# Goldline Service

# Year End Report

## 1st April 2018 to 31st March 2019

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Airedale Digital Care Hub

NHS Airedale NHS Foundation Trust

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## Executive Summary

Goldline was developed with the support of the Health Foundation and subsequently commissioned by Bradford Districts (BD), Bradford City (BC) and Airedale, Wharfedale & Craven (AWC) CCGs (population 585,304 (ONS, midpoint 2017)) to support the delivery of high quality end of life care. The service can be offered to anyone registered with a GP in the Bradford, Airedale, Wharfedale and Craven CCGs (BAWC) who meet the eligibility criteria for the Gold Standards Framework or GSF (i.e. any person thought to be in or approaching the last year of life).

A range of NHS and voluntary sector providers and commissioners across organisations work collaboratively to provide care for patients at the end of life and their families. Within this area the Electronic Palliative Care Coordination system (EPaCCS) is well established and all information can be shared where appropriate via the electronic patient record held in SystmOne, which all providers use or have access to, including out of hours services. This linkage enables holistic care goals and patient preferences to be recorded and accessed by all services at the point of need. Regular GSF meetings occur across the community in the CCG areas, and support has been given to GP surgeries to enhance the use of EPaCCS during these meetings and ensure information is updated.

Goldline provides a 24/7 single point of contact for patients and their carers to enable them to access support, help, advice and onward referrals to other appropriate services if required. It aims to support patients in their preferred place of care (PPOC) wherever possible and is staffed by experienced health care professionals, mainly nurses. The Goldline team have access (with patient consent) to the full electronic patient record on SystmOne to inform and enhance care advice, specifically information recorded within our local EPaCCS via a dedicated palliative care template.

Referrals to Goldline are made electronically via a simple process within the EPaCCS template on SystmOne. All primary healthcare teams, specialist palliative care services and staff at Airedale NHS Foundation Trust (ANHSFT) can use this process to refer patients. Bradford hospitals, care homes and community hospitals send referrals by secure fax or email (faxes will be withdrawn in the coming months). Referrals from care homes are made following discussion and agreement with the residents' primary health care team.

Goldline has been established since November 2013, and the number of calls taken per year has grown from just under 400 in the first 5 months, to nearly 15,000 calls in 2018/19. Referrals have grown from 569 in the first 5 months, to over 3,000 in the year 2018/19. Of the 4863 deaths within Bradford, Airedale, Wharfedale and Craven CCGs (BAWC) in 2018/19, 2,354 patients were registered with Goldline, and this approximates to 48% of all deaths in these CCG areas, and 65% of all deaths which could have been predicted (assuming that 25% of deaths occur unexpectedly: *Ref. Predicting Death, Estimating the proportion of deaths that are 'unexpected'. National End of Life Care Intelligence Network*).

Broken down into individual CCG areas, we can see that AWC has the highest proportion of people who died registered to Goldline (56% of all deaths and 75% of 'predictable' deaths). This means that a high proportion of people who are in their last year of life within AWC are identified. This enables anticipatory care planning and is likely to contribute to some of the best EOL performance measures in England and Wales, including fewer deaths in hospital. 33.5% of all deaths in AWC were in hospital, and only 17% of AWC deaths registered to Goldine, died in hospital. This compares to figures for England overall where 45.5% all deaths are in hospital. AGH also has one of the lowest figures in the country, and the lowest across the STP, for the percentage of people who have 3 or more emergency admissions in the last 90 days of life (4.8% vs 6.9% across England) This outcome is within the 'CCG Improvement and Assessment framework' as an End of Life care indicator .

Goldline has a reach beyond those referred to specialist palliative care (only 59% of Goldline patients who died were known to specialist palliative care services) and a wide range of diagnoses, with 57% of referrals this year having a non-cancer diagnosis. The majority of people who call Goldline remain in their home after the call, enabling them to have the care and support they need in their place of preference. Goldline co-ordinates well with other services, but is increasingly able to deal with calls without an onward referral (2017/18: 38% of calls 2018/19: 43% of calls).

Goldline is now established as a vital link in the services available to people in the last year of life, working with the other service to support them to live and die with the right care and in the place of their choosing.

