

Macmillan Partnership Report 2021

Age UK Cornwall & the Isles of Scilly & Macmillan
Working together to help those affected by cancer



Credit: Macmillan Cancer Support



Credit: Macmillan Cancer Support



Community Helpline: 01872 266383



www.cornwall-link.co.uk

Transport Helpline: 01872 223388



[/AgeUKCornwall](https://www.facebook.com/ageukcornwall)



[@ageukcornwall](https://twitter.com/ageukcornwall)

“You have set me on a journey - a good start to improving my understanding, knowing where to look for further resources and help, and being able to discuss cancer in a professional and supportive way, thank you.”



What we know

The number of people living with and beyond cancer in Cornwall & IOS in 2018 was 26,169 (cancerdata.nhs.uk) 50% of cancer patients survive 10 years or more from diagnosis, (Cancer Research UK data for England and Wales 2010-2011).

Our learning from the initial phases of this programme, informs us that not all communities are able to have open conversations and respond appropriately. Whilst it might not be clinical, or perfect, we are creating people-centred and positive conversations, where people can find and use the right language.

Through engagement with people and communities - we have employed a test and learn approach. This approach has shaped the development of cancer friendly language. This is underpinned by understanding cancer and its impact on a person and their loved ones. We have found a way of conveying this simply and clearly, clinically correct but translated to everyday life and common language.

Our intent is to **share this learning** with others by creating a guide and training/mentoring programme that creates an inclusive and improved experience for those affected by cancer in the Cornish community.

Our programme has also operated against **the backdrop of the COVID-19** pandemic and associated restrictions & controls. This has added yet another dynamic to the test and learn methods we have been able to use. It has emphasised the criticality of language used.

For many, talking and listening has been the only option available. Our approach has not only had to address the isolation experienced by those affected by cancer, it has also been needed to create a sense of reassurance to maintain and sustain positive outlooks.



Why We Do It

By upskilling our organisation, and striving to mainstream activities across our communities, we are creating a sustainable legacy for those affected by Cancer.

Our collaboration with Macmillan has enhanced this journey, giving confidence to have the difficult conversations, developing our listening skills, and learning from a different organisation.

We also work with other organisations who support vulnerable people and those who need a helping hand. This has influenced the development of a collaborative approach to raising awareness of people affected by cancer, and of the work being done by Macmillan. Nurturing links with small local charities, such as St Petrocs, engenders community support within local regions - **building co-produced solutions and better outcomes for the individuals we support.**

Partnership Insights

In 2020-21, our partnership with Macmillan has:

- 1. Appointed a Programme Coordinator** overseeing the milestones of the partnership, its progress and developments.
- 2. Employed two Community Navigators** increasing our reach across the County to increase awareness, offer support and engage with communities.
- 3. Liaised with our partners, community leads and groups, volunteers and staff of Age UK C&IOS** to create and integrate a navigation model that brings sustainable support to people affected by cancer.

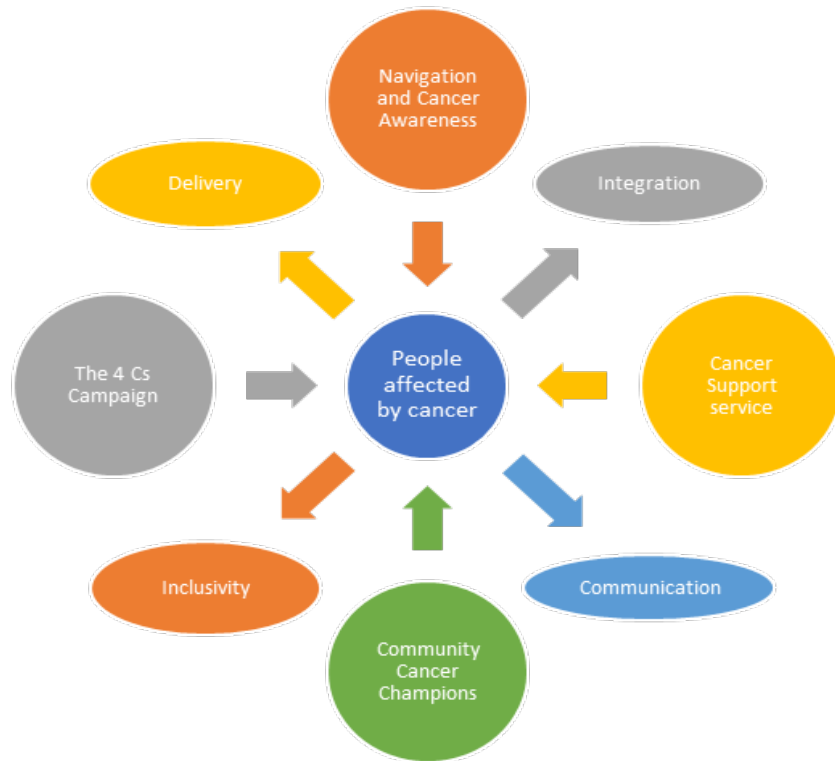
“Working closely with other Age UK Cornwall Services, such as the Inclusion Matters and Information & Advice teams, enables us to respond more fully to the range of physical, practical, emotional and psychological needs of those living with Cancer in a more holistic way to positively impact their health and wellbeing”

