Full report

Digital health and inclusion in palliative and end of life care

January 2024

hospice UK

Contents

About this document

This document has been designed to inform hospices and other providers of palliative and end of life care, as well as policymakers and commissioners, of the possible role of digital services in the sector and the potential risk of digital exclusion which comes with the introduction of those services. It provides recommendations on how providers might integrate digital tools and services in a way that includes and empowers people at the end of their lives, people who care for them and hospice staff and volunteers.

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How to cite this document

Hospice UK. Digital health in palliative and end of life care. London: Hospice UK; 2024

www.hospiceuk.org

Executive summary

Digital services are increasingly used across the health and care system in the UK. The expansion of these services reflects national and local system-level commitments to increasing health system sustainability, reducing waiting times, empowering the public and widening access to health and social care services. The COVID-19 pandemic fast-tracked elements of this transition from in-person to digital and virtual services, with many services switching over a matter of weeks or even days.

Hospices and other providers of palliative and end of life care are no exception to the trend of increasing digital transformation. Many hospices around the country began delivering digital services during the acute phases of the pandemic, while others had already begun to work in these new ways in the decade leading up to 2020. The hospice ethos values the whole person and takes account of that individual's physical, social, emotional, psychological and spiritual needs, while also caring for the other people who are impacted by their illness.[1] It is of crucial importance that this ethos is maintained as more and more services are offered digitally.

The hospice sector is committed to expanding access to people who are often minoritised or excluded.[2] Digital services can increase access to health and social care for some groups of people. For example, bringing services closer to people living in remote areas, far from in- person facilities, or enabling people who generally find it difficult to travel to access appointments via telephone or video call. However, the introduction of digital services can also increase inequalities and decrease access among those who cannot or do not want to access care in this way.

Hospices are seeking to navigate these challenges as best they can. However, in carrying out the research for this document, we found that the key building blocks of user involvement and digital inclusion are frequently being missed in designing digital services. A lack of clear guidance on how to use digital solutions, variations in the quality of infrastructure, limited funding streams and workforce shortages all contribute to the challenges hospices face when approaching digital solutions.

Following a review of the literature and interviews with hospice staff and academic experts we recommend that providers interested in providing digital services in palliative and end of life care:

1. Take time to understand the needs of people at the end of life, carers, staff and volunteers when designing and using digital solutions.
2. Encourage collaboration and shared learning between providers to prevent duplication and with specialist organisations to increase digital skills, confidence and trust among all user groups.
3. Support and invest in people who are passionate about adopting and promoting digital health.
4. Invest in the digital skills of staff.
5. Provide online/digital services in appropriate community languages and accessible formats, ensuring that they meet the Accessible Information Standard.[3]

Beyond the tips for hospices and other providers, the research behind this document also led to the following recommendations for wider health and care system actors:

6. Allocate adequate digital health funding to providers and networks, including for crucial basic digital infrastructure within the hospice sector.
7. Invest in digital skills training for staff across the health and care system.
8. Support providers to maintain in-person options while developing digital services and connect them with relevant expertise from beyond the health and care system.

This document also includes a suggested workflow which hospices could take towards developing digital solutions which fit the needs of people who need palliative and end of life care.

Introduction

This report examines how end of life care providers might utilise digital tools and services and how they can work to ensure inclusion of people receiving end of life care, carers, clinical and non-clinical staff and volunteers, so it works well for all and reduces health inequalities. It also provides suggestions on how hospices and other end of life care providers might develop and deliver digital services that promote and maintain the hospice ethos of holistic person-centred care that addresses and alleviates suffering.

The health and social care system in the UK is on a trajectory of increasing integration and reliance on digital tools and services (see Appendix A). Policymakers hope that digital health has the potential to alleviate pressure on health and social care services, freeing up the time of highly trained healthcare professionals, reducing the physical space needed to deliver care and placing more power in the hands of patients.

Providers of palliative and end of life care, including hospice staff and health and social care professionals working in acute and community settings will need to adapt to this changing world, where there are increasing expectations from policymakers and improvement bodies that they will engage with new technology. In the context of an ageing population, living longer and with ever more complex health needs, more people will need to access palliative care in the coming decades. The high symptom burden and sometimes complex symptoms experienced by many people when they come to receive end of life care means that ensuring quality, safety and accessibility are maintained when using digital and virtual services is of optimum importance.

In recent years, research has revealed stark inequalities in access to palliative and end of life care in the UK.[4, 5, 6, 7] Using digital health tools and reaching people through virtual services could, in theory, widen access, provide choice and increase coverage, but unfortunately the spectre of digital exclusion could also widen and increase existing inequities. A significant proportion of the UK population continues to be unable to access digital services for a variety of complex reasons. Others, for similarly complex and diverse reasons, do not want to use digital healthcare options, or, in some cases, to use the internet or other technology at all.

Unsurprisingly, the number of virtual services being delivered by hospices and other providers of palliative and end of life care has increased substantially since the start of the COVID-19 pandemic in 2020. According to data gathered by The Nuffield Trust, more than 120,000 community support contacts were delivered virtually by hospices in the year 2020/21.[8] Community support was the service most commonly delivered virtually, with welfare, bereavement, therapy and public education services also being common. This is unsurprising given that the pandemic precipitated an unplanned shift from acute to home settings for palliative and end of life care.