Goldline 24/7 Patient Care

## 1.0 Patient and carer feedback

Many thanks for all the telephone support, assistance and practical care the Goldline team gave us as a family during {his} long illness. It was incredibly reassuring to know someone would always be there when we were unsure or struggling, and was invaluable during the last few days of {his} life, helping to make a terrible situation that little bit easier. Everyone we came into contact with was caring, professional and working in the best interests of {...}, to help make him comfortable and live the ending his life with dignity and according to his wishes. On behalf of {...} we would like to thank you all very much.

The creation of Goldline was a great idea, puts my mind at rest as I know medical aid is available at anytime, day or night. I have used Goldline on three occassions, twice for advice and once in an emergency. Received an excellent response in all situations.

To all staff working on Goldline - You are the most amazing team who were there for us at the most difficult time. You supported us to take our dad and care for him at home during the last days of his life, which is the most precious gift.

Your advice, support and kindness showed towards our amazing loving dad will never ever be forgotten by our family, and especially myself as I stayed 24/7 with dad in his final days. Without your support this would not have been possible. Dad was in his own home, in his own bed. I/we cannot praise you enough as you are truly amazing.

# REAL SERVICE. REAL FEEDBACK.

It gives peace of mind that someone is on the end of a phone. I used Goldline on numerous occassions and found the support they gave invaluable. The Call Handlers are obviously trained and have a lot of experience. They offer support and give reassurance, whilst managing calls/queries in a professional, compassionate manner. A 5* service.

Without your teams' help we could not have managed to grant him his last wish, and that was to die at home in his own bed. We would particularly like to thank Goldline for getting us help when we needed it at such short notice, and on numerous occassions. You all do a wonderful job, many, many thanks.

Thank you so very much to all the Goldline for all your care and advice when needed. Having someone on the phone when scared, panicked, unsure was invaluable to me and my Grandma. What an amazing service.

Extremely helpful, I would not have known who to contact particularly at weekends. Helped me manage at home, absolutely brilliant service.

Goldline enabled us to get equipment and support at the right time to care for mum. Enabled me to meet work commitments in the knowledge my dad could call for help. Enabled my mum to die at home with family and dignity, as per her wishes.

It provided extra reassurance to know a health professional is available 24/7. It is a useful service and helped me manage at home.

## 2.0 Activity Reports

The figures below relate to the period 01/04/18 to 31/03/19 unless otherwise stated.

### 2.1 Deaths

In the year Jan 18 - Dec 18 there were 4863 deaths (ONS Rolling annual death registrations) across the three CCGs, split as below:

| CCG figures | Popn. | Deaths | % Deaths |
|---|---|---|---|
| Airedale, Wharfedale and Craven CCG | 159,822 | 1661 | 1.04% |
| Bradford City CCG | 84,958 | 458 | 0.54% |
| Bradford Districts CCG | 340,524 | 2744 | 0.81% |
| Totals | 585,304 | 4863 | 0.83% Mean |

It is clear that the profiles of deaths across the CCGs are different with twice as many deaths per head of population in AWC compared to BC CCG.

**Appendix 1** summarises the most recently available data from the National End of Life Care Intelligence Network.

### 2.2 Referrals

Eligible patients need to consent to being part of the Gold Standards Framework and also to allow health care professionals to access their electronic patient record if they use Goldline. This consent is taken verbally and recorded on their EPaCCS template. Patients and/or carers are given written information in the form of a patient leaflet (see **Appendix 2**), which also includes a sticker with the Goldline telephone number.

Referrals are made electronically via a quick and simple process within the EPaCCS template on SystmOne. All primary healthcare teams, specialist palliative care services and staff at ANHSFT can use this process to refer patients. Other acute hospitals, care homes and community hospitals send referrals by secure fax (to be discontinued and replaced with online referral form in Summer 2019) or email. Referrals from care homes are made following discussion with residents' primary health care teams.

Electronic referrals are received as a task by the Goldline team; all referrals are then registered on the Goldline caseload on SystmOne. This ensures that the patient details are immediately available to the Goldline staff at the point the patient/carer calls.