Age UK Cornwall, Community Wellbeing Coach

- 4. Developed and facilitated our new online Navigation and Cancer Awareness workshops.** We extended our training as e-learning to create a wider reach across communities in Cornwall and provide upskilling to create Community Champions supporting people affected by cancer.
- 5. Increased our single information point on our Community platform, Cornwall Link,** to include a campaign, [The 4 Cs: Creating Cancer Caring Communities, in Cornwall.](#)
- 6. Provided a Cancer Support Service** that enables people affected by cancer to access the support they need, find the services relevant to them, whilst providing that all important listening ear.



Our Model



As mentioned previously, during 2020-21 our delivery model had to respond to the changes brought about by a worldwide pandemic and three nationwide lockdowns. Our original model planned for 6 Hubs and Drop-ins in specific locations for the East and West of Cornwall.

The concept of these Hubs was not fully abandoned; however, the restrictions and lockdown meant that the sources of our Drop-ins such as libraries, churches and community centres were mandated to close, as were many community support and social groups.

Despite the restrictions, our team demonstrated resilience and responsiveness, created solutions, energised old and new relationships, and engaged with the community to continue support for people affected by cancer in Cornwall.

Our Impact

The following outputs and outcomes were achieved:

- ✓ Developed our Cancer Support Service for individuals affected by cancer.
- ✓ Adapted our Navigation and Cancer Awareness training day as **3 independent online workshops run bi-monthly, giving a more flexible way of learning.**
- ✓ Coached, between Jan 21 & July 21, **37 people in all 3 Navigation and Cancer Awareness sessions with a further 29 attending between 1 & 2 workshops each.**
- ✓ Increased the number of agencies, groups and networks providing support and services on the **Cornwall Link platform by 42 (listings & events).**



Our Impact

- ✓ Responded to and supported **113 clients** through our **Community Navigator Cancer Support Service and Community Cancer Champions**
- ✓ **Launched The 4 Cs Campaign: Creating Cancer Caring Communities, in Cornwall**
- ✓ During a time of increased social isolation and deprivation, our Macmillan Team have developed a Cancer Support Service that enables our volunteer Community Navigators to **support people affected by cancer, increasing their levels of wellbeing and connecting them to crucial services**
- ✓ **The Macmillan team mapped local provision in the 6 Hub areas**, providing insight and information to the wider Age UK C&IOS services, especially the Cornwall Link Covid response team and Age UK C&IOS Helpline.
- ✓ **Developed a network of Community Cancer Champions who take a lead navigation role in their communities;** increased their confidence when speaking to someone affected by cancer and raising awareness of what it is like for those who are living with and affected by cancer.
- ✓ **Our campaign, The 4 Cs, Creating Cancer Caring Communities, aims to build compassionate and caring communities and bring resources and services together under one digital roof** so every person's cancer journey is as stress free as possible.
- ✓ **The Macmillan team provide a connection between those affected by cancer and Macmillan's cancer support services in Cornwall:** The Cove and The Mustard Tree as well as the new Macmillan Telephone Buddy Service



“Our Community Navigators will be your researchers and guides when you’re in a tough place.”



