CUMBRIA RURAL HEALTH FORUM

Use of Digital Technologies in End of Life Care in Cumbria

Outline proposals from a workshop held in October 2015

NORTH WEST COAST ACADEMIC HEALTH SCIENCE NETWORK

ACADEMIC HEALTH SCIENCE NETWORK NORTH EAST AND NORTH CUMBRIA

1. Introduction

The Cumbria Rural Health Forum[1] has developed the Cumbria Strategy for Digital Technologies in Health and Social Care[2] and is conducting a number of digital implementation workshops, between October 2015 and March 2016, with the aim of proposing specific ways in which digital technologies should be implemented within a pathway, place or around a particular group of individuals. As with all our activities, workshops bring together professionals from the public, private and third sectors, linking to suitable technology providers as needed. The scope for our work on digital technologies includes telemedicine, telehealth, telecare and assistive technologies, e-health products and services that are commercial available[3] .

This first digital implementation workshop focused on End of Life Care (EOLC). The objectives described and reported here are:

- Share an understanding of what is possible, what technologies have been used in EOLC elsewhere and how successful they have been found to be;
- Brainstorm and propose opportunities for implementing digital technologies in EOLC in Cumbria;
- Develop and agree an action plan for the group, to influence change in Cumbria and elsewhere.

2. Use of digital technologies in End of Life Care: how has it been used?

Internet and literature searches were undertaken, as well as a review of the mapping work undertaken in 2014-15 in Cumbria[4].

Implementations of digital technology specific to EOLC include:

- The Canada Virtual Hospice[5] provides 'information and support on palliative and end of life care, loss and grief'. It is a comprehensive web-based resource for both professionals and non-professional carers or individuals.

- A number of interventions, including the use of telehealth for pain and symptom monitoring and videolinks to replace face-to-face consultations, are being trialled in the Highlands and Islands, Scotland[6].

- In Cumbria, the CCG is rolling out its Strata e-referrals and resource matching programme to hospices and care homes. At the time of the workshop, installations were just taking place. There was no experience of using Strata yet, but significant enthusiasm and recognition of its transformational potential[7].

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[1] See www.ruralhealthlink.co.uk
[2] See http://www.ruralhealthlink.co.uk/about-us/cumbria-strategy-for-digital-technologies-in-health-and-social-care/
[3] See http://www.ruralhealthlink.co.uk/assets/uploads/reports/Briefing_paper_Digital_technologies.pdf for a fuller discussion
[4] See http://www.ruralhealthlink.co.uk/activities/
[5] See www.virtualhospice.ca
[6] A. Taylor et al. Developing Hospice Care Over a Distance in Highland Scotland: a Knowledge Exchange Process. CHI 2013 Extended Abstracts, April 27–May 2, 2013, Paris, France. ACM 978-1-4503-1952-2/13/0 http://radar.gsa.ac.uk/2993/1/P397.pdf
[7] See http://www.ruralhealthlink.co.uk/activities/list/strata

Many other implementations are in different fields, but could be relevant in EOLC. For example:

- Video links for scheduled and unscheduled consultations (or other non f2f – phone, email, sms). This can be with or without a nurse, carer or GP in attendance and can be to the patient's home or perhaps a local clinic. Examples within Cumbria are the telestroke service[8] and early pilots in fetal telemedicine[9] and orthopaedic post-operative care[10]. Outside of Cumbria, Airedale Hospital Trust[11] are nationally leaders in teleconsultation support and have a major programme. Some GP practices are successfully using Skype and there are many informal uses of phone and email.
- Ways to conduct Multi-Disciplinary Team reviews (MDTs) digitally, to provide more responsive support to a patient's needs.
- Symptom and pain management, through telehealth monitoring. Examples include the Breathe project[12] in Alston and South Cumbria and the Florence Telehealth system[13] used widely in the North East and to a limited extent in Cumbria.
- Alarms and alerting systems – fall detectors, movement sensors, emergency call buttons, inside or outside the home – to provide appropriate and rapid support to patients living independently. Cumbria County Council provides telecare and assistive technology[14] solutions to nearly 2,100 individuals, using family and friends to provide response services. Within Cumbria a further 4,700 or so individuals receive community alarms and some telecare services from independent providers. Some of these employ staff or use volunteers. This type of service is widely used nationally[15], with a range of products and services.
- Patient record sharing between services is already being addressed by the work of the CCG, but will take some time to be fully rolled out. There are also a number of consumer based options for patient or carer owned records.
- There are an increasing number of health and medical apps, available either free of charge or at low cost, for use by a patient or carer. A the time of the workshop, there were two health and medical app libraries where some form of review and categorisation is available – the NHS England library and MyHealthApps[16]. As of 16th October, the NHS library has been withdrawn and a new service will be available in due course. Apps can be easily downloaded onto any smartphone, tablet or PC device, either from an app library or from one of the device app stores (Apple or Android).
- Information services, forums, social networks clearly also have a role and are many and various, including those around the major disease/condition specific charities.