Total number of referrals (all BAWC CCGs) = 3,079
Demographic information: Female = 1,720 (56%); Male = 1,359 (44%)

| Age Range | Number | Percentage |
|---|---|---|
| 80+ | 1,889 | 61% |
| 70-79 | 637 | 21% |
| 60-69 | 329 | 11% |
| 50-59 | 152 | 5% |
| 40-49 | 49 | 2% |
| 30-39 | 16 | 1% |
| 20-29 | 7 | 0% |
| 10-19 | 0 | 0% |

| Ethnicity | |
|---|---|
| White British | 2,325 (76%) |
| Other ethnic group | 277 (9%) |
| Asian incl. Mixed | 239 (8%) |
| Black/African/Caribbean incl. Mixed | 13 (0%) |
| Unknown | 225 (7%) |

- 57% of the patients referred to Goldline who died during the year ending 31/03/19 had a non-cancer diagnosis
- 41% of the patients referred to Goldline who died during the year ending 31/03/19 have never had a referral to specialist palliative care services

## 2.3 Length of time patients are on Goldline

Of those who died in the year (n=2,354)

- Minimum number of days on caseload = 3 days
- Maximum number of days on caseload = 2,017 days (approx. 67 months)
- Median number of days on caseload = 316 days (approx. 45 weeks)
- Average number of days on caseload = 416 days (approx. 14 months)
- 949 (40%) were on the caseload for more than 12 months
- 371 patients (16%) were on the caseload for over 24 months

Of the 2,686 active patients on the Goldline caseload (caseload snapshot May 15th 2019)

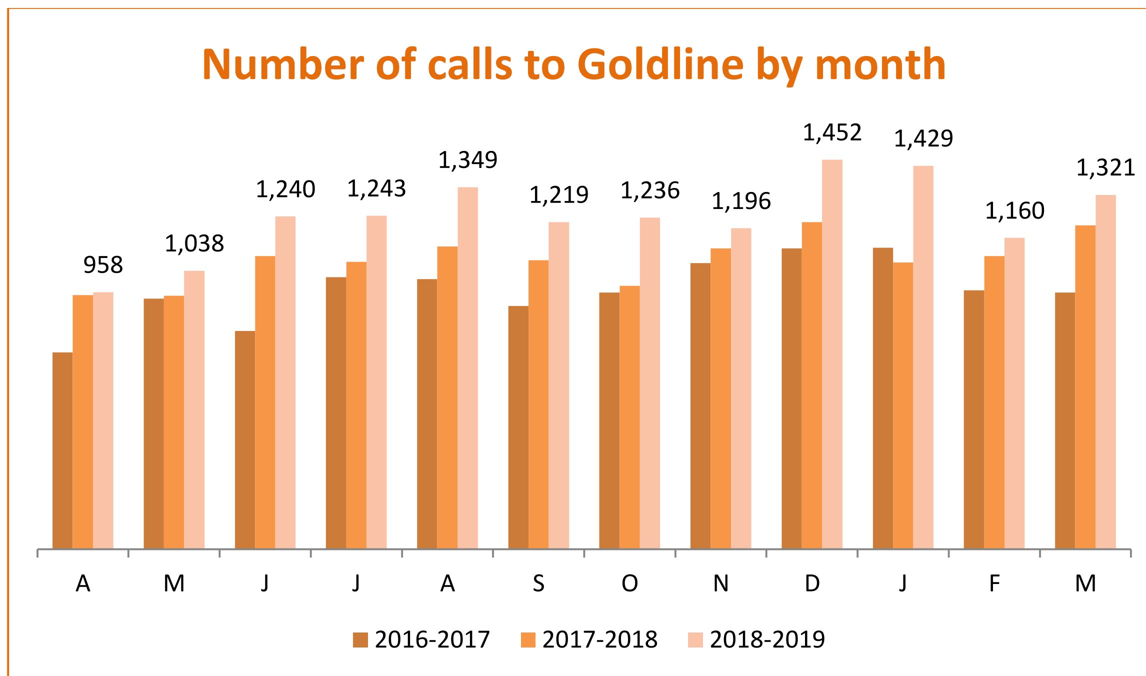
- Minimum number of days on caseload = 1 day
- Maximum number of days on caseload = 2,063 days (approx. 69 months)
- Median number of days on caseload = 295 days (approx. 42 weeks)
- Average number of days on caseload = 420 days (approx. 14 months)
- 1,190 (44%) have been on the caseload for more than 12 months
- 570 patients (21%) have been on the caseload for over 24 months
- 199 patients (7%) have been on the caseload for over 36 months

40% of patients who died this year were on the caseload for more than a year before they died, however, only 16% were on for more than 2 years, suggesting that professionals can be reassured that they are identifying patients appropriately even though this can feel a challenging task.

