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NHS
North West

CENTRAL & EASTERN CHESHIRE END OF LIFE
SERVICE MODEL TEAM

e-PAIGE
WEB-BASED RESOURCE
FOR END OF LIFE CARE

SUMMARY

e-PAIGE is an Electronic Prognostic Assessment and Information Guide for End of Life Care (EOLC). This web-based resource was developed by Central & Eastern Cheshire's End of Life Service Model team to support health and social care professionals deliver care to patients at the end of their lives. It was launched in January 2013, and has already been adopted by many organisations across Central & Eastern Cheshire, including those in the voluntary sector. It will be rolled out to all care homes in the area from March 2013 onwards.

This dynamic, easy-to-use tool is available across all care settings and is used to support the management of patient pathways during the last year of life and into bereavement. It is based around the North West's EOLC Model and 'The Surprise Question' which was first proposed by the Gold Standards Framework (GSF) – *'would you expect your patient to live; months rather than years, weeks rather than months, or days rather than weeks'.*

KEY OUTCOMES

As e-PAIGE is still within the early stages of implementation and roll-out, this overview is designed to give an outline of how the tool works. A case study will follow to capture key metrics, once a full evaluation has taken place. Anecdotally, from the pilot phase, there is already evidence that the tool is beneficial to staff and patients alike, and there has been widespread support from frontline staff across a range of care settings. Within the East Cheshire Hospice many clinicians, from ward nurses through

to consultants, already use the tool on a daily basis.

- **Coordination and integration –** the creation of this tool and its roll-out has already led to stronger partnership working between health and social care services across East and Central Cheshire. This has led to a greater level of collaboration between staff in acute settings, the community, the voluntary sector, care homes, hospices and local authorities. Breaking down barriers in this way fosters integrated care, which is vital within a modern National Health Service

"The e-PAIGE is user friendly and reflects both national and local initiatives/policies/projects that are current and shaping the way for palliative care across our health economy within East Cheshire. There are many sections that direct you, the learner, to courses, conferences, further education events, local policy, New DNAR/CPR policy and much more. East Cheshire Hospice nursing team have given the big thumbs up to this new creative way of learning – being e-PAIGE". Jim Cunningham, Charge Nurse, East Cheshire Hospice, Macclesfield

- **Communication –** a broad range of organisations and clinicians currently provide EOLC, yet due to the wealth of information available many are not following the same protocols. This tool gives everyone a common language.

'I have found the e-PAIGE invaluable. I utilise this tool daily. It allows me to have quick easy access to contact

numbers, guidelines, protocols and advice which facilitates my every day practice as a specialist nurse working within palliative care. The information available is up-to date and evidence- based thus supporting my delivery of care to patients within East Cheshire.' Sarah Dale, Advanced Nurse Practitioner, East Cheshire Hospice

- **Knowledge –** Access to information and evidence-based resources will empower the workforce and provide them with the knowledge and skills they seek to improve their clinical abilities to support their patients, which will lead to higher standards of care

"I find e-PAIGE to be an incredibly useful resource. It has the potential to aid decision making with regards to specific patients but is also a fantastic resource for supporting continuing professional development. The potential of the tool to support CPD has expanded since being available online (i.e. accessible from home). I also find the tool useful when supporting colleagues (for example as to where to find particular guidance / forms) and think it is a real asset to our organisation!" Caroline Walker, Community Matron East Cheshire Trust

"Using the e-PAIGE to access information about fatigue really reassured me that this was normal while empowering me to give advice and information to the patient and carer" M Bell, Out of Hours GP

- **Efficiency –** due to the nature of this tool, the EOLC team can offer advice remotely on how to use it. This allows staff to access vital resources without necessarily having to take time out to attend a formal training session.

  "For me the e-PAIGE works well as all relevant end of life care literature and supporting documents are in one easy and accessible place, I can access the e-PAIGE at any time and anywhere" Alison Colclough, Cheshire Hospices Education

BACKGROUND

EOLC Team

Across Central & Eastern Cheshire there are an average 4,400 deaths per year and it has the fastest-growing ageing population in the North West, with 80% of the predicted population increase aged 65 and over. In response to this a partnership was formed between Central and Eastern Cheshire Primary Care Trust and a large range of local stakeholders, and an EOLC Service Model Team was created in 2010. This team is responsible for improving EOLC services across the region, and acting as a main point of contact for any queries. The team has been refined over the last three years to best fit the needs of local stakeholders and the Central & Eastern Cheshire workforce.

Rationale for the Tool

Prognosis at end of life presents a major challenge within both health and social care settings. Although it is intrinsically difficult to predict or identify which patients may be in their last year of life there are a number of resources and guidelines available that focus on improving prediction of need, and thereby guiding the delivery of a more supportive or palliative care approach. However many of these useful resources are under-utilised in practice, because often those caring for the patient are unaware or have forgotten that they exist. Health and social care professionals may not appreciate the true value of many EOLC-related resources unless they are applied within a particular context, and quite often the resource itself may not be easily accessible at the time when it is most needed.

