

Curated Care



Enhancing and Embedding Care in Highland Communities

This book gives an overview of the Flourish project, led by Professor Irene McAra-McWilliam, Dr Lynn-Sayers McHattie, and Dr Cara Broadley from The Institute of Design Innovation at The Glasgow School of Art, and their work with Dr Jeremy Keen, Andrew Leaver, Emily Patrick, Maria Cuthbert, and a group of volunteers from Highland Hospice on Curated Care.

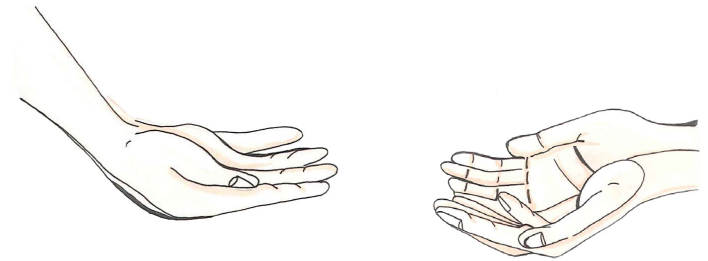
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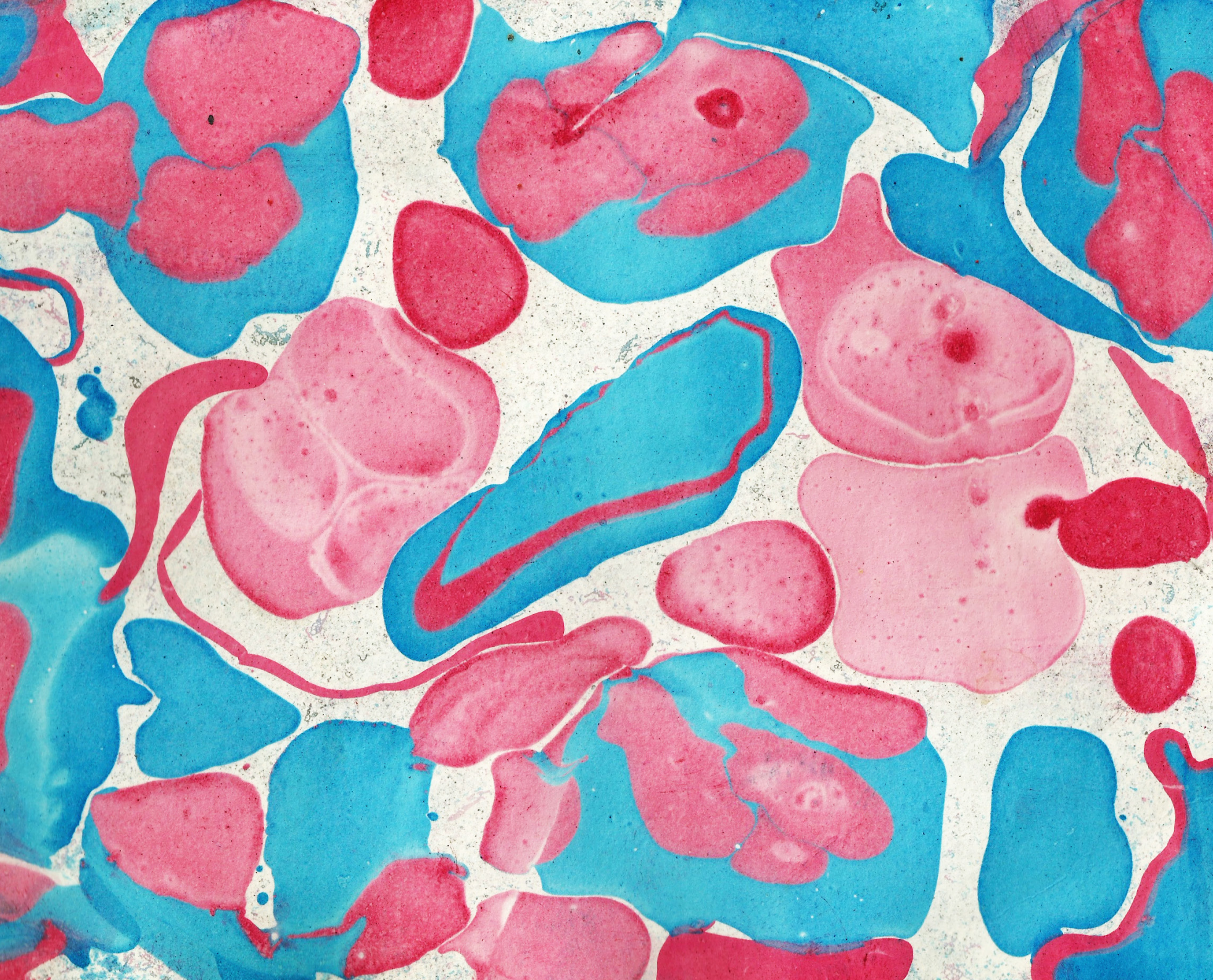


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**Highland
Hospice**



Flourish

'Integrative Care is an approach to health and wellbeing built on the concept of personhood: the integration of the physical needs of a person together with their psychological, social and spiritual needs. We want to include the needs of families, medical staff, and carers in hospital, hospice, home and other settings to create participatory models of distributed care.'