Of patients who remain alive, the percentage who have been on the caseload for longer than a year has increased to 44% from 40% last year.  21% of the same caseload continue to be registered at 2 years.

Since the beginning of 2017, the Goldline team have been identifying all patients who have been on the caseload for longer than 30 months. A request is sent by task to the primary care team to check if the referral is still appropriate- some patients will have moved away from the area, the clinical situation may have changed etc.  If a referrer feels that the Goldline is still appropriate for that patient, the referral will be left open.

## 2.4 Details of calls




| Total incoming calls in the year | |
|---|---|
| 2016/17 | 11,597 calls |
| 2017/18 | 12,951 calls |
| 2018/19 | 14,841 calls |

| 2018/19 Incoming calls by CCG | |
|---|---|
| Airedale, Wharfedale and Craven | 5,754 calls (39%) |
| Bradford City | 1,266 calls (9%) |
| Bradford Districts | 7,792 calls (53%) |
| Other CCGs | 29 calls (<1%) |

Of the 14,841 calls received, 916 were to report a death. Having support from the Goldline team when dealing with a death is invaluable to grieving carers and family members, who have compassionate support and help to cope with the practicalities of the situation, including verification of death processes and referral to funeral directors.

## 2.5 Number of patients the calls relate to:

The 14,841 calls were made by 2,379 individual patients.

| 2018/19 Patients calling by CCG | |
|---|---|
| Airedale, Wharfedale and Craven | 1,012 (42.5%) |
| Bradford City | 170 (7.1%) |
| Bradford Districts | 1,188 (49.9%) |
| Other CCGs | 9 (<0.5%) |

## 2.6 Timing of calls

68% calls are taken 'out of hours' i.e. outside 8am to 6pm on weekdays, the remaining 32% occur between 8am and 6pm on weekdays. Patients and families frequently comment on the reassurance that Goldline provides them, knowing they will receive timely advice especially when other services are closed or less easily contactable out of office hours.

## 2.7 Outcome of calls

Each telephone call to Goldline is assessed by the team member who takes the call. When the call is closed they record the care/advice/actions etc. taken during/following the call and document this in SystmOne.