OBJECTIVES

- More effective and proactive EOLC for patients and their families

- Better prognostication and earlier identification of EOLC requirements, to enable people to plan their own care

- Inbuilt reporting mechanisms showing increasing activity on the site

- Improved communication and coordination between health professionals across all health and social care settings

- User-led content being available throughout the resource and EOLC information put into context, so that relevant information is brought directly to the user

- Anecdotal evidence

- Measurable change in practice e.g. increased use of EOLC tools

- Increased confidence and empowerment of the local workforce evidenced through user evaluation, facilitated via Survey Monkey

- Improved access and increased uptake of education and training opportunities

- Raised profile of EOLC and of the EOLC Services team in all care settings

- Quality control of essential documents and pathways to support EOLC

KEY STAGES OF SETUP

Collaboration

Prognostication of dying often happens far too late, with patients often in the last hours of their life before someone realises. Mid Cheshire Foundation Trust pioneered the idea of bringing the Gold Standard Framework 'surprise question' into an acute care setting, to help clinicians see the big picture and to ensure earlier prognosis. This question helps staff to step back and look at things from their patient's perspective. The trust developed an electronic traffic-light system Prognostic Indicator Guide (PIG) which helps clinicians to apply this question in real clinical scenarios to determine where individual patients are in terms of EOLC, i.e. whether they are expected to live for months, weeks, or merely days.

In 2010 Mid Cheshire presented the PIG to the End of Life Service Model team, who had just carried out an audit at East Cheshire NHS Trust to examine why clinicians weren't initiating the Integrated Care Pathway for the Dying in a timely way, and what barriers were preventing them from recognising EOLC earlier. As a result the team decided to create an open-access, dynamic website, using the PIG and the Central and Eastern Cheshire EOLC model as a base to build upon. Originally the site was going to be acute focused, as it was at Mid Cheshire, however due to recent vertical alignment between acute and community services it was decided that e-PAIGE should be accessible to all care professionals, from a broad range of settings so as to be as inclusive as possible.

Market Research

Starting in the spring of 2010 the team ran focus groups and drop-in sessions with both acute and community based teams across East Cheshire NHS Trust, to determine how e-PAIGE could best meet staff needs. They used the following key questions to guide team specific content; 'what type of service do you provide to people who may be in the last year of life?', 'what would a good referral to your service look like?', and 'if we were to talk to a patient about your service what information would you like us to give them?' This allowed e-PAIGE to meet the needs of those teams who were delivering services as well as the needs of individual clinicians accessing the services on behalf of their patients.

Website Build

The End of Life Service Model team designed the site and commissioned East Cheshire's ICT Department to build it. An IT lead was assigned to the project to ensure that e-PAIGE met the team's outlined requirements.

HOW IT WORKS

Central to the design of *e-PAIGE is the North West EOLC model and the GSF surprise question*. As such the site offers a unique approach to EOLC, prognostication and management.

e-PAIGE brings together resources tailored specifically to the needs of the patient, family or clinician at any given time. It contains information gathered from a wide network of local, regional and national sources which are *aligned to individual stages of a patient's pathway.*

It can be accessed from any PC, tablet or smart phone and in any setting. Information is placed into context via *four individual management plans,* covering the assessment, ongoing management and discharge planning for a patient which a prognosis of months, weeks or days. The final manage-ment plan covers the first hours and days after death, into on-going bereavement care, therefore providing a local common language and a truly collaborative approach to the delivery of EOLC, regardless of patient diagnosis or place of care

Local generalists, specialists, voluntary and social care teams who have access to e-PAIGE have themselves contributed to the content of the resource, with many of them choosing to develop their own page within the site, where they profile the service that they offer and signpost professionals to relevant literature, and referral/criteria forms.

Additional unique selling points of e-PAIGE include:

- Built –in 'Suggestions tab' which allows users to share resources, websites and other documents which are then uploaded to the site by the End of Life Service Model team

- A Learning and Development page which supports the workforce and showcases local and national training opportunities

- A 'search the site' facility for quick and easy access to topic related resources

KEY CHALLENGES

Collaboration

- **Capacity –** it is difficult for the team to visit all care settings across the region in order to deliver training on e-PAIGE. Therefore, as well at providing bespoke face-to-face training and attending team meetings, the team offers telephone support where possible. Also, key partners such as Cheshire Hospice Education (CHE) regularly link back to e-PAIGE when running training courses.

- **Ownership –** ensuring that the site is kept relevant and up-to-date, and that it is actually utilised requires local health professionals to take ownership of it. To support this, the team has offered a lot of hands-on training rather than just circulating leaflets. The suggestion tab on the site also allows two-way commu-nication and enables people to submit content themselves. In addition, if the team notices that an area of the site is under-utilised they will either remove that content, move it to somewhere more appropriate, or launch a marketing campaign to raise awareness of that section. For those services which are signposted via the site, the team will email them every six months to check whether they need anything updated.