PROFESSOR IRENE MCARA-MCWILLIAM, THE INSTITUTE OF DESIGN INNOVATION,
THE GLASGOW SCHOOL OF ART, 2014

In Flourish, The Institute of Design Innovation at The Glasgow School of Art have explored the ways in which qualities of life are generated and sustained, how personhood and collective wellbeing can flourish, and how design can enable a flourishing society.

Working together with clinicians, fundraisers, and voluntary services staff from Highland Hospice in Inverness, Curated Care focuses on the care provided by the 750-strong volunteer community, the factors that motivate people to share their talents and time to care for others, and how this can influence wellbeing in transformative ways.

This book is presented in four sections. Positioning the work in the context of informal care, Emily Patrick and Maria Cuthbert introduce their experiences of working with the volunteers in Highland Hospice. We then describe our design approach to participatory inquiry, before profiling the motivations and experiences of four volunteers – Jim, Wilma, Derek, and Audrey. From this, we draw out themes emerging from the stories of the volunteers we have engaged with, and go on to offer our impressions and reflections around how the social qualities of personhood contribute to a landscape of collective wellbeing, the integration of health and social care in the distributed region of the Highlands and Islands, and the role design can play in connecting communities of care.



Emily

Emily is the Voluntary Services Co-ordinator at Highland Hospice and is responsible for supporting the delivery of voluntary services to all areas within the hospice. Appointed to her role in June 2012, Emily became involved in volunteering because she loves to see the difference that it can make to the individual volunteer, as well as the cause they are supporting.

Highlighting the historical importance of volunteers in establishing Highland Hospice and their contributions to its day-to-day operations, volunteers provide 'much needed support to staff and one another to ensure that the Hospice delivers a seamless service to its patients and their families'. Volunteers are valued greatly by the hospice, and as Emily recognises, 'as well as having a number of volunteers who have achieved recognition for long service (5, 10, 15, 20, 25, and 30 years), we also have volunteers who regularly clock up at least 20 hours of volunteering per month'. Because of their passion and commitment, and the sense of camaraderie that they engender, Emily finds it rewarding and a privilege to work with the volunteer community.

Emily believes that a contemporary vision of care in the community 'should recognise and celebrate the informal "good deeds" carried out by individuals'. Considering how distributed care can be delivered and accessed, she believes that technology has a role to play in enabling those who have a 'desire to help but who perhaps don't have the contacts, means or confidence to carry out the type of tasks typically associated with informal care'.



Maria

Maria supports Emily in her role as Voluntary Services Administration Assistant. Previously a volunteer herself, Maria is inspired by the welcoming nature and personal approach that the Highland Hospice volunteers give to the service users.

Maria feels honoured to work with the volunteers at Highland Hospice and points out that 'each of them has a story to tell of why they give up their time so freely to help others and the Hospice organisation gains so much from their commitment and support.'

Reflecting on the importance of informal care for individual and collective wellbeing, Maria highlights how volunteering presents 'a great opportunity to help another person, support your community and also increases your own personal awareness'.

She recognises the need to confront the challenges of a shifting social landscape, and how, for those living in remote and rural environments, 'communities have changed so much with families living a great distance from one another'. For Maria, distributed models of care can 'help bridge some of the gaps left by these changes, and volunteering in the community forges bonds with people – we can all be a friend in a small way'.