Much of the high level discussion around digital health technology focuses on artificial intelligence, machine learning and complex interventions that have a futuristic air. This is in contrast with a reality where many people working in the health and care sector are still struggling to gain access to devices that are reliable and fit for purpose,[9] as well as to engage with many members of the public who need care. This can be alienating and diminish people’s confidence in engaging with technology. There is a need to focus on the ways in which digital health tools and virtual services can improve and enhance personalized person-centered care that meets the distinct needs of people at the end of their lives.

What is digital health?

Digital health can range in complexity all the way from a video or telephone call between a healthcare professional and a patient, to the use of artificial intelligence to aid diagnosis or identify people at risk of particular health conditions or wearable sensors for monitoring signs and symptoms. The term ‘eHealth’ is sometimes used interchangeably with ‘digital health’, while the term ‘mHealth’ (mobile health) is used to refer more specifically to the use of mobile phones and other wireless devices to deliver care.

According to a survey conducted by Lloyds Bank in 2021, 37% of people over the age of 16 living in the UK use the internet to manage their physical health in some way.[10]

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How might digital health be used in palliative and end of life care?

There is considerable potential for digital health to address challenges facing palliative care. With many people expressing that their preference would be to die at home, the use of 'hospice at home' services, supported by tools including remote symptom reporting and video consultations can help to facilitate this. By better managing symptoms through continuous monitoring, palliative care teams may be better equipped to prevent avoidable hospital admissions, which can be distressing to both people receiving end of life care and those caring for them.

Hospices also deliver many services to people who are not in the last stages of their lives. Services such as support groups, relaxation and breathlessness management can all be delivered remotely for patients who prefer this medium. For people whose symptoms make travelling to hospice sites unpleasant, those living in remote and rural areas or who prefer to remain in their own homes for these activities, remote/virtual services can be a good option. In remote and rural areas, or in areas of high need, remote supervision and consultation systems can also enable specialist palliative care staff to support generalist community teams who may be based closer to the person's home.

Despite this considerable potential, reviews of the literature around the role of digital solutions in palliative and end of life care and bereavement have revealed that, while many solutions have been described, there has not yet been much evaluation. This is partly a result of the rapid deployment of virtual/digital services at the onset of the COVID-19 pandemic, but is also indicative of a wider reactive, rather than proactive use of digital health tools and services in palliative care, where interventions are implemented with limited in-depth consultation or long- term goal-setting.

It is crucial that developments in the delivery of palliative and end of life care are evaluated to ensure that they align with the ethos of palliative care, addressing not only physical symptoms, but also psychological, spiritual, emotional, social and practical suffering.[11] They should also support more recent goals of palliative and end of life care, including the national Ambitions Framework for Palliative and End of Life Caren, first developed in 2015 by a partnership of national organisations, including NHS England, a number of clinical professional bodies and voluntary and community organisations, and updated in 2021. The partnership developed a national framework for local action in palliative and end of life care, which is based upon the following six ambitions[12]:

1. Each person is seen as an individual.
2. Each person gets fair access to care
3. Maximising comfort and wellbeing
4. Care is coordinated
5. All staff are prepared to care
6. Each community is prepared to help.

A long-observed challenge to research and evaluation in palliative and end of life care has been the reluctance of professionals to involve people with lived experience, including carers, in research and evaluation. As the success of digital health services is dependent on their usability, there will need to be a concerted effort to involve the public in design.

Digital services can bring considerable benefits to people receiving palliative and end of life care, including:

- allowing people to remain in their homes while receiving end of life care
- reducing pressure on in-patient palliative care beds
- improving communication between different providers caring for the same person
- reducing emergency admissions
- reducing infection risk, and
- reducing the cost and discomfort of travel.

However, there is limited available research on the real-world impact of digital services on people at the end of life, or on their experiences of digital exclusion. There are many factors at play in the lives of people receiving end of life care which are likely to complicate their relationship with digital services. These complicating factors may include high symptom burdens, including pain, fatigue, anxiety and nausea, reductions in capacity over time, the effects of polypharmacy, multi-morbidity and, increasingly, frailty and dementia. The motivation to acquire digital skills in order to access a wide variety of digital services in the future is also less likely to be present in people at the end of their lives. In order to better support people at the end of their lives to benefit from digital services, there should be a concerted effort to consult service users on their needs and preferences when it comes to digital health in end of life care.