Our non-clinical cancer support service, **available to any adult, 18-plus directly or indirectly affected by cancer in Cornwall, provides that all-important listening ear, finding out what matters to you so you can access the support you need.** We can then signpost you to: Macmillan services and professionals; Age UK Cornwall services and link you with cancer support and social groups in your community (related to cancer or otherwise).

Reassurance - Case Study

A client was referred to our team from one of our Welfare Support Volunteers - via Govenek Active Living Hub. The Client was in her 80’s, and had been receiving weekly welfare calls during lockdown from one of our Age UK C&IOS volunteers.

The Client had been diagnosed with breast cancer at the beginning of lockdown, had been seen at the appropriate Cancer Support Centre and was receiving treatment. She told us that her main concern was that she didn’t know when her course of treatment was due to finish or when her next appointment was. We asked her if she had been given any information on who to contact and she told us that she had.

We talked to the client about The Cove and the help they are able to provide if she wanted additional support. When we called the volunteer a couple of weeks later they said that the client was a lot happier & more upbeat since getting the information she needed and the support.

Hair loss, sight problems and an overgrown Garden

Highlighting the impacts of post-cancer treatment.

When we spoke with this client she explained that hair had not grown back and she was concerned it wasn’t going to. With a compassionate approach, we discussed wig options and asked if she had any information.

She had several leaflets but hadn’t ordered anything as she was unsure what style or colour would suit her and said she would like support in choosing. We talked about the options for wig support, explaining that the Cove would be able to give her the most up-to-date information for this. We were able to support her in finding the guidance she needed in making her choices.

She was also struggling with her vision and was overdue an Optician’s appointment. Previously, she explained that she had home visit opticians, but was unsure if they were currently operating due to COVID-19. We let her know about the home-visit service opticians, this included the company who had visited her previously, and we also provided details of the local opticians that were open if she was unsuccessful getting a home visit appointment.

We talked about her garden, which was overgrown with brambles and discussed Volunteer Cornwall’s Macmillan Gardening services. She was delighted and got in touch with Volunteer Cornwall regarding the Macmillan Gardening service, and they came around to do an assessment. ***She was happy with everything we discussed and the support we were able to give at a time she felt particularly isolated.***

Working Together

[Pam's story](#) is an example of how digital solutions, when complemented with person-centered and specialist support, can reduce social isolation and break down digital barriers.

Pam, 74 years old, was referred to the Macmillan Community Navigator Team, with the idea of accessing the internet to overcome her social isolation. Pre COVID-19, Pam took 5 trips out a week, but those had unfortunately stopped because of travel restrictions and self-isolating/shielding. Pam lives alone, and though she has a brother living in London, she had no family living nearby.

Pam had been personally affected by breast cancer and lived with on-going health conditions, some of which affects her mobility. She lived in rented accommodation, so was limited as to what could be installed in her home. She had no previous ICT experience but did own a basic mobile phone (not a smartphone).

By **working together with one of our Inclusion Matters partners, Digital Inclusion, we were able to provide the resources, individual training and 1-2-1 support she needed to get online.** Giving Pam support through the learning, and reassurance of going online, which helped her build confidence, reduced her social isolation and gave her new skills.

We are very sad to announce the passing of Pam, but we know her legacy will be the inspiration for others to reach out

Community Stories

During lockdown, when Drop-ins were still closed, the team shared community stories on our Age UK C&IOS community platform, Cornwall Link, to reach out and support those affected by cancer.

Here is an example of one of those stories shared during Breast Cancer Awareness month

Breast Cancer Awareness

Raising awareness for people affected by breast cancer - a woman shared her journey through breast cancer to help “**others gain an insight into what their journey may contain...**” and to support those in the Cornish community affected by cancer.

[Click here to read this story](#)



“I didn't know how much I was missing! It's one of the most wonderful things ever done for me. It's brilliant, a godsend.”