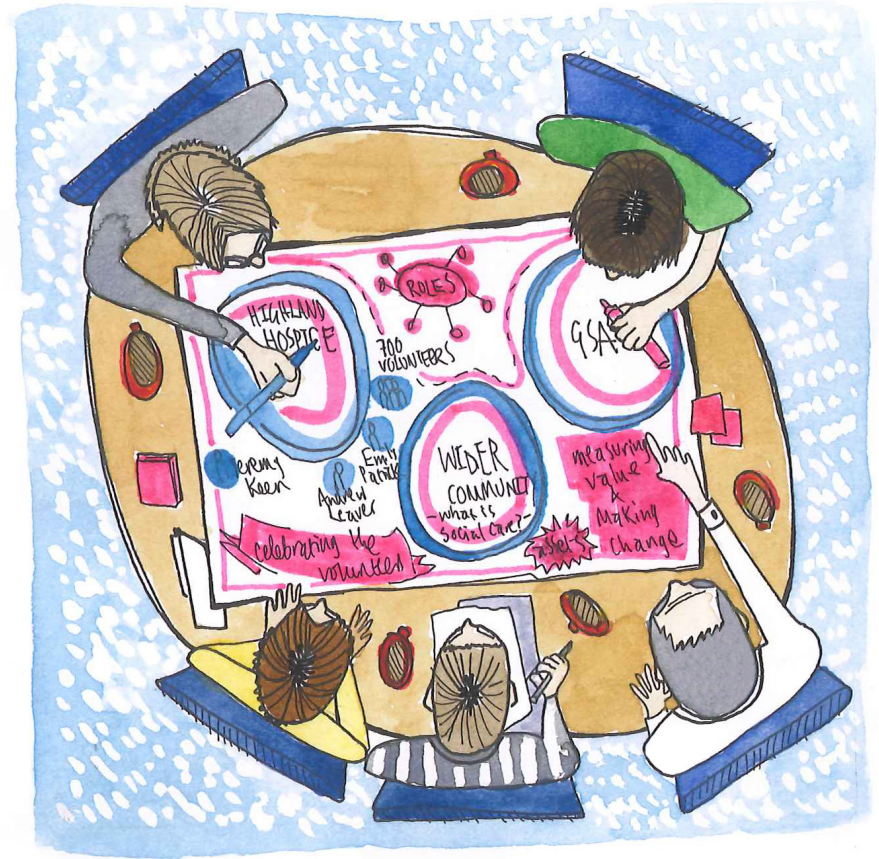
Approach

In the Spring of 2014 our team met to discuss shared interests around integrative health and social care and ways of working together. Collaboratively mapping the infrastructure of Highland Hospice, we considered creative ways to give voice and expression to the volunteers and celebrate their valuable contributions.

'What is social care and how is it created?'

EXTRACT FROM COLLABORATIVE PROJECT MAP, 2014

Three cooks from Highland Hospice, Marion Irving, Doreen Morrison and Ann Mackay, had recently been finalists in the 2014 BBC Food and Farming Awards. Providing meals for the entire hospice community, the cooks take a personal approach by visiting patients individually, taking the time to understand their preferences, and cooking them their favourite foods. This story of dedication and bespoke support underpinned our collective aims to share experiences of care from across the volunteer community.





Introducing Curated Care and gaining an insight into Highland Hospice's wide range of volunteer roles from Receptionists to Patient Drivers, we met with a total of 19 volunteers – both individuals and established friendship groups. Placing the volunteers at the centre of the project and seeking connections between their experiences, we then invited them to share their stories together in a speed-networking session.

Volunteers discussed their daily volunteering patterns and routines, personal motivations, their relationships with others in the hospice community, the characteristics or qualities needed to volunteer, and the ways that volunteering has impacted upon their lives. The role of the volunteer community in extending the reach of the hospice across the Highlands and Islands, ways to enhance volunteer recruitment and retention in urban and rural environments, and communicating the emotional and social value of volunteering across Scotland were also highlighted throughout their conversations.

The volunteers and the research team documented these interactions by writing, drawing, taking photographs, and through audio recordings. Piecing together these fragmented narratives and illuminating the personal and professional stories that were shared, we go on to present four volunteer portraits.

Jim

Jim is a retired hotel manager and has been volunteering with Highland Hospice for four years. He works in the hospice Coffee Shop and also assists in coordinating the sales of Christmas cards.

Jim's working life has given him valuable experience of working with people to meet their needs, but volunteering has taught him more about working with a diverse team.

As a volunteer, he thinks of himself as getting 'down to the nitty gritty of volunteering' by contributing to 'anything that needs doing.'

Upon recovering from a stroke, Jim was overcome by a desire to give back as an expression of gratitude for the care he received. He often meets patients' relatives and has developed an intuitive ability to know when someone wants to speak with him, and when they prefer time alone with their thoughts.

Through this, Jim recognises that volunteers are advised not to become too attached to patients, and that there is a need to be 'professional, but human.'

Proud and passionate, volunteering gives Jim a strong feeling of 'satisfaction and gratification', as well as benefiting his fitness levels due to being more physically active.

In relation to his own role and ability to be flexible, volunteering is 'not about the individual, but what we do as a team'.



