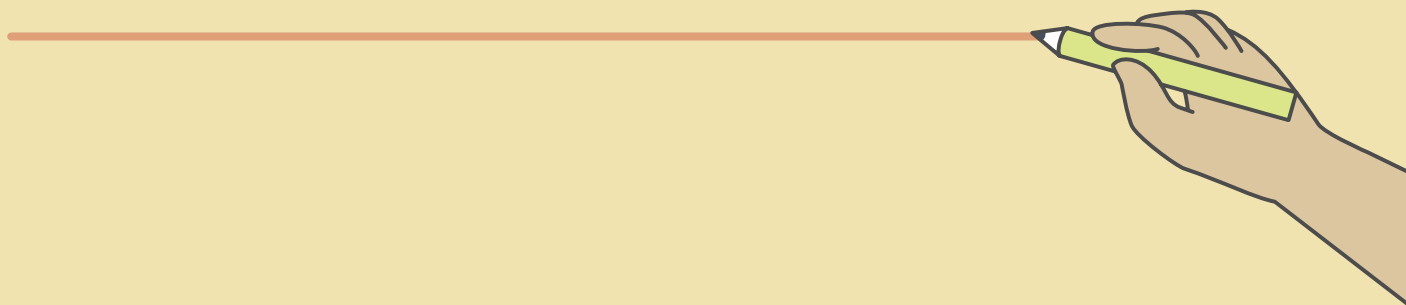
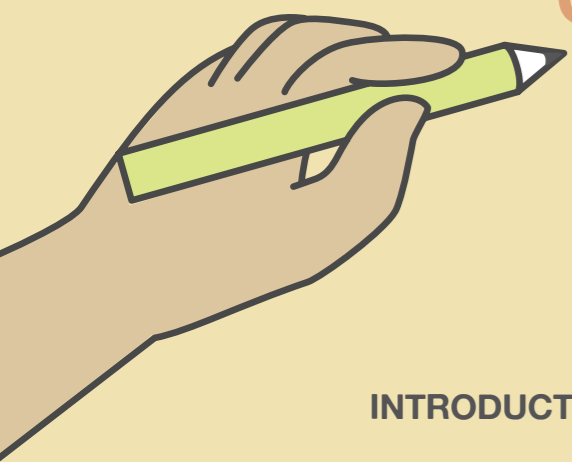


Electronic Palliative Care Co-ordination System (EPaCCS)

Review and Benefits Summary



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INTRODUCTION

This document was developed by members of the Greater Manchester and Eastern Cheshire Strategic Clinical Networks, Electronic Palliative Care Coordination Systems (EPaCCS), Network Implementation Group. A review of 31 available articles was undertaken to present the following information in this document.



BENEFITS TO INDIVIDUALS AND THOSE IMPORTANT TO THEM

- Increased number of individuals dying in preferred place of choice
- Increased Anticipatory Prescribing for those nearing the last days and hours of life
- Individuals consenting to information sharing improved (data sharing not a big concern for individuals)
- Communication with 'out of hours' improved
- Offered advance care planning and discussions
- Individual and family involved Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) decisions
- Increased support for carers
- Enhances collaboration between individual and professionals
- Reduces the burden of information sharing reduced for the individual or their family
- Individuals welcomed a system that would facilitate better transfer of information between services
- Opportunity to communicate, update and record their end of life preferences, empowering individuals



STATISTICS

87% those dying outside of hospital achieved their preferred place of death as opposed to 10% who died in hospital.¹

The likelihood of dying in hospital is substantially higher in patients who do not have a documented preference for the place of death (OR 1.43, 95% CI 1.26–1.62, $p < 0.001$).¹

Patients who were “not for resuscitation” had a 57% lower chance of dying in hospital compared to those who were “for resuscitation”.¹

Similarly, those who preferred symptomatic treatment were 64% less likely to die in hospital compared to patients who preferred full treatment with more interventionist approach.¹

Also, having hospital as their preferred place of care substantially increases the likelihood of dying in hospital (OR 2.77, 95% CI 1.94–3.96, $p < 0.001$).¹

If the preferred place of death is hospital, the likelihood of dying in hospital is more than doubled compared to patients who preferred some other place of death (OR 2.30, 95% CI 1.60–3.30, $p < 0.001$).¹

