helpforce

End of Life Care

October 2021

Contents

All photos shown for illustration purposes only and were taken before the Covid-19 pandemic.
Please note: none of the photos were taken at organisations that were part of this programme.

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Introduction

End of life care (EoLC) volunteer services promote the core NHS values to care for people 'from cradle to grave', and dignified and human care for those in their last moments of life so 'no one dies alone'. Companionship at the end of life from specially-trained volunteers means staff can focus on delivering excellent clinical care and on medical priorities - safe in the knowledge that a volunteer is giving emotional support and comfort.

Executive summary

A combination of expertise - Helpforce's in volunteering and Marie Curie's in palliative care resulted in funding for and development of a companion model of volunteering for people dying in acute hospital settings across the UK.

The ambition for this programme was to identify, enhance and spread a series of impactful volunteer EOLC services supporting front-line service provision across the NHS, particularly focused on services that improve the well-being and experience of patients, staff and volunteers and improve efficiency or effectiveness of services. Locally driven, evolved in partnership with NHS and voluntary sector partners, the projects will be shared nationally.

Seven Trusts and Health Boards across the UK set up or developed current EoLC volunteering services as a result of the project. They started work in July 2019 and without exception, all were affected by the Covid-19 pandemic from March 2020. Some were able to respond to the changing environment, adapt their original plans, and develop a different delivery model. However, others were completely paused as a result. The project funding was completed in July 2021.

The projects have not yet achieved what they originally set out to as many of them have only recently restarted. However, the dedication of staff and volunteers to continue to provide these services has resulted in commitments to continue after the initial funding ends.

This report gives a snapshot of how the services were set up and progressed, the challenges they have faced and the lessons they have learned. The report - coupled with service guides and case studies for each project - will leave a robust legacy for other Trusts and Boards that want to adopt a similar approach to EoLC volunteering.

The volunteer response during the Covid crisis was unprecedented. Many hospitals decided to stand down their volunteers as a safety precaution. Those who managed to keep volunteers on site found their contribution invaluable. The lasting legacy of this response must influence how volunteers are viewed in future workforce planning.

What were the project's original aims?

1. Introduce at least one EoLC volunteer service in each of the four nations (three in Wales, one in Northern Ireland, one in Scotland and one in England), delivered by the participating Trusts and Health Boards with support from Helpforce and Marie Curie.

2. Develop and deliver an integrated evaluation programme to sit at the centre of each volunteer service model, to help improve the service and demonstrate the value the service brought to patients, family and friends, volunteers, staff and the NHS.

3. Develop a training and quality measurement framework/model that wraps around the service models ensuring the quality and sustainability of services. Marie Curie was tasked with delivering 'train the trainer' sessions to Trusts and Health Boards.

4. Package up the EoLC models to enable effective scaling across the NHS.

5. Develop and deliver a marketing, communications and PR plan to share the benefits of the partnership and the learning from the EoLC volunteer service models.

The impact of Covid-19

The Covid-19 pandemic had a significant impact on the volunteer services within the project. For at least six months from March 2020, the EoLC services were paused. Volunteers were either stood down completely or only able to work remotely.

The participating Trusts and Health Boards showed considerable flexibility and resilience in the face of these challenges and did what they could to adapt their services. The result was implementation delays and the introduction of different service models than originally planned.

Project funding

Each participating Trust and Health Board received grant funding to help them implement their EoLC volunteer service.

The funding for the project came from:

- Marie Curie, supporting projects across the UK
- The National Lottery Community Fund, supporting projects in Wales, Northern Ireland and Scotland
- The Welsh government
- The Peter Sowerby Foundation , supporting the overall project and implementation in a single UK location

> *"Volunteers who stepped up in such challenging times to be involved in such a worthwhile service providing invaluable support to families faced with bereavement is immeasurable. The bereavement comfort call volunteers and the team involved are such an inspirational group of people and I feel honoured to have been part of something special."*
>
> VOLUNTEER NOW, MANAGER – HELPFORCE REPRESENTATIVE AND MEMBER OF THE NORTHERN HEALTH AND SOCIAL CARE TRUST'S BEREAVEMENT COMFORT CALL SERVICE STEERING GROUPS

Choosing services to take part in the project

Trusts and Health Boards were invited to apply to participate in the project. Both existing services that wanted to develop and new services starting from scratch were eligible.