Age UK Cornwall & Isles of Scilly Cancer Support Services in Action



Making a difference

The Macmillan Team hosted a socially-distanced Macmillan's World's Biggest Coffee Morning at Boscawen House, Truro. Staying inclusive, the team invited all staff and volunteers onto a Zoom session so everyone could feel involved. Whilst we couldn't hold the event in a busy street, we still managed to share some light-hearted banter and happiness with anyone who wanted to join in.

“It was really great to see Truro Launderette and MBA consultants drop by for a cake or two.”

The team successfully raised awareness of cancer in the community and involved several local businesses to reach people affected by Cancer. A person known to the team shared their personal experiences, and the navigators were able to offer continued support and guidance on the day, listening to how her experience had progressed.

A local builder shared he had previously been homeless and how St Petrocs had supported him to get back on his feet. He thought it was incredible how our two charities were teaming-up.

A friend of one of our Community Navigators had made a wonderful cake for the coffee morning, which was donated to St Petrocs, a local charity working to end street homelessness in Cornwall.

Age UK C&IOS staff also fed back it was great to have a feeling of 'normality' again, in a really informal way; having a natter, eating cake whilst ultimately, making a difference. Sharing and supporting one another is a vital need for all of us, especially those affected by cancer (either personally or otherwise).



“On behalf of us all at St. P'S a sincere and heartfelt thank you for including us today. To you and your colleagues you will never know how much this cake has meant.... god bless yer.”

Steve CEO St Petrocs

We worked with Macmillan to develop and provide training as part of our partnership strategy. By upskilling our organisation and striving to mainstream activities across our communities, we are building on impact to create a sustainable legacy for Cornwall. Creating bridges and connections between clinical, community and individual needs.

With the advent of the online trainings sessions we have engaged with partners, community groups and other charities who have maintained a presence, thereby supporting local activity throughout the pandemic - increasing their skills and knowledge through training. These include: **Age UK C&IOS Staff & Volunteers, Man Down facilitators, St Petrocs' staff, Cornwall Council Mobile and Micro Library Service volunteer drivers, Social Prescribing Link Workers, Inclusion Matters Community Coaches, The Fishermen's Mission, Sports Therapists and Charity Shop managers.**

Navigation Training

Our fully-funded workshops are interactive sessions delivered by Judith Clapp, Macmillan Primary Care Nurse Facilitator, and the Community Navigator team. These sessions are designed to increase confidence and skills for professionals, volunteers and anyone dedicating their time and effort to their community, to improve support for people affected by cancer across the county.

An introduction to Cancer: Covering some of the basic clinical elements of cancer, improving your understanding of key medical terms and providing an overview example of a cancer journey.

Psychological & Social Impacts of Cancer:

Exploring the many thoughts and feelings that can be provoked by cancer both for the person affected and those around them and thinking about ways to manage these.

Good Conversations, Information & Signposting:

This element of the training is designed to enable you to learn about sharing available resources and finding information to support people affected by cancer. It will also help to reduce fear and improve confidence to talk about cancer.

“Excellent sessions, thank you Judy and Ellen.” **Emma**

“This has been so useful and has provided us with lots of resources.”

Angela

- Results of Questionnaires & Feedback -

What worked well

- The caring approach** – of those who presented the course
- Not having to travel!**
- The form of delivery** - was enjoyed, despite it being such a heavy topic.
- The informal, interactive format and knowledge of the presenters**
- Removing the ‘Fear’** – about cancer and those living with a diagnosis as positively as possible.
- The structure of the course**
- It was focused & concentrated** - to the point, informative - with no side-tracking