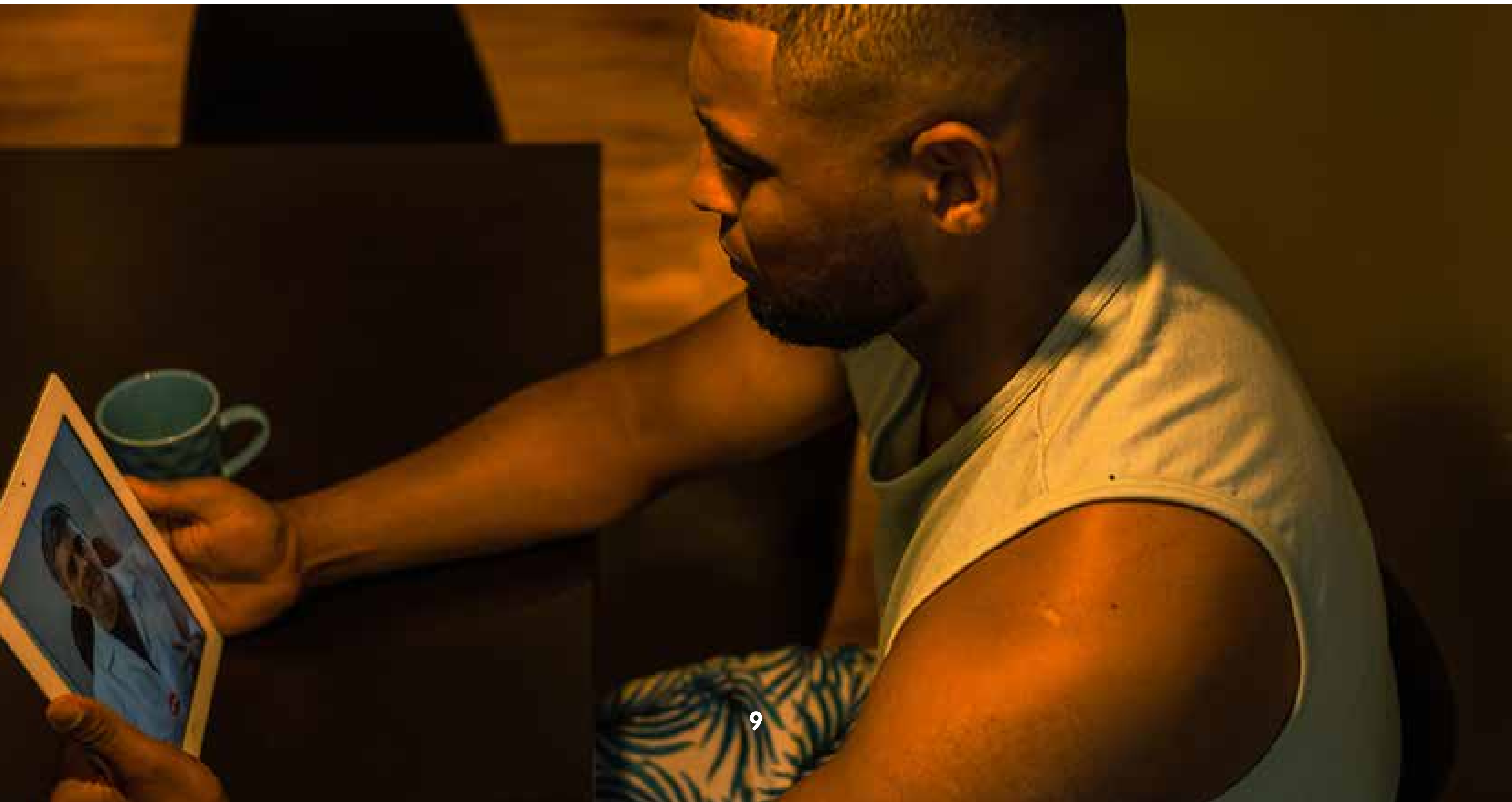
Engaging seriously with the question of digital inclusion in palliative and end of life care could improve the situation of service users beyond the delivery of specific end of life care services, as being digitally excluded can make it considerably more difficult for people to access other resources and services, including applying for benefits, that further exacerbate inequalities at the end of life.[13]

How might digital solutions be used to deliver bereavement services?

There is also considerable potential for digital solutions to support the provision of bereavement services. In 2022, the UK Commission on Bereavement estimated that around three million people experienced bereavement in the years 2020 to 2021.[14] The Commission's report identified several areas in which bereaved people were digitally excluded during the acute phases of the pandemic, when administrative processes were necessarily online due to social distancing measures. However, they also highlighted the innovative ways in which organisations began to provide virtual bereavement support. Online counselling sessions, peer support groups and forums allow bereaved people who are working, have caring responsibilities, or who may not want to travel to in-person sessions to access bereavement services. Online peer support can be particularly powerful for people who have shared experiences of grief, e.g. younger people who are widowed or children who have lost parents, allowing them to come together in ways that might not have been possible in person.[15]

Digital services can also act as a useful stopgap for bereaved people while they are waiting for in-person sessions to become available and have the benefit of increased flexibility, allowing people to decide how much or how little to engage in sessions.

However, as is the case with the provision of end of life care, we know that access to bereavement support is not equitable across the population. A 2022 survey revealed that more two thirds of voluntary and community sector bereavement services were aware of population groups with unmet support needs.[16] People from ethnic minority communities were the most likely to be excluded from traditional (non-digital) bereavement services and providers found that, without concerted efforts to make digital services more inclusive, the same patterns would be perpetuated.



A Pathway for developing digital services in palliative and end of life care

Define the problem/gap you are trying to solve. Ideally involve staff, people with lived experience and carers.

Bring together potential users of the tool, including patients, carers and staff.

Work with them to understand their needs, define what success will look like and how to measure it.

Reach out to other hospices and to your local ICB network to understand their use of digital services, aiming to avoid duplicating work.

Engage with developers (if needed). Plan for cycles of evaluation and improvement from the outset.

Take time to train staff and support people to use the tools and devices required.

Test your solution over a time-limited period, measuring according to the definitions of success from Stage 2.