Deliverables from the project

For each service we have produced a a service guide and/or a case study. These will support scaling these models of end of life care going forward. They will also be useful for other Trusts and Health Boards that want to adopt similar services.

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The organisations that took part

Northern Health and Social Care Trust

(NORTHERN IRELAND)

GIG CYMRU NHS WALES
Bwrdd Iechyd Addysgu Powys
Powys Teaching Health Board

(WALES)

NHS
West Hertfordshire Hospitals
NHS Trust

(ENGLAND)

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Hywel Dda University Health Board

(WALES)

GIG CYMRU NHS WALES
Bwrdd Iechyd Prifysgol Aneurin Bevan University Health Board

(WALES)

NHS
Borders

(SCOTLAND)

NHS
York and Scarborough Teaching Hospitals
NHS Foundation Trust

(ENGLAND)

Initially all Trusts and Health Boards planned to deliver an on-ward model of EoLC volunteer support. However, they had to adapt service models in response to the pandemic.

The service models introduced were:

Northern Health and Social Care Trust (NHSCT) - bereavement comfort calls service

Northern Health and Social Care Trust in Northern Ireland developed its bereavement comfort call volunteer service to enhance bereavement support for loved ones of those who die in hospital.

After somebody dies in hospital within the NHSCT area, a volunteer will make contact within 3-7 days to offer condolences and support. Bereaved families are given information on practical issues and on grief and bereavement, and can be sent a bereavement pack. The service also provides signposting to voluntary and community support organisations, and offers families the option of a follow-up call by the Trust chaplaincy service.

Powys Teaching Health Board - virtual companion model

Powys EoLC companion volunteers provide support to patients at the end of life, including those who lack family support/visits and are at risk of dying alone. They also support patients' families and friends. Support takes the form of a phone or video call and includes signposting to local community support services.

The virtual companion model was introduced across three community hospitals (four wards) with the potential and ambition to develop the service across more sites.

West Hertfordshire Hospitals NHS Trust - Rose Volunteers companion service

Specially-trained end of life volunteers (known as Rose Volunteers) provide companionship and support for patients at the end of life, and their families, across all wards throughout Watford General Hospital. The service aims to improve the hospital experience for patients and their loved ones during the last days of life, while allowing staff to focus on providing excellent clinical care.

Hywel Dda University Health Board - virtual companion model

Hywel Dda Health Board developed a companion EoLC volunteer service - named 'Llaw yn Llaw'/'Hand in Hand' to reflect the service's values that 'no one should die alone'. It delivers a virtual model operating across a 14-bed community hospital ward. Volunteers provide emotional and practical support to patients using iPads to connect with patients on the ward and/or the patient's family or carers.

Aneurin Bevan University Health Board - companion volunteer service

Aneurin Bevan University Health Board's EoLC volunteer companion service provides emotional and social support to patients approaching the end of their lives and their families. This includes patients who lack family support or visits and are at risk of dying alone. Companion volunteers provide respite breaks for family and friends from the bedside vigil, offering assurance that their loved one is not left alone, and signposting to chaplaincy and bereavement support.

NHS Borders - hybrid volunteer service model

Borders had a delayed start to developing their EoLC volunteer service. They appointed an EoLC project officer in March 2021 to develop a companion volunteer service for patients and those important to them in the last days and hours of life. The service is being piloted within the Margaret Kerr Unit (MKU) at Borders General Hospital, before being rolled out to the acute wards engaging with the MKU Hub. Companions provide support on the ward and are being trained to support and facilitate virtual visit calls between patients and loved ones.

York and Scarborough Teaching Hospitals NHS Foundation Trust

The York service model involved the deployment of on-ward volunteers. Ongoing delays to volunteers returning to wards following Covid-19 resulted in the project not proceeding.