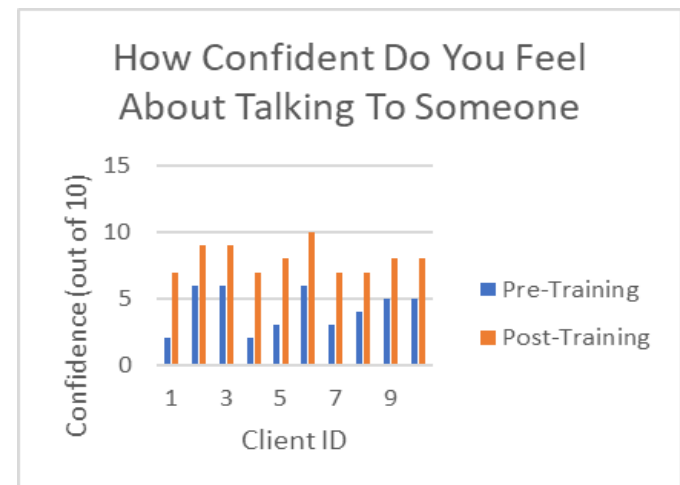
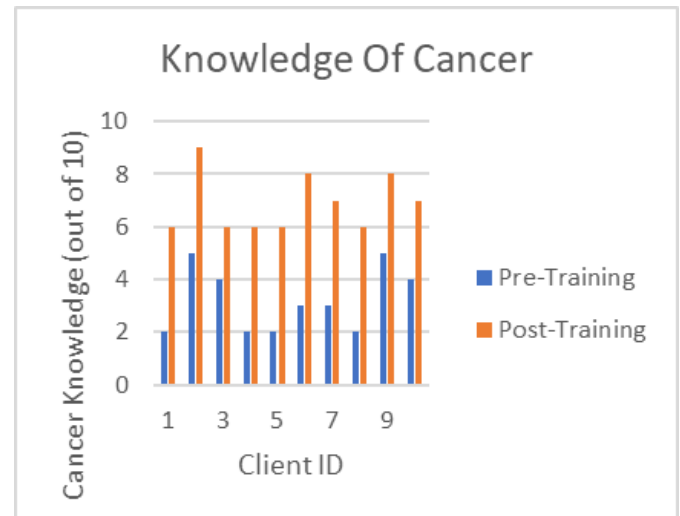
“This was a delight to attend, a refreshing change to the waffly courses/talks I normally end up sitting through without learning much. Well done. The Power Point slides worked well too.”

Ideas for the future

- ✓ **Update participants on resources available** - offer annual refreshers based on changes to local provision/support and best practice
- ✓ **More widespread sharing of information** - especially the impact that physical activity can have at all points of a persons journey, pre-treatment, during and post.
- ✓ **Meeting everyone who participated in our virtual sessions**

What we have learnt

- ✓ Some of you didn't enjoy having to train digitally **but appreciated the virtual sessions under the circumstances** but would love to meet face-to-face as soon as the regulations allow
- ✓ Some of you had prior knowledge of the content in our information and signposting session **so we are revising and improving the content for future sessions**
- ✓ You enjoyed the opportunity to have the information **broken down over several weeks** as opposed to taking it all in over one day
- ✓ Your knowledge of cancer increased overall from pre to post training, **with many showing a significant increase.**
- ✓ Your confidence in talking to people affected by cancer increased overall **from pre to post training, with some showing a significant increase.**



Your feedback shows you felt you had gained:
100% better understanding of the Age UK CIOS/ Macmillan role
80% better understanding of a typical person's journey and diagnosis
100% knowledge of useful resources to help support someone affected by cancer
80% greater confidence when talking to someone affected by cancer
70% improved knowledge of the clinical presentation of cancer

"I will be able to apply your advice to discussion of other long-term health conditions and life-limiting illnesses too - thank you.



The 4 C's Our Campaign

Our strategy is to be responsive to community needs, engage and support communities to change their culture, and create empowered and compassionate localities.

Our Age UK C&IOS partnership with Macmillan has provided us with a wealth of learning to support people affected by cancer within our community. We knew that with community involvement we could increase this vital support.

Here in Cornwall, we have fantastic resources and services for people affected by cancer. Our campaign, Creating Cancer Caring Communities, aims to share those resources and services under one digital roof, whilst providing a digital community space for health professionals, carers and people to access, and creating Community Cancer Champions, to increase our support for people affected by cancer.

Our Aims and Ambitions

Sharing Cancer Resources and Services in Cornwall - We need to bring resources and services together so every person's cancer journey is as stress-free as possible.



Increasing Membership and Support for the Campaign - Cornwall Link provides us with the platform to build a membership of health professionals and community to keep people affected by cancer up-to-date with events related to cancer and link them to cancer support services in Cornwall, all under one digital 'roof'.