Assess and evaluate the outcomes of your initial pilot. Investigate whether sustainable funding is available and present your evaluation to potential funders.

If the intervention is effective and financially viable, refine through consultation with staff, patients and carers and relaunch.

Share what you have learned with relevant organisations within your ICS.

What is digital exclusion and how might it impact on palliative and end of life care?

A review of ‘digital technology and health inequalities’ conducted by Public Health Wales in 2020 defines ‘digital exclusion’ as a concept used to describe the situation when people and groups in society are unable to exploit the benefits that using digital technologies might make available to them.[17] Digital exclusion acts as an additional layer of exclusion and inequity which often exacerbates existing health inequalities.

The UK government identifies the following sections of the population as being more likely to be digitally excluded:

- older people
- people in lower income groups
- people without a job
- people in social housing
- people with disabilities
- people with fewer educational qualifications
- people living in rural areas
- people experiencing homelessness
- people whose first language is not English.[18]

These groups are already more likely to experience the negative impacts of health inequalities. Digital inclusion depends on connection, accessibility, skills and motivation, all of which can be addressed and influenced by the inclusion of prospective service users in the design and evaluation of tools and services. However, it is important to recognise that some people,

perhaps especially at the end of life, will never want to use digital services. To avoid exclusion, digital should never be the only way of accessing care.

While there is increasing evidence of stark inequalities in access to high quality palliative and end of life care,[19, 20] we have identified an apparent gap in research looking specifically at the mechanisms and impacts of digital exclusion on people who need end of life care or their unpaid carers.

We know that people who are receiving end of life care can have complex physical, emotional, social and psychological needs, which can be difficult to meet through in-person services, especially in the context of workforce and financial pressures, but less is known about how digital exclusion may add to these challenges.

The digital landscape within palliative care is not particularly mature. Although there are examples of hospices developing their own tools and services, often precipitated by the pandemic.

The reasons why people do not use the internet and other digital services are both varied and complex:

Connection - Do people have adequate and reliable devices and internet connection that enable them to engage with digital services?

Research conducted by Ofcom in December 2021 revealed that 6% of the UK population do not have access to the internet at home, while a further 5% can only access the internet using mobile data, a dongle or USB device.

People who do not own or have access to internet enabled devices, or to a good quality internet connection are likely to be excluded from digital services. Connectivity may be compromised due to location, or because people cannot afford to pay for data. People who are experiencing homelessness may struggle to charge devices if they do have access to them.

A survey conducted by the Digital Poverty Alliance, Currys' and YouGov in December 2022 found that 36% of adults in the UK had cut back their spending on digital access due to cost-of-living pressures.[21] In late 2022, Ofcom also found that the proportion of households struggling to afford communication services had doubled in the past year. We know that people who are on lower incomes and people living in poverty face life-long health inequalities, which extend to the end of life.[22] Ill-health in itself, and terminal illness in particular, can also be a driver of poverty[23], further impacting on access to services, devices and connectivity.

People living in remote and rural areas are also more likely to experience digital exclusion due to lack of high-quality internet connection. While research in the realm of palliative care inequities for people living in remote and rural areas of the UK is still relatively sparse, we know that it is already more difficult for people who live in these areas to access in-person palliative care services.[24]

For some health and social care services, there is a suggestion that people could use the internet in public spaces, such as libraries and community centres, or attend Digital Health Hubs to develop their skills for engaging in digital health services but this is unlikely to be appropriate for people receiving end of life care.[25]

6% **of the UK population do not have access to the internet at home**

Accessibility - Are the digital tools available accessible to the people for whom they are designed and do they meet their specific needs?

People can be digitally excluded when services are not accessible to them. Accessibility barriers in digital health services might include a lack of provision in different languages, resources that are incompatible with accessibility aids such as screen-readers and closed- captioning and failures to supply easy-read versions of resources.

In a 2023 report based on a round of public workshops, The King's Fund reports that 'being online' or having access to devices does not mean that digital health tools and services are fit for purpose for the people who want to use them.[26] One individual they spoke with, who is deaf, has developed a range of strategies and systems using technology so that she can engage with digital services. However, she has faced several barriers to using these strategies when engaging with her GP practice, where, when video appointments have been offered, they have not been accessible as staff do not want to use closed captioning or share transcripts with her after a video consultation. Although she is able and willing to use digital tools, the tools being offered to her by her healthcare providers do not meet her needs.

Skills - Do people have the digital skills needed to use tools and services in a way that benefits them?

People may be digitally excluded when they have not been equipped with the skills required to engage with digital tools and services. This form of exclusion can overlap with low levels of traditional literacy, but can also exist independently.[27] Some people may be unable to use internet-enabled devices such as computers, tablets and smartphones because they have never been shown how, while others may only have learned how to utilise specific applications, such as emails or messaging apps as ways of staying in touch with family during the COVID- 19 pandemic or because certain applications are a minimum standard required by their workplace.

There is a danger of further entrenching pre-existing health inequalities, as people who are already marginalised and excluded from society are also more likely to be digitally excluded.

Motivation - Do people believe that digital services can be useful to them and add value beyond the status quo?