Wilma



With experience of working in administration, personnel, finance, and tourism, Wilma has volunteered as a Receptionist in the past but prefers her current role as a Patient Driver. Transferring her experience of 'working with people' into volunteering, she became involved with Highland Hospice when she retired.

The strength and positivity of patients of all ages has led Wilma to re-evaluate her priorities, helped in grounding her and encouraging her to 'stop moaning about her bad back'.

Bringing her friendly disposition to this role, she always has a smile for patients, and highlights that 'it's great when you hear them laugh' in return.

Being a Patient Driver takes Wilma away from the central location of the hospice and out into the extended Highlands and Islands. Frequently visiting towns and villages across the region, Wilma recognises that feelings of connectedness and closeness amongst communities vary depending on the size of their population and how they are distributed geographically.

Due to the nature of her role, Wilma does not mix with the other volunteers regularly, but always looks forward to meeting as a group at social events organised by the hospice.

In Wilma's experience, volunteering can have a transformative affect on increasing confidence, and in Highland Hospice, 'everyone is valued equally'.

Derek

A retired Police Officer, Derek previously drove the vans that service the Highland Hospice Charity Shops and has also volunteered as a Patient Driver, but has recently begun volunteering for Administration and Events. His career had brought him to Highland Hospice in the past, and although he had always been interested in volunteering, Derek felt it was 'the right time' after he retired.

Throughout his working life Derek found that he had an aptitude in offering both practical and emotional support to people whose relatives had suddenly passed away. In comparison to his previous employment, Derek benefits from an infinite amount more personal satisfaction and pleasure volunteering, and 'giving back' is not connected to financial gain for him.

Due to his responsibilities to coordinate the Patient Driver rotas over the telephone, Derek is familiar with many other volunteers' voices despite often not knowing them face-to-face.

When meeting with patients and their relatives, he approaches each in different ways depending on their individual circumstances, and often enjoys a sense of rapport with them. This is an instinctive response that he has cultivated to 'treat people the way that he would want to be treated'.

As Derek reflects on, 'we all have different priorities in life, and it is important to value the little positives that emerge from bad situations. For Derek, 'the entire experience of volunteering is greater than the sum of its parts'.



Audrey

Audrey currently volunteers on the reception desk in Ness House, as well as having a role in coordinating the Christmas cards that Highland Hospice sell each year. A volunteer for 20 years, she has extensive knowledge of the hospices' history, the layout of building, and the work of the staff.

Audrey came to volunteering in her mid-30s. She was content with her life, but decided that she wanted to take part in some form of volunteering at weekends, and a family friend recommended Highland Hospice to her. She later lost a family member and a close friend to terminal illnesses, and through volunteering she has gained a deeper understanding of palliative care from different perspectives.

Reinforcing the importance of community, Audrey recalls that in the early days when the hospice was smaller, 'it really felt like a family'. Through this, she emphasises the need for the volunteers to remain as a cohesive unit during Highland Hospices' decant to Invergordon while the new premises are being built.

Explaining that many of the volunteers have a background in health and care and that this is evident in how they approach volunteering, Audrey highlights the Reception volunteers' abilities to engage with patients and their relatives with empathy and compassion.

She sees value in the smallest details of volunteering at Highland Hospice, from flower arranging, to preparing and displaying cakes and fresh fruit, and recognises that 'everyone here takes great care and beauty in everything that they do'.



Reciprocity

The volunteers in Curated Care expressed an overwhelming desire to help, and explained that they receive so much in return. Exploring this idea of reciprocity more deeply, the spare time presented by retirement is accompanied by a determination to keep busy, and in turn, the flexibility of volunteering maintains routine and certainty, by 'giving shape to your week'. Depending on each volunteer's specific role and responsibilities, opportunities to interact with staff, patients, their relatives, other volunteers, as well as the wider community across the region are rewarding results.