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Project oversight and implementation

To its support design and implementation, each volunteer service had:

- A steering group to guide the design of the project and provide oversight
- An EoLC working group to help implement the project
- A Helpforce programme manager, who worked closely with the Trusts and Health Boards to help them develop and implement their EoLC services. This included 1-2-1s with EoLC programme leads, facilitating quarterly cohort support group meetings where all the participants could discuss their projects and share good practice and challenges - particularly related to measuring impact
- Working with steering groups and programme leads, Marie Curie provided service design advice and train the trainer support, utilising their experience in supporting end of life volunteering. The comprehensive training programme covered a variety of topics including, patient confidentiality, safeguarding, communication skills, death, dying and bereavement.

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Insights and Impact

EoLC support presents some specific challenges when it comes to evaluation:

Unlike many other health-related services, EoLC support is provided to patients whose health is not expected to get better. As a result it is difficult to demonstrate benefits to patients' health.

Getting feedback from patients who are in a lot of pain, and heavily medicated, isn't always possible, or appropriate.

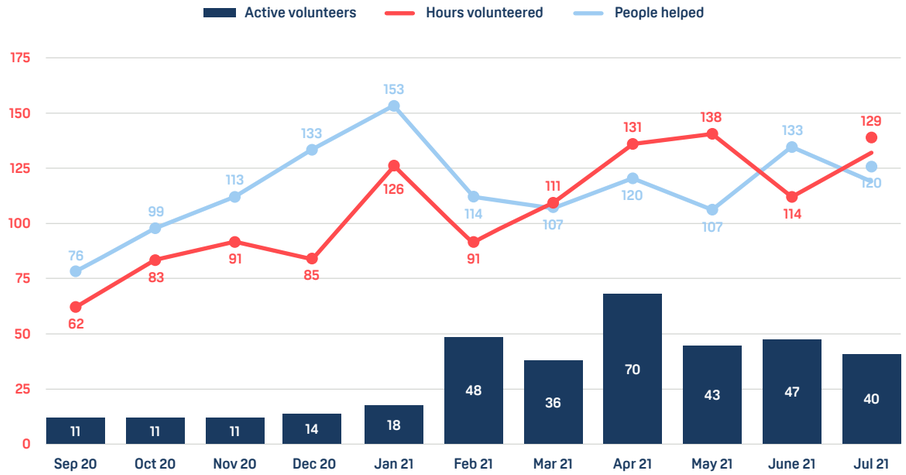
Staff and volunteer feedback and family or carer feedback often seem to be the most realistic avenues to explore.

The Covid-19 pandemic and the resulting delays mobilising volunteers into the roles resulted in poor progress against intended targets, but the services did make some progress.

As part of the evaluation, Trusts and Health Boards were encouraged to gather activity data for their respective EoLC services on a monthly basis. Returns weren't always forthcoming, and in some cases, where they were received, they contained very little evidence of activity (largely because volunteers had been stood down).

As a result the data for the programme as a whole is patchy, but based on what was received we believe that the programme helped at least 1,275 families and carers between September 2020 and July 2021. During the same period there were an average of 20 active volunteers working across the programme each month and they provided a total of 1,159 hours of volunteer time to programme-related activities.

VOLUNTEERS, HOURS AND PEOPLE HELPED



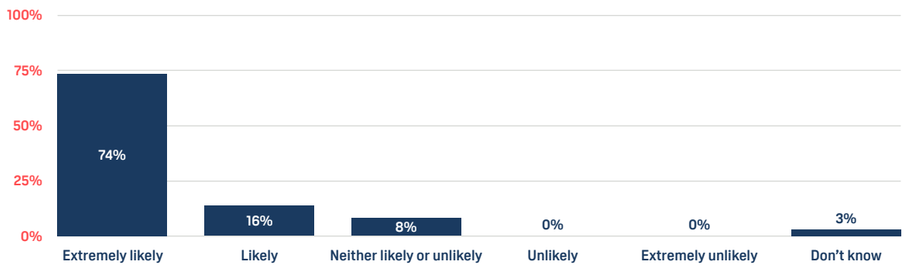
Note: 'People helped' is a sum of beneficiaries supported (families and carers), end of life patients supported, palliative care patients supported and last days of life patients supported.