For those where EPaCCS was implemented, achievement of PPD was 95% (19 of 20 patients).²

82.4% of the patients of ‘Coordinate My Care (CMC)’ (an EPaCCS system) have died outside of hospital; 77.8% died in their preferred place, with 71.8% of them dying in the place of their first preference.³

Only 18% of those who died in a large cohort had an EPaCCS record. Few of these had non-cancer diagnoses.⁴

- ¹ The impact of advance care planning on hospital deaths: (2018). (A total of 21,231 anonymised individual CMC records with recorded place of death were included).
- ² Electronic palliative care coordination system (EPaCCS) in practice: A useful tool?: (2021) A retrospective analysis of the 65 decedents from last 12 months in the registered list of a single practice
- ³ Crash course in EPaCCS (Electronic Palliative Care Coordination Systems): 8 years of successes and failures in patient data sharing to learn from: (2016).
- ⁴ Underutilisation of EPaCCS (Electronic Palliative Care Coordination Systems) in end-of life-care: a cross-sectional study: (2021). Looking at 1723 deaths recorded between 22 February 2018 and 21 February 2019

PROFESSIONAL BENEFITS

- Good for emergency out of hours staff
- Accessible 24 hours a day 7 days a week
- Once identification tools and clinical validation have identified an individual to be in last year of life, EPaCCS is a positive tool to share their key wishes
- Helpful to service planners for commissioning future services for people in the last year of life.
- Well coordinated care
- Provide staff with key information/make appropriate decisions “real time”
- Improved quality and speed of decision making by paramedics
- Identified numerous barriers to data sharing
- Improved communication and ease of information sharing between professionals involved in a person’s care
- Makes a huge difference to where people die
- Improves confidence
- Improved professional patient relationship
- Remote workers may gain the most out of EPaCCS



SYSTEM BENEFITS

- Multiprofessional workforce
- Training on identification of and care planning discussions with patients with a potentially life-limiting illness.
- Drive training, systems and cultural change
- More patient information is a key factor in enabling paramedics not to adopt a 'default' approach of transferring patients to hospital
- Offers a solution to the inconsistent availability of information
- Decreases the percentage of hospital deaths and increases in the percentage of deaths at home and in hospices

INFORMATION GOVERNANCE

- Patients consenting to information sharing improved
- Templates to ensure consistent data entry and coding/Information standards can help
- Offers a solution to the inconsistent availability of information
- Although patients recognised that protecting patient confidentiality was important, the benefits of sharing information were perceived to significantly outweigh these concerns.

CHALLENGES AND BARRIERS

Information Technology

- Interoperability of IT systems
- Burden of inputting data and difficulties with IT systems as main challenges of implementing EPaCCS
- Numerous barriers to data sharing, primarily practical and technological, resulting in low use of the project tools
- Potentially only primary care staff could update the EPaCCS
- Significant challenges to aggregating data from EPaCCS systems
- Data ownership, consent, engagement of health professionals (particularly GPs) and funding
- Reliability of mobile devices and electronic systems
- EPaCCS need stronger integration into generic data sharing initiatives
- Professional resistance to engage with the system
- Ability of systems to report on progress and outcomes effectively
- Incompatibility of the Key Information Summary (KIS Scottish tool) with other clinical systems
- Investing time learning a new system would be wasted if ongoing infrastructure was not available to support its continued use



Advance Care Planning Conversations

- Difficult for GPs to start discussions about palliative care where a person living at home was gradually becoming frailer
- Time consuming to complete with much duplication
- EPaCCS relies on HCPs initiating conversations about death and dying
- Early discussions before a patient is deemed end of life would not have been documented so well and would therefore not prove useful.
- Results suggest that it may stop conversations completely and that patients would rather have repeated conversations than no conversation
- Not going to improve care if the information recorded within them is of poor quality or insufficient detail, or has not been completed
- Care home staff keen to contribute to Advance Care Planning, but little understanding of EPaCCS. Not sure it is part of their role
- Harder to remember to start a Key Information Summary (KIS Scottish tool) for people with advanced progressive illnesses other than cancer



General/Resources

- Information must strike a balance between being comprehensive, and yet succinct enough, to facilitate decision-making in an emergency situation