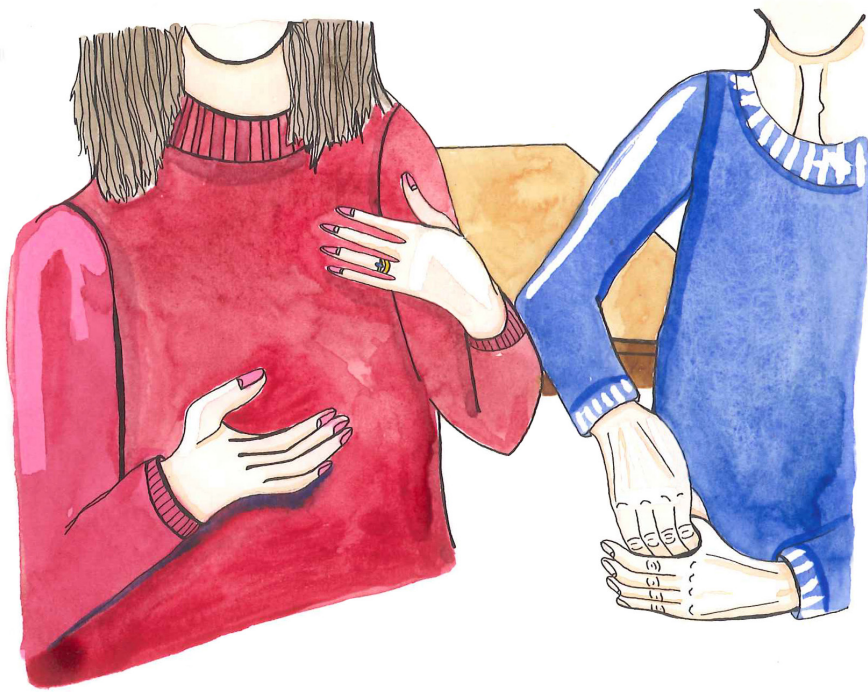
'The hospice would still run without volunteers but it wouldn't be as efficient. We're supporting the nurses so that they can help the patients.'

KIRSTI, 2015

Giving and receiving support is central to a caring community, and pride, pleasure, satisfaction and gratitude are positive emotions to be gained through volunteering. Selflessness and altruism are principles associated with volunteering, yet the volunteers agreed that 'there has to be a gain on both sides'. Appreciation, acknowledgement, and 'feeling involved and not anonymous' highlight the volunteers' senses of achievement and purpose.



Dignity & Empathy



The volunteers identified strongly with the nature of the hospice movement, the emotional distress caused by bereavement, and the importance of 'dying with dignity'. Interpersonal skills of empathy and compassion enrich their roles in Highland Hospice – an innate 'need to care', the ability to know intuitively whether patients and their relatives want to talk or simply be silent in the company of others, and listening without judgement are essential components of informal social care.

'I will never ask how you are, but if you want to speak, then I will listen.'

WILMA, 2015

Through meeting patients, often younger than themselves, approaching the end of their lives, the volunteers are acutely aware of their own mortality, and recognise that life is precious, unpredictable, and that 'we are well off'. The strength of the nurses and the positivity of the patients are rich sources of inspiration and contribute to 'the sense that one day someone else will care for you, if you need it'.

Making Care

The qualities, characteristics, and traits needed to volunteer were a key focus of discussion, with the volunteers balancing their practical abilities such as IT and driving, with social skills such as politeness and trustworthiness. Two volunteers wondered: 'do you need to be compassionate if you're a volunteer gardener?', but agreed that volunteering is holistically concerned with 'caring to make things better'.

'Imagine how you feel when you make a piece of art – that's what volunteering feels like. It's all about taking great care in making something, giving it a form, and seeing how others can benefit from it.'

DEREK, 2015

Care is evident in small but sensitive acts of generosity, communicating through kindness, and displaying creativity and beauty in presentation. This idea was echoed through the volunteers' references to the Flower Arrangers, whose displays can be seen throughout the hospice; the time taken by the Charity Shop volunteers to meticulously sort, repair, wash, iron, label, and display donated clothes, amongst other items; and the wedding favours produced by the Fundraising and Events volunteers. In these ways, there are opportunities for roles to be co-created in action with the hospice staff, in response to the volunteers' particular talents and interests.