Even in cases where people can access digital health tools and services, they may not see the value of those services and tools to their lives, or they may see them as an active source of potential harm. Many people are vulnerable to exploitation online and may have legitimate concerns about data privacy. Others may just not want to use digital tools, because they prefer face-to-face services. Following the acute phases of the COVID-19 pandemic, when in-person contact was severely limited, a desire to connect with other human beings in person should not be ignored. People should never be forced to use digital services or be left with no face-to-face option.

For this reason, both The King's Fund and the Patient Coalition for AI, Data and Digital Tech in Health recommend that, while national policy in the UK should encourage digitally enabled services, this should not be to the exclusion of in-person services, which will always be more appropriate to some people's needs.[28, 29]

Ensuring that people derive value from digital services is particularly crucial when people are approaching the end of their lives. As has often been stated, in palliative and end of life care, there is only 'one chance to get it right'.[30]

The rapid movement of health and social care services online during the COVID-19 pandemic is likely to have further widened the already substantial inequalities driven by digital exclusion, while the cost-of-living crisis and the increase in poverty and deprivation seem likely to increase the problem. As people face difficult decisions, including choosing between heating and eating, the cost of data must also be a consideration.[31, 32] In May 2023, a survey by Citizens Advice suggested that up to a million people had cancelled their broadband packages over the previous year due to the rise in the cost of living.[33] Work by Marie Curie has highlighted the financial burden of terminal illness.[34] 43% of people caring for someone with a terminal illness say that they are struggling financially, which is likely to further compound this risk of digital exclusion due to poverty and deprivation.

A 2023 report by The King's Fund[35] recommends that organisations attempt to tackle digital exclusion in three ways:

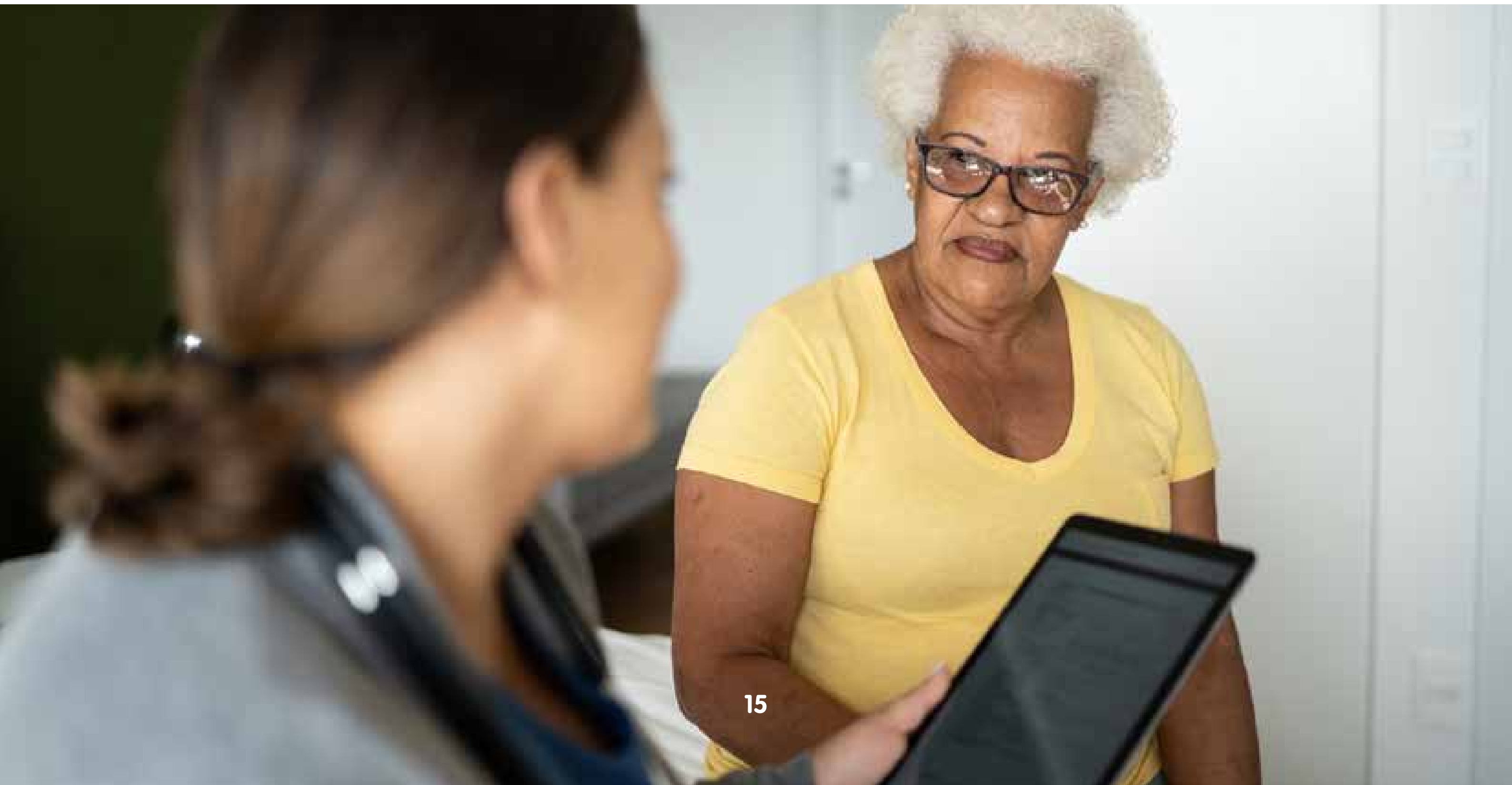
1. **Fixing the fundamentals,** by providing people with access to devices and data, building digital skills and confidence through education and support
2. **Structuring services around people's needs and preferences,** by identifying people's capability and preferences, offering services with different levels of digitalisation and working with communities to develop more inclusive services
3. **Improving the quality and consistency of services.**

What are hospices and other providers doing to embed digital services, while enabling digital inclusion?

