

REPORT TO: Health Policy & Performance Board
DATE: 29th June 2021
REPORTING OFFICER: Chief Commissioner, NHS Halton CCG
PORTFOLIO: Health & Wellbeing
SUBJECT: Palliative and End of Life Review
WARD(S) Borough-wide

1.0 PURPOSE OF THE REPORT

1.1 To update the Board on the Palliative and End of Life project in Halton.

2.0 RECOMMENDATION: That:

- i) The Board note the experienced based design engagement and co-design approach and feedback as part of the project.
- ii) The Board acknowledges that the palliative and end of life care project should provide Halton with a more integrated and coordinated provision of care for palliative patients and their families.

3.0 SUPPORTING INFORMATION

3.1 The project was established in November 2020, a funding bid was secured from Macmillan Cancer Support, which funded the role of Macmillan Project Manager and the extension of Programme Manager. The project team initially developed a storyboard, setting the baseline utilising all sources of available data in respect to those in the last 12 months of life. This was communicated with stakeholders and the public to share insight. The project established a monthly stakeholder steering group to support in developing and driving the project forward.

The project has developed documentation to support in line with the requirements of the project management office including milestone plan, logic model, risk and opportunities register, equality impact assessment, quality impact assessment, data protection impact assessment and outcomes. To date the project has met all milestones and is on track to meet future milestones.



Halton Int Pall & EOL
milestones.xlsm

3.2 The project will support the requirements of *Ambitions for Palliative and*

End of Life Care - A national framework for local action 2015-2020 (the framework is currently being refreshed).

CCG's are required to deliver against the national requirements for Palliative and End of Life Care:

- Increased percentage of people who die that have been offered the opportunity for personalised care planning in their last year of life: Nationally 39.6% (currently on GP palliative care register) increase to 75% in 10 years.
- Over 80% of people achieving their preferred place of death (nationally currently 59%).
- Improve experience of care reported by patients, carers and bereaved families, from current baseline, year on year.

This will be delivered through:

- Identification of people who are deteriorating from their condition(s) and likely to die within next 12 months.
- Better, proactive conversations through shared decision-making and personalised care and support planning.
- Appropriate sharing of key information.

3.3 NHS Right Care data set out strategic priorities for end of life care for 2020/21 to support to significantly improve patient choice in end of life care, including ensuring an increase in the number of people able to die in their place of choice, including at home.

Right Care data highlighted Halton's inconsistencies using data from the 10 most demographically similar CCGs in order to identify realistic opportunities to improve health and healthcare for the population:

- Below average percentage, nationally and against peers, for death in usual place of residence for people with cancer.
- Lowest quintile, nationally and against peers, of deaths in usual place of residence for people with circulatory diseases.
- High number of days (nights) emergency hospital admissions during last year of life for people with dementia, circulatory and respiratory diseases in comparison to peers.
- High number of days (nights) ordinary hospital admissions during last year of life for people with dementia, circulatory and respiratory diseases in comparison to the national average.
- High percentage of dementia and respiratory patients with an emergency hospital admission during last year of life 2013-2015, in comparison to peers.
- Highest quintile nationally of percentage of patients with Dementia with emergency hospital admissions in last year of life 2013-2015.

Measures of success:

- Increase in people with a life-limiting progressive illness identified as being in the last year of life.
- Increase in the number of people offered the opportunity to develop, record and share a personalised care plan.
- Interoperable Electronic Palliative Care Co-ordination system (EPaCCs) in place and used across the country by 2020.
- Increase in % of people who are cared for and die in their place of choice.

- Improvement in patient and carer experience, especially in symptom control, decision-making processes, coordination of care and knowing where and how to access help and advice when needed.
- Specialist palliative care advice is accessible 24/7 regardless of care setting.
- Increase in % of patients with non-malignant disease involved with specialist palliative care.

3.4 The project key drivers for change:

- Hospice UK (2016) state that 75% of deaths were 'predictable deaths' this allows for proactive advanced care planning, including acknowledgement of preferred place of death.
- In Halton in 2018 only 40% of patients died at home, 51% of deaths were in a hospital setting. The aim would be to increase the number of deaths outside of the hospital setting, this provides an opportunity to improve outcomes for patients, workforce and achieve financial sustainability.
- Current inconsistencies with Gold Standards Framework (GSF) meetings in Primary Care.
- Poor (Electronic Palliative Care Co-ordination Systems) EPaCCs uptake.
- No standardised in-depth retrospective death audit.
- There is currently no agreed Advance Care Plan document in Halton.