Volunteer and staff surveys were developed to help the participating services capture feedback. Where these surveys were used, the feedback was largely positive.

A total of 38 volunteer survey responses were received from NHSCT, West Hertfordshire, Aneurin Bevan and Hywel Dda. Only West Hertfordshire staff completed the staff survey (16 responses were received).

As part of the volunteer survey, respondents were asked if they would recommend volunteering at the Trust to friends and family. Across the four projects, 89% of volunteers were either extremely likely or likely to recommend the volunteering experience.

HOW LIKELY ARE YOU TO RECOMMEND VOLUNTEERING AT THE TRUST TO FRIENDS IF THEY WERE TO VOLUNTEER?

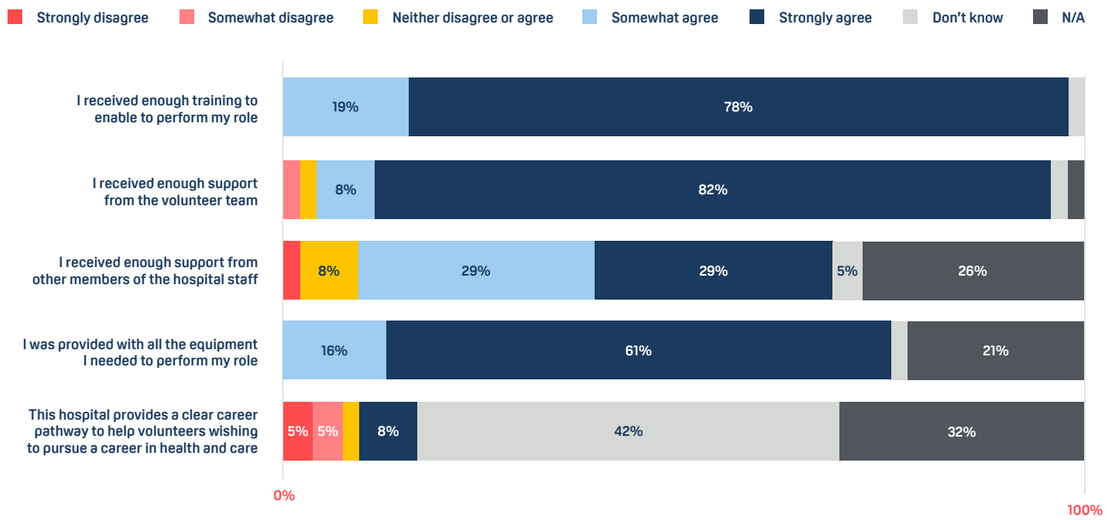


Note: Figures are based on 38 volunteer survey responses. All totals have been rounded so they do not sum to 100.

> *"Our companion volunteers feel privileged to share those precious moments with our patients and we greatly value this extraordinary service that has such an immediate and direct impact on patient care."*
>
> LEAD NURSE FOR PATIENT EXPERIENCE AND PUBLIC PARTICIPATION, WEST HERTFORDSHIRE HOSPITALS NHS TRUST

> *"I am delighted to share my skills, experience and knowledge for this hugely important initiative supporting people who may be feeling frightened and isolated. Acting compassionately does not need an expert – the most valuable thing is that the person does not feel alone and that someone cares."*
>
> CLINICAL SKILLS TRAINER FOR END OF LIFE COMPANIONS, ANEURIN BEVAN UNIVERSITY HEALTH BOARD

TO WHAT EXTENT DO YOU BELIEVE THE FOLLOWING STATEMENTS TO BE TRUE?