Creating Community Cancer Champions

- Who take a lead navigation role for their community and increase social inclusion
- Have increased confidence when speaking to people affected by cancer
- Help strengthen collaboration between health professionals and people actively engaged in their community
- Help raise awareness of what it is like for those who are living with, and affected by, cancer

Jacqui, Macmillan Cancer Support:

"Our collaboration enables us to raise awareness of the issues faced by those affected by cancer and the services available to them from the NHS, but also the support available from our partners in the voluntary and community sectors.

The Macmillan/Age UK Cornwall and the Isles of Scilly project team aim to spread information, knowledge, learning and support to improve the lives of those people affected by cancer and are leading on this exciting campaign to build on the work we have already done, offering more individuals and groups the opportunity to get directly involved in the creation of Cancer Caring Communities locally.

I wish the campaign every success and look forward to seeing how things develop further."



Maria

Programme Coordinator

My journey in this wonderful partnership began as a Community Navigator, in the days where Drop-ins were held in libraries and community centres, and training was an all-day event in our Age UK C&IOS training room with shared banter and a free lunch! I loved the face-to-face interactions and community engagement, along with all the networking.

In March 2020, I was offered the post of Programme Coordinator I was overjoyed and so excited about the prospect of managing a team of Community Navigators who would: expand our delivery from 3 to 6 Hub areas, develop online training and increase our reach across Cornwall to support people affected by cancer. I was buzzing with ideas.

Whether it's Laughter or Tears

And then, on March 23rd 2021, the announcement came of a National Lockdown and, where possible, to work from home. My work-life was tipped on its head as communities faced the world's worst pandemic crisis. Like many other people my role changed from coordinator to one of Covid-responder, whilst also managing the changes the pandemic brought to the Macmillan partnership.

Initially I did a bit of everything, from providing transport for patients to writing for our, then, dedicated COVID-19 Cornwall Link platform. A large chunk of my time was also spent providing Telephone Support and Welfare Calls.

"Thank you for your call Maria, it makes a huge difference to me and shows you care."

My Macmillan role continued: developing a new programme delivery model, taking on and managing the new Community Navigators in the West and East of Cornwall, mapping services and gaps in provision, re-working our Drop-ins to become a Cancer Support Service, our full-day training programme to become the new 3 online sessions and developing the campaign space on our community platform, Cornwall Link.

I cannot say enough how proud I am of my team of Community Navigators who worked tirelessly beside me. Their dedication, determination and creative solutions were the bed-rock for the new virtual Macmillan partnership. The teamwork and bond created, at a time when we were working in isolation, only coming together as a team when easing allowed, was beyond compare.

And none of this could have been made possible without the support from our Macmillan Project Team who helped us resolve problems, provided the information we needed and helped to lift our spirits when times were tough.

In the face of the challenges the pandemic brought to the team, in both a professional and personal way, I still can't quite believe the results: a revised service that has supported many people affected by cancer throughout lockdown; an excellent online version of our Cancer Awareness and Navigation training; and a brand-new campaign, The 4Cs, that sits in the heart of our community platform with the invitation to 'create cancer caring communities'.

My colleague, Debbie said last year, 'It's what we do'. I would go further than that and say, 'It's what we do - above and beyond'.

[Whether it's Laughter or Tears by Maria - read the full story here...](#)



Judy

Macmillan Primary Care Nurse Facilitator

My job title is Macmillan Primary Care Facilitator and I have been in post for 6 years; a post which was originally funded for 2 years by Macmillan and managed in partnership with Royal Cornwall Hospital Trust.

My role is not clinical, but focused on improving pathways, processes, knowledge and communication, to help us to improve care for cancer patients throughout their journey. Prior to this role, I worked in Oncology and a Hospice - and was a Practice nurse for 27 years.