Resources


- Additional workload for primary care
- Demonstrates a need for investment in training for health and social care professionals in Advanced Clinical Practice discussions and documentation to instil confidence and improve quality





FOCUS ON SOLUTIONS

- 


Securing early buy-in from stakeholders tends to ensure better partnership working
- 


Chose a platform that stakeholders are familiar with
- 


Consider possible difficulties of interacting with IT providers - changes in staff managing the contract/IT glitches etc
- 

Consider data set that would be useful to collect. The core data set
- 

Require champions/project leads to continually advocate its benefits, ease of use and usefulness
- 

Appoint a clinical lead as well as an IT lead
- 

Consider training/don't rely on a cascade model
- 

Work together across localities - don't try to solve the issues alone
- 

Make it useful to patients and professionals

COST BENEFIT

Hospitalisation around end-of-life care currently costs between **£2800 - £3400 per admission¹**

.....

Only **22%** of individuals died in hospital with **78%** of patients dying in a non-hospital setting²

.....

Increased DIUPR figures from **37.9%-42.9%** with resultant saving from an unscheduled admission to hospital¹

Result in a saving of **£52 million.**

This study assumed a reduction of 229 admissions per year resulting in **£687,000** of savings in the area¹

.....

Cost of an admission to hospital ending in death has **reduced** but no reduction in the average cost of all unscheduled admissions³

1 London Journal of Primary Care. 5(2):106-10, 2013. Millington-Sanders C, Nadicksbernd JJ, O'Sullivan C, Morgan T, Raleigh A, Yeun P, Ormerod G Ovid MEDLINE(R) Electronic palliative care co-ordination system: an electronic record that supports communication for end-of-life care - a pilot in Richmond, UK. <https://www.ncbi.nlm.nih.gov/pmc/articles/PMC3960646/> [online] Accessed 4th February 2022.

2 Thomas C., Julia R., Stephanie A., Natasha W., Rosalind T., Joanne D. May 2018. Palliative Medicine. Conference: 10th World Research Congress of the European Association for Palliative Care, EAPC 2018. The impact of advance care planning on hospital deaths. 32 (1 Supplement 1) (pp 31), 2018.

3 NHS Improving Quality 2013 Economic Evaluation of the Electronic Palliative Care Coordination System (EPaCCS) Early Implementer Sites <https://www.thewholesystem.co.uk/wp-content/uploads/2014/07/economic-eval-epaccs.pdf> [online] Accessed 10th February 2022.

GREATER MANCHESTER OPPORTUNITIES

EPaCCS NETWORK IMPLEMENTATION GROUP

The Greater Manchester and Eastern Cheshire Strategic Clinical Networks EPaCCS Network Implementation Group has been established and consists of clinical, business intelligence and governance leads from across GMEC. The group meets bi-monthly and aims to accelerate standardised access and use of EPaCCS within the electronic systems of Greater Manchester via the Greater Manchester Care Record (GMCR), across health and social care providers, including primary care, secondary care, community providers, Hospices, The Christie Tertiary Centre, North West Ambulance Service (NWS), 111 out of hours services and other urgent care providers.

EPaCCS ROADMAP OF IMPLEMENTATION

A roadmap has been developed to support localities at whatever stage they are at in terms of implementing EPaCCS - by clicking onto any area of the map, resources can be found which may be useful to them at each stage. The roadmap and all the resources can be found on the

GMEC palliative and end of life care NHS Future Collaboration Platform. The roadmap takes you from the planning stages to full live use of EPaCCS and has been developed in partnership with areas who have successfully implemented EPaCCS.

COLLABORATION WITH THE GM DIGITAL WORK-STREAM, GREATER MANCHESTER CARE RECORD (GMCR)

The GMCR will provide clinicians and other primary secondary and third sector staff and organisations in Greater Manchester the ability to complete a prepopulated, bidirectional EPaCCS summary template that will be available across various organisations. There is a genuine opportunity to use the GMCR as a central tool to spread the adoption and use of EPaCCS and reduce the amount of siloed information. The GMEC Strategic Clinical Networks are working in collaboration with Health Innovation Manchester to support the use of the EPaCCS template on the GMCR as this work will ultimately lead to improved patient outcomes.

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