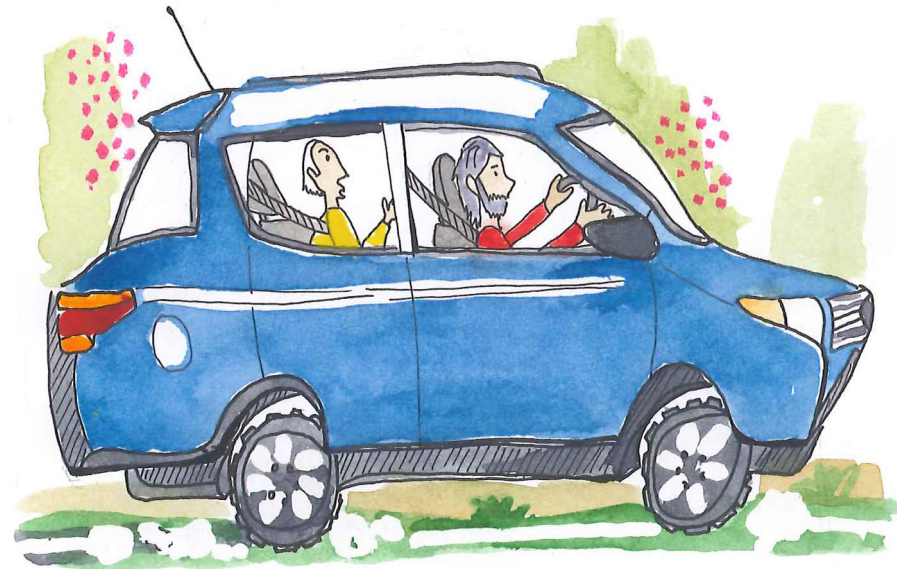
Impressions & Reflections

Throughout this phase of Curated Care we have explored the relationship between personhood and collective wellbeing, a democratisation of social care, and the geographic distribution of people and their communities. Responding to differences in volunteer uptake and participation in urban and rural areas across Scotland, the volunteers proposed a correlation between densely populated, highly connected urban areas and the personal attitudes and values of the people who live there: 'do *central-belters* feel too self-important to care? Is this an aspect of city culture?'.

'Up here, the distances between places make companionship so important.'

WILMA, 2015

Suggesting that close-knit networks of neighbours are in decline in Inverness as its population increases, the volunteers considered if there is less community spirit within larger towns and cities. Conceptualising the Highlands and Islands as a distributed community, informal care plays a vital role in preventing loneliness, and enhancing friendship, cohesion, and social connectedness across the region.





The volunteers have helped us to recognise the practical and emotional challenges experienced by each person who is touched by terminal illness. Appreciating the 'stigma' attached to hospice and the fear that this can evoke, the volunteers agreed that there is a need to promote an authentic vision of palliative care, whilst confronting misconceptions around volunteering and informal care more broadly in the region of the Highlands and Islands.

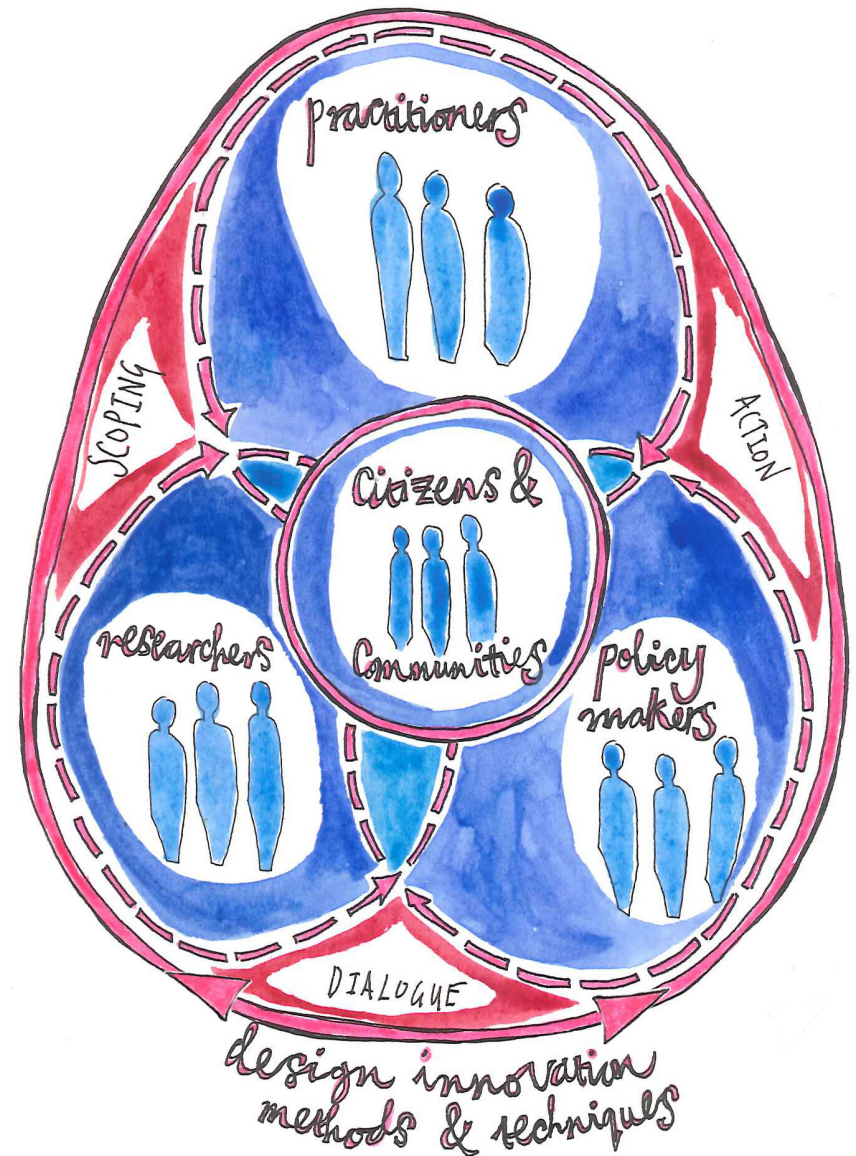
Volunteering is not simply an investment of time, – 'people must understand that an hour a week is really valuable' – but an opportunity to develop a range of different skills concurrently, to enhance our self-awareness, and our abilities to relate to others.

