donated to food banks are now donating to BHB instead. Although some volunteers and their family members have used food banks and were supportive of them, there was a sense that food banks were not universally popular” (extract from evaluators’ own notes).

A second example was tension created over storage space for the back home box office in Inverclyde hospital. As can be seen by the photo in this report, significant quantities of groceries require to be stored, previously in a small cupboard in the hospital basement. It had become increasingly difficult for volunteers to manage the stock-keeping and filling of boxes within the available space. They had just been given a bigger room prior to our last visit. During that visit, one of the transport office staff put his head round the door to ask how the volunteers had managed to obtain that room, which they had been arguing to move into for many years. The room had a window out into the transport bay outside which would have made transport management easier. While the exchange was civil it seemed that the transport officer had a justifiable query.

A third example was a concern that donations to the hospice may diminish in favour of Compassionate Inverclyde. This is ironic given that Ardgowan hospice has had a key role in Compassionate Inverclyde, including use of its premises and funding the secondment of the lead.

There is perhaps an inevitability about such competition arising, particularly in the current context of resource scarcity, but this type of tension needs to be attended to maintain good relationships and ensure that the contributions of all can be sustained. This risk of competing for funding or for volunteers is an important issue when considering the design of the next phase of Compassionate Inverclyde.

The Moral of the Story – Distilling Key Messages

It is hard to capture the essence of Compassionate Inverclyde. We came to our metaphor of community woodland for a reason; trees take a long time to mature. The moral of the Compassionate Inverclyde story is that it takes time, patience and a lot of hard work before the benefits can be harvested. Much of this work may be unseen, taking place beneath the surface through informal networks and social functioning of the community.

Given their strong, interconnected roots, the Compassionate Inverclyde ‘trees’ cannot simply be picked up and transplanted. As the Compassion Communities Charter has long recognised, every community is different and every community will have to find its own way. While there is no real substitute for ‘being there’ and experiencing Compassionate Inverclyde first-hand, we are tasked with distilling key message for others, as follows:

- Compassionate Inverclyde is first and foremost concerned with ordinary people doing ordinary things to help ordinary people
- It centres around the values encapsulated in its logo of being compassionate, helpful and neighbourly, with kindness increasingly emphasised as the key or super-nutrient for all
- It is not policy driven yet aligns with multiple national and local policies
- It does not espouse allegiance to or use the language of any leadership philosophy yet embodies the tenets of many and the key ingredient in this regard is humility
- It was not driven by governance or procedural considerations, but loose supportive governance arrangements ensured compliance with all requisite procedures in a seamless way
- It has not subscribed to a particular methodology or model of spread, yet its growth and reach have captured the attention of many onlookers
- It purposefully rejected the imposition of a performance framework, instead listening to and placing its faith in the community, guided by intrinsic community values and four key objectives which were not rigidly adhered to but have evolved with learning on the ground
- It did not start with predetermined outcomes but allowed space to see what outcomes were generated; as it happens, individual outcomes respond to many existing evidence-based Scottish outcomes frameworks for adults and also for children and young people (SHANARRI) as well as new distinct outcomes relevant to loneliness and bereavement
- It values community, relational and individual wellbeing as an end in itself and not merely something that may help to alleviate health and care system pressures, yet system contributions can be inferred
- In putting relationships at the centre, it recognises that community is much more than the sum of individuals who live within it – often overlooked inter-personal relationships, networks of support and community groups all play an invaluable role
- What is most striking about Compassionate Inverclyde is its success in bringing together local people of all ages and from all walks of life in an unprecedented way
- Understanding intrinsic local values, listening to the ideas of local people, respecting everyone as equals, fostering a can do attitude, making things easy to do and taking the time to recognise all contributions are critical to growth
- There are some pollutants and growing conditions to avoid - especially the permafrost of performance management in its increasingly rigid forms.

Appendix 1

Evaluation of the Compassionate Inverclyde Programme

Participant Information Sheet

You are being invited to take part in the evaluation of the programme known as 'Compassionate Inverclyde'. The evaluation aims to find out the difference made to the lives of individuals who have been involved in the programme in different ways and the difference made to the local community. It also aims to understand how the changes made have been achieved, what has helped and what has made things more difficult. As someone who has been involved in the programme you are in a position to help us.

Do I have to take part?

No, it is up to you to decide whether or not to take part. If you do decide to take part you will be given this information sheet to keep and will be asked to sign a consent form.

What does the evaluation involve?

The evaluation will involve collecting information about the programme in different ways, including individual interview, group discussion and observation of programme activities. We will use a machine to audio record discussions and may also write notes.

What am I being asked to do?

You are being invited to take part in the following:

Individual interview	
Observation of programme activities	
Group discussion	

What will happen to the information collected?

All of the information that is collected will be held on a password protected computer. All audio recordings will be typed out word for word and the original recordings will then be deleted.

The information will be used to inform an evaluation report. It may also be used in briefing papers and journal articles.

You will be given the option of being named in the report or remaining anonymous.

If you wish to say something that will NOT be recorded or used in any way, please let us know and we will ensure that it is not recorded.

Who is conducting the evaluation?

The evaluation is being carried out independently by the International Foundation for Integrated Care (IFIC) Scotland. The two academic researchers who will be collecting the information for the evaluation are Dr Emma Miller and Dr Karen Barrie.

If you later have any questions about the evaluation please do not hesitate to contact Emma or Karen at xxxx

Many thanks for reading this information sheet

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