Many hospices and other providers of palliative and end of life care across the UK are delivering services using digital methods. These services are diverse and at different stages of development and roll-out, but include:

- Remote consultations
- Virtual wards
- Remote symptom/outcomes monitoring[36]
- Bereavement support services
- Outreach services for people living with long-term illnesses
- Facilitating multidisciplinary/multi-agency working.

Reviews of existing literature that were carried out to develop this report have found a lack of investigation into the specific needs of people who may wish to use digital services when receiving end of life care. Although staff who work delivering digital services report a range of responses to the prospect of using digital services, these have not been adequately investigated on a larger scale. The complexity of digital exclusion and the time and thought required to address it when delivering digital health interventions makes this work very challenging, especially in a sector where funding and workforce pressures can limit capacity for consultation, research and evaluation at all stages of a project.



Case Studies

Case Study – Weldmar Care – Weldmar Connect App

The challenge

Weldmar Hospicecare's community palliative care services cover a wide area across Dorset, with community nurses visiting people in their own homes across the county. The high caseload and long distances covered by the service made it difficult for staff to prioritise work and ensure that they were visiting the people with highest need promptly.

The digital 'solution'

Having started a telehealth programme in 2017, which enabled patients to access advice via phone, the hospice applied for funding from the Department for Digital, Culture, Media and Sport's Digital Inclusion Fund in 2018.[37] This funding was used to develop and build an app in partnership with the development company, Inhealthcare.

In 2020, the hospice launched the Weldmar Connect App, which was initially accessed via dedicated telehealth pod devices, but was soon made available on all internet-enabled devices, including personal smartphones, tablets and PCs. The app allows patients to fill in a daily questionnaire about their symptoms, including nausea, pain and anxiety, based on the Integrated Palliative care Outcome Scale (IPOS).[38]

If their symptoms are particularly severe, the patient will automatically be sent further questions about symptom management and may be provided with advice. The data can be accessed by community nurses who have logins to the provider side of the app. While data entered into the app should not replace phone calls to trigger emergency visits, it can be used to help nurses prioritise their workload and enables patients and carers to track the progression of their symptoms over time.

The impact

Since it was launched in 2020, 243 people have activated the app. However, one of the limitations of the app is that it is difficult for staff to see easily how many people are regularly completing questionnaires.

Where patients have regularly filled in questionnaires via the app, clinical staff have found that the information helps them to prioritise their work and act fast to help alleviate people's symptoms and concerns. One nurse stated: "it has enabled me to monitor patient symptoms remotely and more regularly, and pick up on issues sooner than maybe I would normally. This has meant that I've been able to resolve/act on problems quicker."

People receiving end of life care and their unpaid carers have also found the app very useful, in that it enables them to track and visualise their symptom patterns over time.

More recently, staff at the hospice have become aware of the potential benefits of switching from the Weldmar Connect app to an application that is linked to the SystmOne record- keeping system that is used across the health and care system in Dorset. Switching to this system could make remote symptom reporting more accessible to people receiving end of life care, as they are more likely to have used the same app when interacting with their GP or other care providers. Using this app would also allow Weldmar Hospicecare to share patient information more easily amongst their staff and update records from their mobile phones in real time.

Case Study – Trinity Hospice Blackpool – Video consultations and links to care homes

The challenge

Trinity Hospice, Blackpool works closely with local community hospitals, providing clinical support for patients with palliative and end of life care needs. Visiting patients in the community hospitals was taking up a lot of time for hospice staff, partly because they were being asked to see extra patients during their visits and partly because of travel. In peak Blackpool holiday traffic, it could take up to two hours to drive to and from Clifton community hospital.

The digital 'solution'

Since 2014, the clinical team at Trinity Hospice in Blackpool have been using video calls to run virtual clinics in care homes and community hospitals.

Each virtual clinic takes place at a set time. The hospice's clinical team speak to hospital patients and staff via video call, monitoring each individual's progress and agreeing what care they need. The hospital uses a tablet device for the video calls, which staff carry to each patient. They also help them to hold and operate it during their consultation.

Staff were initially reluctant to try using virtual ward rounds in these settings, as they were concerned that patient care would be compromised, but the deviser of the programme encouraged them not to assume that patients were concerned with seeing specialist palliative care staff face-to-face, especially when they were already surrounded by health and social care staff who could be empowered to provide excellent care through consultation with the hospice.

The member of staff who led on the initiative collected data on costs and time saved through virtual consultations at the early stages of implementation and was able to share this with the wider team to show how it was enabling them to reach more patients.

During the acute phase of the COVID-19 pandemic the wards at the community hospital were repurposed as COVID wards and many staff left both the hospice and the hospital. This meant that the virtual consultation programme was paused, but the hospice is now reinstating some virtual consultations, both in care homes and in patients' own homes.