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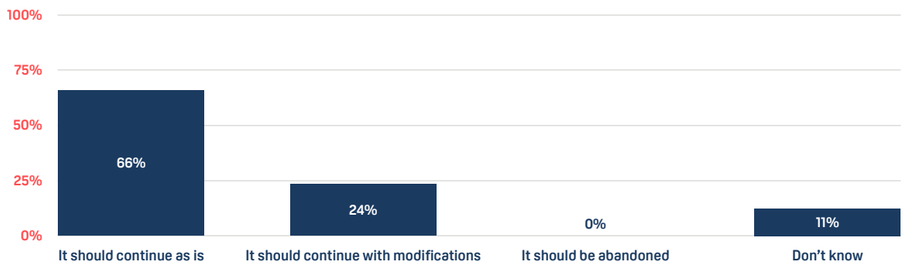
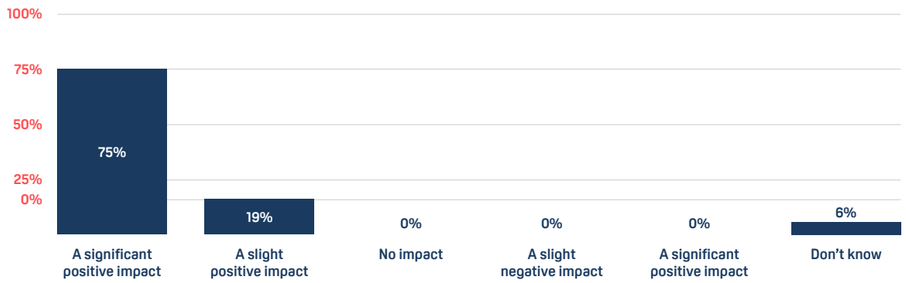
Volunteers were asked to reflect on what should happen next to the service they were helping to deliver. Although feedback was positive, it is interesting to note that 24% of respondents believed their service would benefit from modifications.

IN YOUR OPINION, WHAT DO YOU BELIEVE SHOULD HAPPEN NEXT IN RELATION TO THIS VOLUNTEER SERVICE?



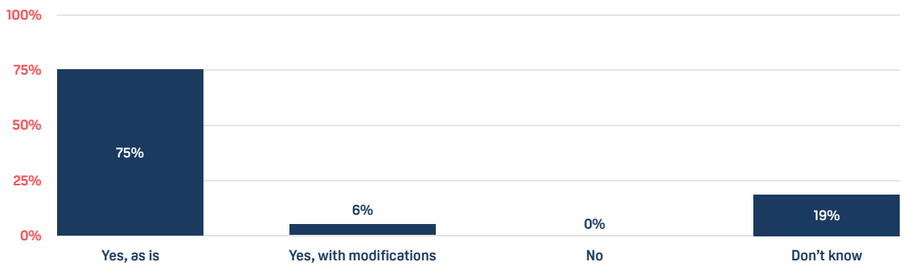
West Herts asked staff who had experience of working alongside EoLC volunteers to complete our staff survey and received 16 responses. 75% of these respondents told us they believe the volunteers had had a significant positive impact on the quality of the service provided to palliative care patients and patients at end of life.

WHAT TYPE OF IMPACT DO YOU BELIEVE THAT THE INTRODUCTION OF VOLUNTEERS HAS HAD ON THE QUALITY OF THE SERVICE THAT YOUR ORGANISATION PROVIDES AND TO PALLIATIVE PATIENTS AND PATIENTS AT THE END OF LIFE?



The staff at West Herts were also asked if the volunteer service introduced as part of the project should be retained. 75% were happy with the service and saw no reason to change it.

DO YOU BELIEVE THAT THE VOLUNTEER SERVICE INTRODUCED AS PART OF THIS PROJECT SHOULD BE RETAINED?



> *"Staff on the wards do not always have the amount of time needed to sit and chat with patients. Even if patients have visitors the day can seem long, lonely and overwhelming. Having a companion volunteer service gives our staff peace of mind knowing that people are not alone. It helps us to improve the care we give to our patients, relieves pressure off staff and improves staff wellbeing."*
>
> WARD SISTER, HYWEL DDA UNIVERSITY HEALTH BOARD

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In addition to the surveys created for this programme, all projects were encouraged to capture ad hoc comments and suggestions from service users, families and carers, staff and volunteers.
This was valuable feedback which we have used to enhance our EoLC service guides.

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Key considerations

From our work with Trusts and Boards over this this project, we can share the following thoughts:

- Virtual support at an end of life may not be a like for like replacement for face-to-face support. Further work is needed on this but early feedback from volunteers in this programme is that the technology can be cumbersome and using it can make it more difficult to build a relationship. However, it is worth noting that feedback from a separate volunteer-led service has shown that the technology can work well for clients and it is possible to build rapport in some types of delivery models.