3.5

An aim of the project is to further development and implementation Electronic Palliative Care Coordination system for Halton. Which will facilitate sharing of up-to-date information about patient preferences and plan of care, in a format that allows sharing of information across different healthcare providers. A baseline of patients on the Gold Standards Framework was completed in November 2020, which highlighted that 1.1% of patients in Halton were registered on the GSF register, this is above the expected 1% however it varies significantly between practices and areas with Runcorn reporting 1.68% and Widnes reporting 0.46%. It is recognised that support is required to ensure that the right cohort of patients are being identified.

A potential reason for the reported poor performance could be that Primary Care are currently not recording the correct GSF codes. As part of the project, the EPaCCs template is being reviewed in collaboration with key stakeholders and then will be rolled out across Primary Care.

3.6

The Halton End of Life Care project's engagement process took place over a two-month period from February – April 2021. There were 12 responses submitted in the form of completed word documents. There were 38 professional/ staff responses to an online survey (the questions were the same as those in the word document). Additionally, there were 16 responses from families/carers/third sector groups. This makes a total of 66 responses, some of which represent a service/team. The responses are from a good range of different organisations and staff groups.

The feedback was independently analysed, and the main themes were:

- Communication and documentation need to be improved – with families, carers and professionals around what to expect, and what services are available.
- Identified need for a standardised advanced care plan. Some GPs seem to be very well engaged and work well together, others less so.
- Some specific mentions of not sharing, feeding back of information from e.g., GSF meetings.
- There are several mentions of requiring a ‘specialist’ palliative care hospice. Additionally, some mentions of specific outpatient clinics. This is a particular issue in the town with the Hospice being underutilised but at the same time incidents of referrals being declined. There is a sense that care needs to be equitable (particularly in the ‘hopes’ question).
- Some comments on CHC (Continuing Health Care), the process and not being available certain times (weekends/bank holidays).
- It is clear that care and support needs to be timely and responsive to patient need. Delays are frustrating for the patients/families and professionals.

Halton undertook a whole system self-assessment against the *Ambitions for Palliative and End of Life Care - A national framework for local action 2015-2020* in 2019. The areas highlighted as requiring improvement from the self-assessment were:

- Honest conversations, advanced communication training.
- Central information point where people can access.
- Integration of services
- Equity of end-of-life provision
- Person centred outcome measures
- Addressing all forms of distress
- Shared records, EPaCCS
- Single point of referral
- Everyone matters, inclusive strategy i.e. Learning Disabilities
- Education and training strategy available across all settings
- Use of new technology
- Public awareness and discussion, information available
- Volunteers to specifically support end of life patients

This was added to the report to provide a whole picture of work undertaken in Halton.

An engagement feedback event was held on 28th April 2021 to present the findings. Attendees at the event were asked to prioritise the themes to identify key workstreams for further development. The five workstreams identified were:

1. Standardised EOL Care Coordination
2. Education and Training
3. Specialist Medical Hospice Provision
4. Single Point of Access
5. Inclusion of vulnerable groups

The workstreams will feature members from the project’s Steering Group and professionals, patients and carers to co-design solutions.

4.0 **POLICY IMPLICATIONS**

4.1 The proposed integration of Palliative and End of Life Care services would ensure Cheshire and Merseyside are compliant with the National recommendations.

5.0 **OTHER/FINANCIAL IMPLICATIONS**

5.1 The reconfiguration is being developed within the existing resources for palliative and end of life care.

6.0 **IMPLICATIONS FOR THE COUNCIL'S PRIORITIES**

6.1 **Children & Young People in Halton** – none anticipated

6.2 **Employment, Learning & Skills in Halton** – none anticipated

6.3 **A Healthy Halton** – none anticipated

6.4 **A Safer Halton** – none anticipated

6.5 **Halton's Urban Renewal** – none anticipated

7.0 **RISK ANALYSIS**

7.1 The risks to the system for the project are being managed within the Palliative and End of Life Steering Group and Clinical Service Development group being assessed and mitigated before and service changes are made.

8.0 **EQUALITY AND DIVERSITY ISSUES**

8.1 An equality and diversity assessment has previously been undertaken as part of the wider palliative and end of life programme.

9.0 **LIST OF BACKGROUND PAPERS UNDER SECTION 100D OF THE LOCAL GOVERNMENT ACT 1972**

9.1 None under the meaning of the Act.