The impact

The virtual clinics are saving time and money for the hospice. Previously, in peak Blackpool traffic, it could take a clinical nurse specialist two hours to drive to and from some community appointments.

Being able to provide a remote service means that patients who are nearing the end of their lives do not always need to be brought to the hospice for in-patient care, if this is not their wish.

Case Study – Willowbrook Hospice – Virtual Outreach Service

The challenge

At the start of the COVID-19 pandemic in 2020, the traditional 'day hospice' service delivered at Willowbrook Hospice in Merseyside could not continue. The 'day hospice' provided relaxation sessions, arts and crafts, peer support and breathlessness support sessions to outpatients in the community.

The digital 'solution'

Soon after the first lockdown began, staff at the hospice began delivering sessions virtually, using Zoom.

Initially it proved difficult to get people set up on the virtual services platform because the first lockdown was so strict and staff struggled to support users who lacked digital skills or access to devices.

However, once lockdown rules eased a little, staff were able to drop devices at people's houses and assist with device set up from people's gardens. Now the team regularly run digital drop-ins and digital awareness sessions and lend out devices to people who do not have their own. They are aware that there is a risk they may not always get devices back, but have decided that this is a risk worth taking if it allows more people to benefit from the virtual outreach services.

The impact

Continuing the virtual outreach services beyond the acute phase of the pandemic has allowed some people to remain included in activities for longer. In the past, when all outreach/day services were in-person, people would stop accessing the service once they were too unwell to come to the hospice, but now they can continue to take part in hybrid sessions from home. Patients have been particularly keen to take part in relaxation sessions and arts and crafts clubs from home.

Using digital technology has enabled Willowbrook to expand the reach of their services. But now people can access the virtual platform whenever they need, right up until their death.

Feedback on this hybrid model of care is good and patients want it to continue. The virtual relaxation sessions and Arts and Crafts Club have been particularly popular. Other services include complementary therapy and one-to-one sessions for counselling or symptom control.

To see more examples of UK hospices' use of digital tools
and services, please visit the Hospice UK Innovation Hub
www.hospiceuk.org/innovation-hub

Supporting digital inclusion in palliative and end of life care – Top tips for providers

Based on the challenges and enablers of digital inclusion in palliative and end of life care seen in palliative and end of life care, we have produced the following tips as a guiding steer for providers. These tips could be an important tool in delivering the policy goal of increasing equitable access to palliative and end of life care when digital solutions are used:

1. Take time to understand the needs of people at the end of life, carers, staff and volunteers when designing and using digital solutions.
2. Encourage collaboration and shared learning between providers to prevent duplication and with specialist organisations to increase digital skills, confidence and trust among all user groups.
3. Support and invest in people who are passionate about adopting and promoting digital health.
4. Invest in the digital skills of staff.
5. Provide online/digital services in appropriate community languages and accessible formats, ensuring that they meet the Accessible Information Standard.[3]

System-level recommendations

Beyond the tips for hospices and other providers, the research behind this document also led to the following recommendations for wider health and care system actors:

6. Allocate adequate digital health funding to providers and networks, including for crucial basic digital infrastructure within the hospice sector.
7. Invest in digital skills training for staff across the health and care system.
8. Support providers to maintain in-person options while developing digital services and connect them with relevant expertise from beyond the health and care system.

Appendix A: Methodology

To develop this piece of work, the Head of Information Support at Hospice UK, conducted an initial literature review in January 2023, using PubMed, Google Scholar, Social Care Online, CareSearch systematic review collection and material from websites compiled by ehospice, Hospice UK, and Together for Short Lives. The search terms used were as follows:

1. Google Scholar: hospice AND (virtual OR digital) AND (feedback OR effectiveness OR evaluation OR impact)
2. PubMed: hospice[Title/Abstract] OR “life limiting”[Title/Abstract] OR “life threatening”[Title/Abstract] OR “end of life”[Title/Abstract] OR palliative[Title/Abstract] OR “terrminal illness”[Title/Abstract] OR “terminally ill”[Title/Abstract] AND virtual[Title/Abstract] OR digital[Title/Abstract] OR online[Title/Abstract] OR telehealth[Title/Abstract] OR telemedicine[Title/Abstract]

The Head of Information Support also conducted a search of the following journals, for articles published between 2018 and 2023:

1. BMJ Supportive & Palliative Care
2. Palliative Medicine

At the same time, staff within the Membership Engagement team at Hospice UK, reached out to their 208 member hospices, asking for examples of digital services to be submitted. While a good number of hospices responded to this call, many of the examples provided were very similar and further examples were sought through a search of both academic and grey literature.

In February and March 2023 staff from the Policy, Advocacy and Research team at Hospice UK contacted staff at hospices and other experts identified through the literature search to arrange interviews. They also conducted further stakeholder mapping and used snowballing to collect further relevant literature to supplement the original review.[39] In drafting this report and the Innovation Hub content that accompanies it, the Policy, Advocacy and Research team reviewed 113 articles and web pages on the topics of digital health, digital inclusion and palliative care. They also conducted interviews with 15 individuals from hospices, universities and research institutions. Most were conducted by video call, with one in person.

Appendix B: How does digital health fit into plans for the health and care system in the UK?