Technologies, products and services were reviewed and discussed by delegates at the workshop.

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[8] See http://www.ruralhealthlink.co.uk/activities/list/telestroke

[9] See http://www.ruralhealthlink.co.uk/activities/list/fetal-telemedicine-improving-prenatal-diagnosis-and-management-in-cumbria

[10] See http://www.ruralhealthlink.co.uk/activities/list/telemedicine-remote-consultations

[11] See http://www.airedale-trust.nhs.uk/services/telemedicine/

[12] See http://www.ruralhealthlink.co.uk/activities/list/breathe

[13] See http://www.ruralhealthlink.co.uk/activities/list/telehealth-monitoring-by-florencetm

[14] See http://www.ruralhealthlink.co.uk/activities/list/category/telecare-and-assistive-technologies

[15] See http://www.ruralhealthlink.co.uk/assets/uploads/reports/Report-Telecare_and_Assistive_Technology_Best_Practice.pdf

[16] MyHealthApps is a portal for apps recommended by users (patients, carers and health professionals. See http://myhealthapps.net/

3. Identification of appropriate digital technologies for use in EOLC

We used the North West End of Life Care Model (NW EOLC Model) as a framework to select, discuss and propose ideas in small groups. These ideas were then shared with the full group.

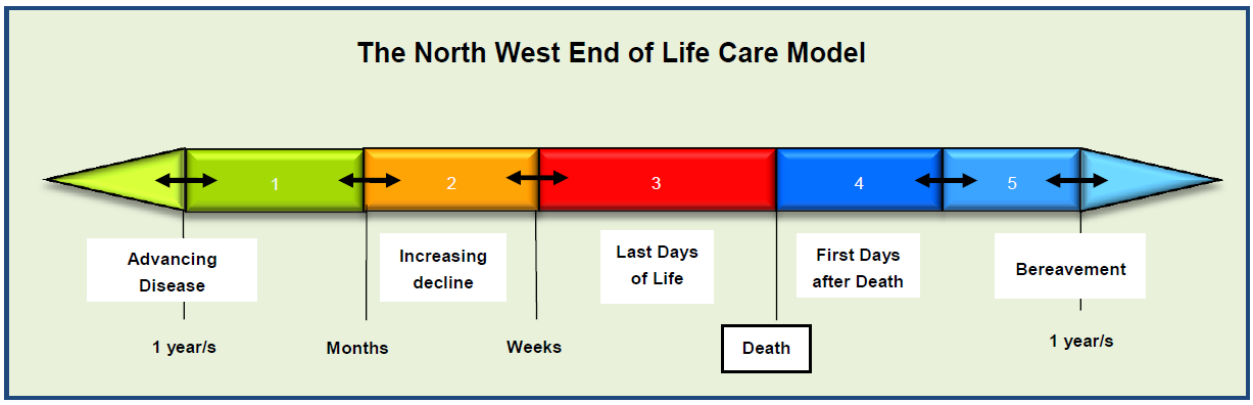

Figure 1: North West End of Life Care Model developed by the North West Coast Strategic Clinical Network (2014)

The NW EOLC Model The model supports the assessment and planning process for patients, from the diagnosis of a life limiting illness or those who may be frail. Within each of the 5 phases shown above, the Good Practice Guide identifies a list of key elements of good practice. These can be used as prompts in the assessment and care planning process.

The 18 ideas from the group are tabulated below.

Phase of EOLC	Technology Idea	Benefits	Barriers or issues to address
Last year of life	Pharmacy/medication app to help clarify new medications	Improve patient understanding (or carer), hence compliance and avoid averting a crisis	
Last year of life	Outpatient letter generation	Clear sensitive communication with patient, better referrals to other services	
Last year of life	E-Template and shared records to clarify where up to W ACP???	Helps clinician to access information	Different IT systems, lack of confidence in confidentiality
Last year of life	DNACPR app linked to the one held by GP and visible to other agencies (NWAS, CPFT, A&E, carers). Include anticipating care plan, donor details, any discussion of deactivation of implantable cardioverter	Benefits to patient and carers – peace of mind. Needs to be something they can have on all the time	Need to ensure it is patient identifiable. Need to address culture within NHS of suspicion of external systems.