My role

The Macmillan Primary Care Nurse Facilitator role aims to:

Support the development of policies and procedures relating to cancer care from early diagnosis to end of life care

Improve communication between primary and secondary care

Promote the importance and awareness of earlier stage at diagnosis

Support and develop education and training for GP's and other health professionals in relation to cancer as a Long-Term Condition

To educate and raise awareness in people, working and volunteering in communities about cancer, and support that may be needed

I am very proud to be part of the Macmillan partnership with Age UK Cornwall and the Isles of Scilly. I have been providing the clinical stream of education in an easily accessible format since the start of this partnership, delivering the two online workshops: An Introduction to Cancer and The Psychological and Social Impact of Cancer.

"I thoroughly enjoy the challenge of trying to improve the way cancer care is delivered across the whole of Cornwall not just for one group of patients"



Linda

Community Navigator

Having joined the team at the very beginnings of the first national lockdown, we were all learning to adapt and be flexible from day one! It's been one of the common themes for everyone during this pandemic, personally and professionally.

Whilst we couldn't venture into the community hubs as planned, we reached out to them via other voluntary organisations who were still active (such as community larders); telephone calls; our contact networks; and of course virtually with Zoom and MS Teams. We also took the opportunity to research our areas and better understand its dynamics e.g. demographic, geography, history etc. Whilst not necessarily making as many in person contacts as we had originally planned, we have raised awareness of our team and training to a much wider community, arguably more so than if we'd only had a hubs presence. There is also a huge potential to engage businesses in our virtual training which will additionally help achieve our 4C's campaign goal.

I've had many memorable conversations with people affected by cancer, from a gentleman on a UK wide trip who was diagnosed whilst travelling in Cornwall, to a family facing the arrangements for end of life care and the impact that would have on a multi generational home.

We've also highlighted community stories including Pam, a lady in her 70's who was incredibly socially active before lockdown, who found herself isolated overnight because of COVID-19, now IT active. Not only did this open her social and learning wider than before, but helped us gain her trust and thus identify other areas of her life where we could give her additional support, especially in collaboration with our IM partners. Our first online video call had us both smiling! I'm often humbled by the resilience, good humour and positivity of people who find themselves in incredibly difficult times and facing difficult decisions, and honoured to have been part of a team who have helped empower them as part of that journey.

Whilst I'm no longer part of the Macmillan Team, and now overseeing Cornwall Link, I'm looking to find ways in which it can support and inform people affected by cancer (both as health professionals and individuals undertaking their own research). It's all about listening, choice and flexibility.

Finally, I'd like to thank Macmillan for the wealth of learning opportunities given to us as navigators and how impactful that has been. It's made us better able to fulfil the role and reassured us there is support for us too.



Programme Summary

The COVID-19 pandemic was not only in itself unprecedented, but also the world and environment which it forced us in to, lockdown restrictions, isolation, no travel, mandated closures of shops and community buildings with their associated activities as well as untried and untested large scale virtual working.

It tested people's resilience, compliance and very existence in a way not experienced since the second World War, it also put immediate enormous pressure on societal and work infrastructures. It was at this time our Macmillan project launched, right in to the heart of global crisis.

It is testament to all involved that we were able to recruit two new Community Navigators during this time, adapting to a virtual way of recruitment and appointment. They themselves demonstrated remarkable patience, flexibility and resilience in completing their induction whilst at the same time initiating the project.

Our programme coordinator and community navigators experienced a moment of hesitation when it was realised that the world was not going to return to normal after twelve weeks, as everyone had been led to believe. However, proactive consultation with the senior responsible officers in both organisations created the co-production of a revised delivery model and programme that would accommodate the overall outcomes of the MIA.

It wasn't perfect at the outset, but each evolution has been its own test and learn. Shaping not only the delivery method, but also reshaping the outcomes required to broaden the reach of the project.



A continued success

The project has been incredibly successful in identifying new ways of engagement and implementing them in COVID-19 secure way with significant and positive impacts.

It has created a new rhythm of providing support across the team, the organisations, communities and the individuals supported. Whilst we are repeating the rhythm, we are bringing new players in all the time to build the tempo and vibrancy so it can continue beyond the life of the project.

What started out as a daunting and COVID undermined project, quickly morphed into an exciting and far-reaching service of immense value to those affected by cancer and those who work to support them.



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With thanks to our supporting partners, fundraisers & volunteers, who all add so much to improving the wellbeing of older people in later life
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