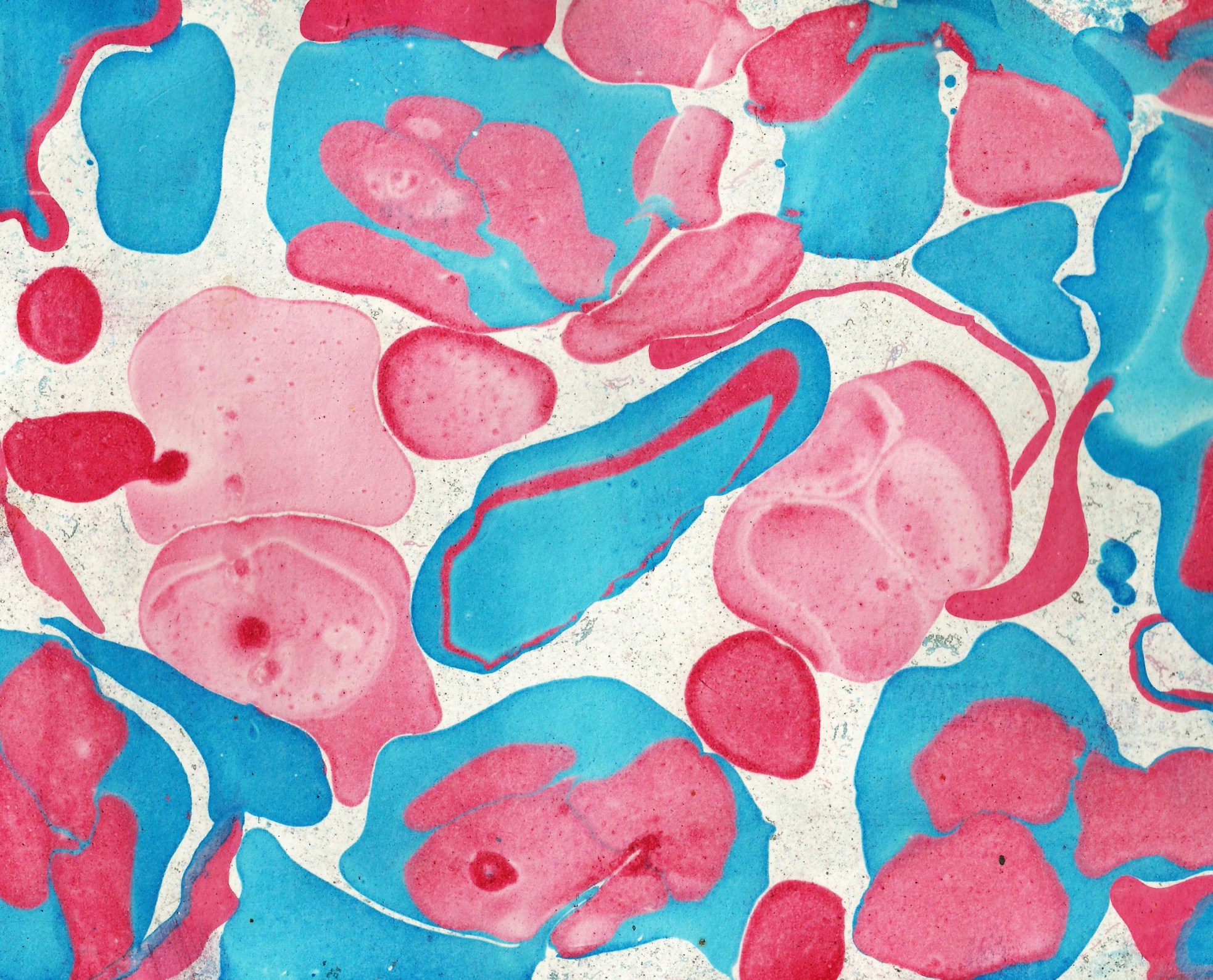
The themes emerging from Curated Care underline that personhood is constructed through complex networks of relations between people, and collective wellbeing accounts for the qualities of life that permeate their communities, regions, societies, and nations. In the remote and rural context of the Highlands and Islands, sustainable integrative care is predicated on individuals' innate capabilities to support each other, and on developing creative ways to curate and share their collective skills and talents in order for people and communities to flourish.