In England

In 2019, the NHS Long Term Plan established an ambition for the NHS to 'offer a 'digital-first' option for most' with people who are unwell increasingly being 'cared for in their own home, with the option for their physiology to be effortlessly monitored by wearable devices'.[40] It is hoped that using digital tools will reduce pressures on workforce, time and waiting lists, which have only worsened since the COVID-19 pandemic.

There is also a commitment within the Long Term Plan to empower people through the use of digital health technologies. The document includes a potentially unrealistic commitment to 'ensure these technologies work for everyone, from the most digitally literate to the most technology averse'. Since 2019, NHS England has published a number of additional resources around digital inclusion and has included the issue within their equalities and inclusion agenda. The National Healthcare Inequalities Improvement Programme's approach to reducing healthcare inequalities defines 'mitigating against digital exclusion' as one of the key priority areas underpinning its work towards the vision of providing 'exceptional quality healthcare for all through equitable access, excellent experience and optimal outcomes'. In 2023/24, one of their key actions is to 'Put digital tools in place so patients can be supported with high quality information that equips them to take greater control over their health and care'.

Since the launch of the Long Term Plan, new teams within NHS England have been tasked with encouraging the uptake of digital tools and ensuring that they reduce, rather than increase health inequalities across the country. One area of focus is Virtual Wards. Between March 2022 and March 2023, more than 100,000 people were treated in NHS Virtual Wards in England, with 340 distinct programmes running across the country.[41]

Integrated Care Systems, established in the Health and Care Act 2022, are expected to embed digital and data into their service delivery. The 'what good looks like' framework calls on ICSs to develop digital transformation strategies to 'digitise, connect and transform services safely and securely'.[42]

In the year 2022/23, more than

100,000

people were treated in NHS Virtual Wards in England

In terms of training the health and social care workforce to deliver and adapt to digital service delivery, the NHS Digital Academy, founded in 2017, provides courses and materials for NHS staff. In a 2021 report on the future of end-of-life care, the Institute for Public Policy Research recommended the establishment of a specialised end of life academy to deliver digital training for all professionals working in palliative and end of life care.[43]

In the realm of clinical guidelines, the National Institute for Health and Care Excellence (NICE) has established an internal Office for Digital Health, which leads on the development of digital health policy and aims to:

- identify technologies that offer the greatest potential to improve health and wellbeing
- establish universal data and evidence standards for digital health technologies
- monitor NICE's evaluation methods and processes to accommodate the evolution of technologies, and
- work with strategic partners to improve digital health approval pathways and reimbursement policy.[44]

In the devolved nations

In 2018, the Welsh government published 'A Healthier Wales: our plan for Health and Social Care', within which they declared their intention to 'increase…investment in digital technologies as a key enabler of change'.[45] The document sets out plans for different ways in which digital technologies would be integrated across the health and social care system, including bringing together patient information from different providers and investing in the digital skills of the workforce. However, they also recognised that 'some people will be unable to access digital services' that 'others will choose not to' and that 'face-to-face and hands on human contact is an extremely valuable and absolutely essential part of care and treatment'.

In March 2021, the Welsh government established the Digital Services for Patients and Public programme (DSPP), which aims to help people across the country to access better healthcare and support providers to deliver care more efficiently through new digital health services and apps.[46] As of early 2023, the programme is working on developing an NHS Wales app.

DSPP's approach to offering services to people who are digitally excluded is to increase the efficiency of in-person services, by providing people who do wish to use digital services with a high-quality online option.

In September 2022, the Wales Council for Voluntary Action, Cwmpas and Digital Health and Care Wales co-hosted a digital summit, at which they devised and signed up to a Digital Inclusion Charter,[47] which has also been signed by a wide range of voluntary and community organisations across Wales.

In Scotland, digital health projects are supported by a Special Health Board, NHS National Services Scotland (NHS NSS), within their 'digital systems and security' workstream.[48] NHS NSS offer providers access to a range of services, including end-to-end design for new technologically-enabled services and a library of pre-existing products and solutions.

A refreshed version of the Scottish 'Digital health and care strategy' was launched in October 2021, building on the original 2018 strategy to respond to the rapid developments in digital health due to the COVID-19 pandemic.[49] The vision of the strategy is 'to improve the care and wellbeing of people in Scotland by making best use of digital technologies in the design and delivery of services'.

The Digital Health & Care Directorate within the Scottish Government was formed to deliver the strategy and to continue with research, evaluation and engagement, under the direction of the Director General Health and Social Care.[50] The directorate is advised by a number of stakeholder committees, including the equality and inclusion advisory group, made up of representatives from voluntary and community sector organisations from across Scotland.

In Northern Ireland, the Department of Health released a new digital strategy for health and care in July 2022.[51] The strategy, which was intended to cover the next eight years, focuses on integrating systems and utilising data so that patients receive better, more personalised care.

The Department of Health also leads Digital Health and Care Northern Ireland (DHCNI), which is an amalgamation of two digitally focused departments which previously existed within the Health and Social Care Board and the Public Health Agency.[52] DHCNI is responsible for a central budget for digital investments and works with other departments to commission digital projects and services within the health and social care system. Within their strategy, the DHNI declares that they will '[aim] to digitally empower citizens by digitally enabling care professionals and digitally equipping the system'.

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