- Specialised training and ongoing supervision for volunteers is essential when it comes to retaining volunteers.

- Senior Board-level support and buy-in for the project is essential, as was demonstrated when the projects had to respond to the pandemic. The Northern Health and Social Care Trust was able to remodel its original service to a bereavement support service at short notice as an effective steering group chaired by the director of nursing was in place.

- Embedding the role that volunteers can play in the Trusts' and Boards' end of life strategy helps to ensure that the full potential of volunteer contribution is realised.

- Monitoring progress and evaluating impact is vital. Tracking volunteer activity is a worthwhile exercise, if only to demonstrate to key stakeholders that there is a demand for volunteers. Where projects do not have access to a volunteer management system to capture this information, processes should be introduced to monitor this. It is particularly important to design an evaluation approach in collaboration with clinical staff and ensure that they are involved with both implementation and progress monitoring. Gathering both qualitative and qualitative data is also important.

- More work is needed to ensure that volunteers are viewed as part of the workforce so they can continue to operate regardless of the environment.

> *"It is very apparent that the work they undertake as end of life companion volunteers is emotive and at times challenging. It is clear that they make a valuable contribution to the care we offer our patients and to our wards. In the counselling support sessions, volunteers have fed back that ward staff are very grateful for support they offer."*
>
> PERSON-CENTRED CARE MANAGER, ANEURIN BEVAN UNIVERSITY HEALTH BOARD

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Conclusion

All the organisations that signed up to this project had clear visions of how their new EoLC volunteering services could develop to enhance the experiences of patients, families, friends, carers and staff, and to ensure 'no one dies alone'. The Covid pandemic significantly impacted their original ambitions.

Key to delivering a successful EoLC volunteer service was the ability to pivot to the changing environment and adapt their model to respond efficiently to the ongoing needs of staff, patients, families, friends and carers. This included standing down and removing all volunteers from wards.

Core to each service was having a dedicated volunteer service co-ordinator or service manager. In some cases staff took on management of the EoLC service in addition to an existing role, while in others co-ordinators or managers were recruited specifically to support the EoLC volunteer service. Co-ordinators and managers worked on recruiting volunteers, developing promotional material for the service for staff, patients and families/carers, supporting volunteers and delivering comprehensive, bespoke EoLC training.

All the services identified forming a steering group made up of key stakeholders to inform and help develop their service and make important decisions as a key piece of best practice. This was crucial for decision-making in response to Covid. A good example of this was Northern Health and Social Care Trust deciding to develop a new volunteer service to support bereaved families/carers/friends.

Another key to services' success was developing a clear EoLC volunteer role description describing core tasks and training and support provided.

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Acknowledgements

The project team would like to thank the Trusts and Health Boards that took part for their flexibility.

We recognise that when faced with what in many cases were significant barriers to implementation, they adopted a very constructive approach to make sure their services continued making progress.

In particular, we would like to thank:

Sir Thomas Hughes-Hallett
Chair, Helpforce

Maeve Hully
Director of Volunteering, Helpforce

Professor John Ellershaw
Clinical Director at the Directorate of Palliative Care, University of Liverpool

Julia Bearne
Marie Curie, Community Engagement and Development Manager Caring Services

Andrew Wilson-Mouasher
Marie Curie, Director, National Programmes and Place Based Systems Caring Services

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Coordinate my Care and Palliative Care Consultant at the Royal Marsden NHS Trust

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Palliative Care Consultant, Chelsea and Westminster NHS Trust

Liz Pryor
Anne Robson Trust

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Consultant Palliative Medicine - Sompar NHS

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Marie Curie, PA to AWM

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Head of PR, Media & Campaigns

Mandy Preece (MP)
Volunteer

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Appendix

Service guides

A guide to Aneurin Bevan University Health Board's End of Life Care Volunteer service.

Case study

How Hywel Dda University Health Board set up an End of Life Care volunteering service.

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Helpforce Community is a Community Interest Company, No: 10919485

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