- **Internet Access –** whilst giving presentations at external conferences or running training sessions off-site it can be difficult to access the internet. Therefore the team purchased an internet dongle which allows them to overcome this problem. They also bring PowerPoint presentations show-ing screen shots of the e-PAIGE to every event as a backup.

- **IT Issues –** originally e-PAIGE was only accessible via the NHS's internal N3 system, meaning that only staff at NHS trusts could access it. However feedback was received that it should be on the internet instead as a broad range of health care professionals need access to it at home or whilst out in the community. Once live on the internet there were also some teething problems during roll out. Staff could not access the site within some trust buildings due to a specific server issue, which was having

a negative impact upon engagement. This issue was resolved once it was reported directly to Cheshire ICT by a clinician, rather than by a member of the End of Life Service Model team.

- **Engagement –** there is need to keep the momentum and passion going for the site amongst health professionals. However by having a strong lead within the team who is passionate about EOLC, and employing people who share her passion the team has been able to continuously drive promotion.

- **Feedback –** a pilot was carried out with GP practices and district nurses, but feedback was hit and miss. This might have been because the pilot was not planned correctly and because this coincided with the roll out of EMIS Web with community teams, so lessons learned will be incorporated into any further evaluation exercises.

KEY LEARNING

- It is crucial to keep the number of web administrators low within the team, otherwise the same document may be uploaded more than once. To help overcome this risk the team has one central email account. Throughout the month each team member forwards new documents to this account, and then a single member of the team uploads them.

- Palliative care can be extremely variable across the country, so e-PAIGE promotes national evidence-based care tools to ensure that it is aligned with what the NHS and Palliative Care Council are promoting.

- Support from NHS Communication Teams is vital in order to help promote the site effectively.

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- An email alert system will be set up, which people can sign up to in order to be informed of relevant training opportunities and events in their area

- The website is open access, but it is currently marketed to care professionals only. The team would like to incorporate a public-facing element, tailored to meet patients and carers' needs. This could be promoted via GP surgeries and NHS Direct to empower the public around EOLC planning

- Consideration is also being given to developing an e-PAIGE smart phone app. This is something that GPs in particular have expressed an interest in.

- A Grand Round Presentation of the e-PAIGE is planned for March 2013 at East Cheshire Trust

- The End of life Service Model Team are now delivering Statutory & Mandatory Training on EOLC to all clinicians working at East Cheshire Trust and as such are using the e-PAIGE to support this training ensuring widespread awareness of the resource

FUNDING

In 2011 Tracy Wright, the area's EOLC commissioner, included a target within the local CQUIN which made it a requirement that local NHS trusts needed to develop electronic tools to signpost clinicians to Advance Care Planning resources. Subsequently East Cheshire Trust provided funding to allow the e-PAIGE project to get off the ground. Additional funding was also sourced in 2012 via the NHS North West's 'Innovate Now' funding stream, which enabled targeted work around branding the e-PAIGE and supporting the marketing of this to the local workforce, which would signpost clinicians towards these tools. Funding was also attained via Macmillan Cancer Support specifically to roll out the e-PAIGE to local Care Homes in return for a feature article on the Macmillan Learnzone site providing tips on how other teams can develop their own version of e-PAIGE.

The End of Life Service Model team which manages the site is currently funded via Macmillan Cancer Support and Multi-Professional Education & Training Monies (MPET) released by the Greater Manchester & Cheshire Cancer Network. Local stakeholders and charities have also allocated funding to the team enabling continuation of this approach until end March 2014. A local sustainability group is proactively seeking funding beyond 2014 and are working to integrate the End of Life Service Model Team into the business structure of local NHS services.

SUSTAINABILITY

To ensure that e-PAIGE remains sustainable the team will continue to promote it within local training sessions, and will use it to help direct people following telephone/email queries. Within East Cheshire Trust all staff are able to directly access the site via a link on the intranet homepage and application launcher, this enables quick access when logged in from any trust computer.

Local ownership of the site is a key priority, as this will encourage care professionals to sustain usage. The site will also be promoted at national conferences, and it is hoped that Macmillan will help to champion it, in order to attain further recognition and uptake.

NEXT STEPS

- A cross-setting Integrated Care Pathway (ICP) audit is planned for March 2013. e-PAIGE will help signpost different staff groups to resources in support of this audit

- An evaluation of e-PAIGE is planned for summer 2013. To enable this reporting system has been built into the tool, and baseline data has already collected to allow effective benchmarking

- The team is currently writing up a 'Top Tips for EOLC' guide for Macmillan, in return for the Care Homes funding and this will be accessible to all professionals via the 'Learn Zone' on MacMillan's website

SUPPORTING MATERIAL

- **e-PAIGE - www.cheshire-epaige.nhs**

- **Case Study: *Central and Eastern Cheshire PCT & Cheshire Hospice Education– End of Life Care Service Model***

- **Case Study: *EOLC Services Team- Integrating EOLC Competencies in staff appraisals***

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