Phase of EOLC	Technology Idea	Benefits	Barriers or issues to address
Last year of life	TV based teleconference	Patient can access care without leaving home. Could also link up to other people – reduce isolation	
Last year of life	Data sharing between case managers and others – digital collaboration	Identify which needs are a priority for scarce resources	
Last year of life	Telehealth to enable self-report of pain and nausea – trigger clinician visit if out of set parameters. Could feed into a 'virtual ward round'	Avoidance of crises, more consistent system management. Reassurance to patients and carers. Reduce hospital admissions.	Need secure networks, need to get questions right, involve professionals in design
Last year of life	App to follow up on positive living group therapy techniques eg. anxiety reduction/ relaxation/ mindfulness/ breathing techniques/ adapted tai chi	Give "permission" for carers to use relaxation app	Self-directed, no professional involvement. Some may not have access to technology.
Increasing decline	Support and education to carers – forums/internet/apps	Keeps carers well. Patient can stay at home, fewer clinical call outs	Investment
Increasing decline	24 hour cover – emergency non-ambulance contacts to help in case of problems.	Reduce emergency callouts and admissions – sometimes people just need advice	Who would provide backup? Social or health call out, who pays, what level is required?
Increasing decline	Specialist advice to OOH teams (could be via telemedicine) and care homes		
Increasing decline	"Virtual ward" for patient. Can phone for advice if required. Could use Airedale services		
Increasing decline	"Around the time of death" App with FAQs		
Increasing decline	Video link to support relatives giving injections and other meds		
Care after death	Prompt on GP record system to follow up bereaved at 3 months, 6 months. Care navigator to call/visit.	Prevent difficult bereavement, depression, PTSD, morbid grief etc.	The bereaved may not have insight into their need. Lack of care navigator resources.
Care after death	Mental health diary app. Health professionals could use to gain insight and signpost	Writing and recording can be easier than speaking. Privacy, family protection. Clinician made aware	Fear of IT. May not wish to engage. Not enough clinicians to act on outcomes

Phase of EOLC	Technology Idea	Benefits	Barriers or issues to address
Care after death	Bereavement care for people living with dementia. Share staff practice, good and bad. Life story map – collection of memories at end of life – virtually put flowers on grave. Prompts and practical steps to take after death to be in control		Reluctance to share unsuccessful stories
Care after death	IT to inform everyone at once that a patient has died. Could alert equipment store to arrange collection		

There has been some evaluative work specifically on use of digital technology in palliative care, again through the Scottish virtual hospice work[17] by Johnson et al. This drew on qualitative semi-structured interview work with those using the services.

Some of the findings of interest were:

- People do prefer face to face, but if the alternative is a long and uncomfortable journey, they are happy with video, phone, skype
- Remotely based professionals also benefited
- It was good to be able to involve family more easily
- One person expressed the value in being at home when receiving bad news.
- Information sharing was still a problem and needed to be improved in Scotland
- Users could see the potential for more remote monitoring of symptoms by patients or carers

4. Action plan: what is possible for us to implement in Cumbria?

With no specific resource and representation from a range of organisations, sectors and interests, it was recognised that the group can only advise and influence change. A further exercise, undertaken initially in 2 sub groups and then combined, focused on practical suggestions for 'easy wins', where resource is either already in place or could be requested.

4.1. The group should work together to build a business case for using digital technology to achieve 24/7 access, building on NICE guidance and the Ambitions paper. This will include:
- Out of hours GP access to specialist advice
- Back up for hospice@home service (H@H)
- Consideration of issues of security, broadband connectivity and agree policies
- iPads for staff/patients – mobile access
- Specialist doctor cover – would need some increase from current provision
- Cost benefit analysis – eg. admissions saved, palliative care currency, social benefit.

An interim solution is to invest in iPads and start to use Facetime to enable communication between professionals and patients. We can also explore the use of Airedale for Virtual Hospice rather than developing own. We would do OOH.

[17] Johnston, Bridget, et al. "An evaluation of the use of Telehealth within palliative care settings across Scotland." *Palliative medicine* 26.2 (2012): 152-161.

4.2. Develop a "Deciding Right App", which would use Touch-ID so don't need to passcode to access.

4.3. Develop a digitally enabled triage inpatient unit – nurses second on call, doctors on rota for advice, with FAQs on website 24/7.

Some other actions were also agreed:

4.4. Find out if it would be possible to use the Florence Telehealth system that Cumbria CCG has licensed.

4.5. Think about what apps are already available, that are suitable for end of life and palliative care, that are available at low or no cost to patients and carers.

Progress has been made on both of these, since the meeting:

4.4. The contact at Cumbria CCG is Cate Swift, Senior Commissioning Manager. She has expressed interest in working with the group.

4.5. We have contacted a new SME, ORCHA, who are developing a platform for assessing and reviewing apps, who have said they will undertake a piece of work collating relevant apps for the group.

Both of these need to be taken forward by a named individual(s) from the group.

5. Authors and affiliations

The workshop was led and co-ordinated by Alison Marshall and Andrew Sullivan, University of Cumbria. It was hosted by St Mary's Hospice, Ulverston. This report is produced jointly by all the attendees of the workshop, listed in alphabetical order:

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