Our participatory approaches to design inquiry are centred on the relationships formed between practitioners, researchers, policy makers and participants whom together determine the scope of the inquiry, identify individual and societal challenges, and in so doing can influence, inform and emancipate citizens and communities. Through research and practice, the methods, tools, and techniques we use, including storytelling, drawing, informal interviews, photography and film, are responsive and chosen – in creative action, in consultation and in collaboration – with people.

This outlines a role for design in making visible the transitory, anecdotal, and often ephemeral accounts of community life that often may otherwise pass unheard or unnoticed, and a means of sharing stories of personhood and collective wellbeing.

Our work on Curated Care is currently informing future research into contemporary concepts of care, addressing loneliness and social isolation, intergenerational relationships, and exploring notions of equality in relation to gender, age, place, and ethnicity at local levels, as well as nationally and internationally. In particular, the theme of kinship is being taken forward by The Glasgow School of Art through their Creative Futures Partnership with Highlands and Islands Enterprise to develop opportunities for enhancing social and economic renewal across a flourishing region.





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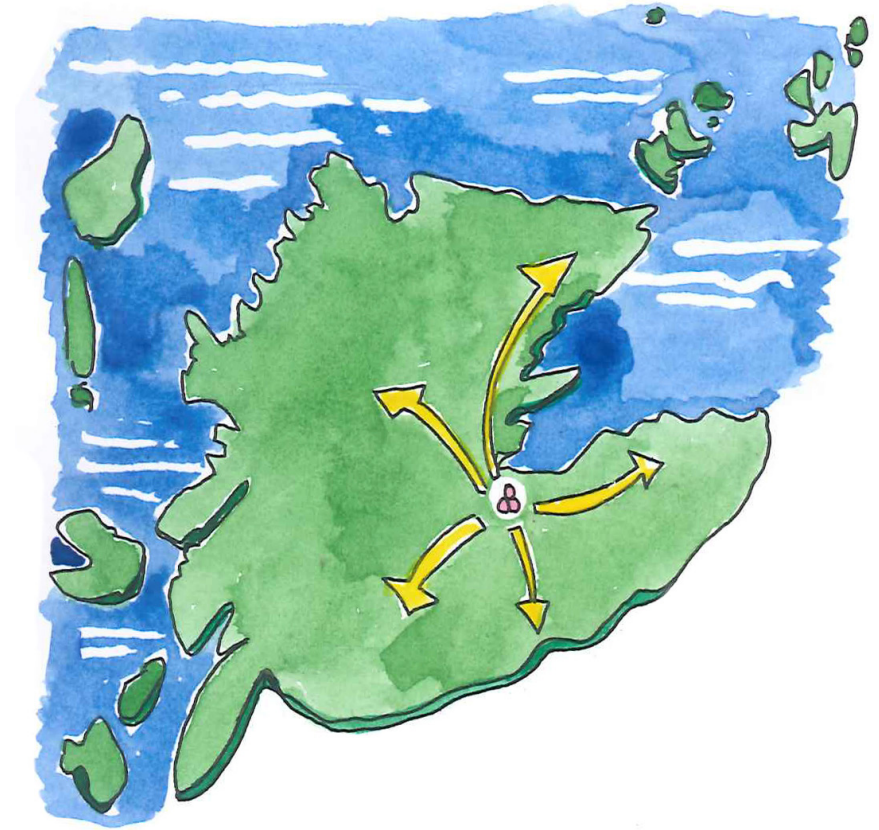
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Kenny Steele, Highland Hospice

George Thomson, Volunteer Scotland

For further information please contact:
l.mchattie@gsa.ac.uk

Illustrations by Cara Broadley



'I was humbled and moved by each of the volunteers' stories and surprised to learn of each person's journey to becoming a Highland Hospice volunteer. From the conversations held throughout this research, it is clear that Highland Hospice volunteers gain as much from their altruism as those they support.'

EMILY PATRICK, VOLUNTARY SERVICES CO-ORDINATOR,
HIGHLAND HOSPICE, 2015

'Being able to show new volunteers the stories and experiences of volunteering gives an insight into the benefits of volunteering and how helping others can help you too.'

MARIA CUTHBERT, VOLUNTARY SERVICES ADMINISTRATION ASSISTANT,
HIGHLAND HOSPICE, 2015



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