## 2.8 Disposition after call

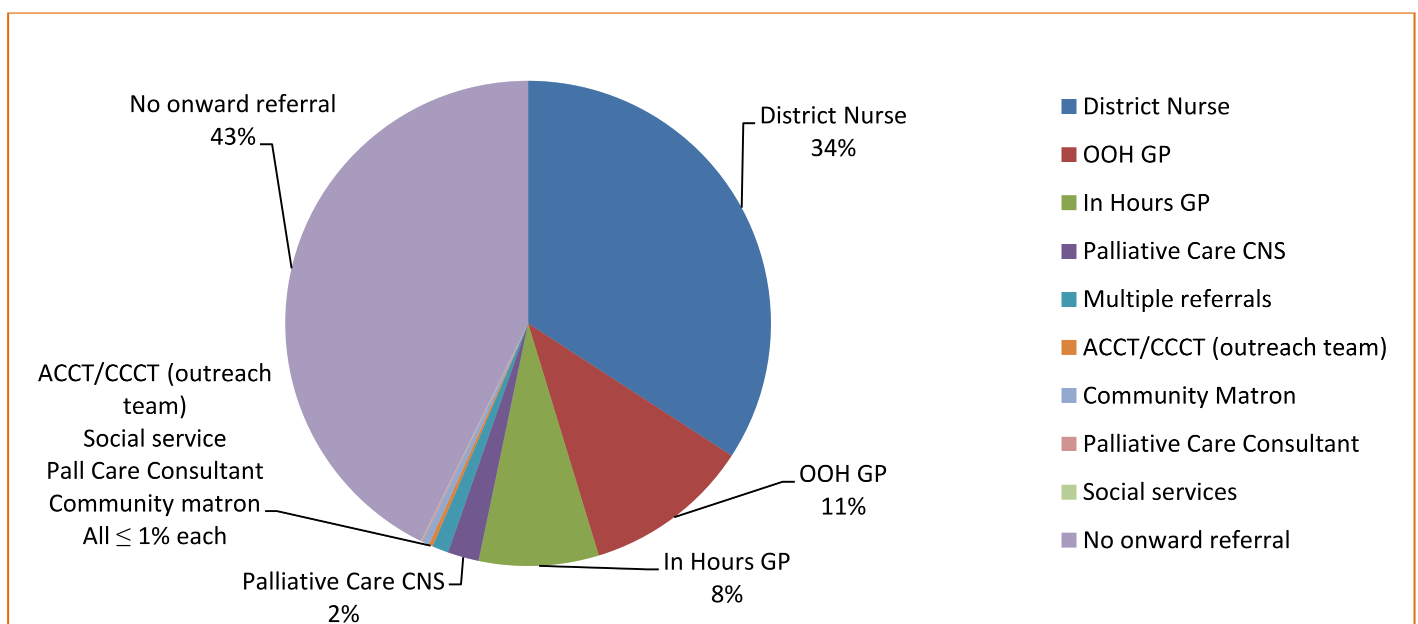
| Disposition after call (excluding calls to report a death [n=916]) | |
|---|---|
| Patient remained in place of residence | 97% |
| Ambulance called to assess | 3% |

Note that although 97% of patients remain in their place of residence at the end of the call, a subsequent visit by a GP (19% of calls are referred on to a GP for a visit) may result in a hospital admission. An audit of calls that were passed on to GPs over a 7 day period showed that of 55 GP referrals, 2 patients were admitted to hospital and 1 to hospice. When an ambulance is called to assess, not all paitnets will be admitted, the ambulance team are often asked to call the hub and a decision is made at that point.

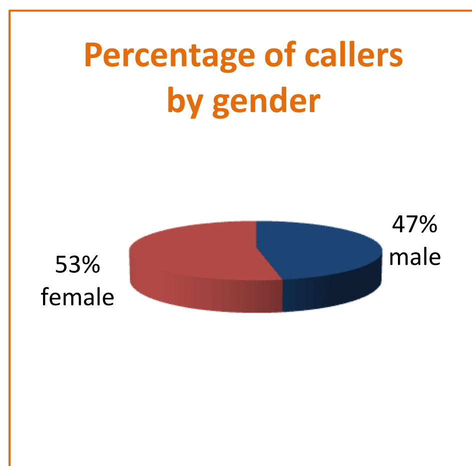
## 2.9 Onward referral

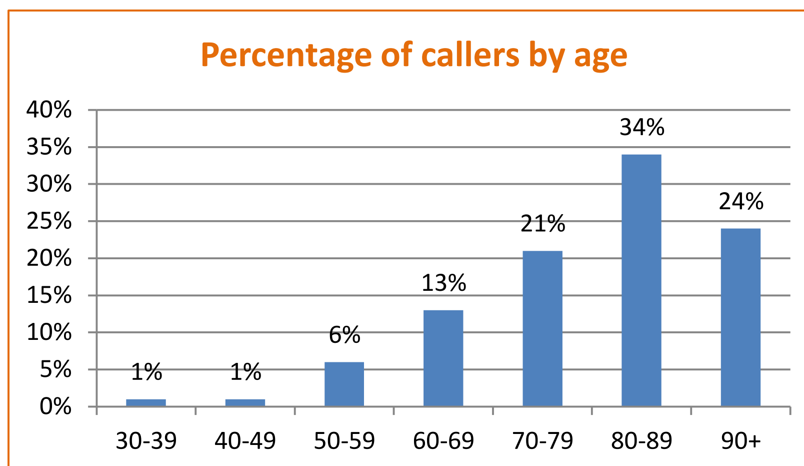
Excluding the calls to report a death (n=916), 43% of the remaining 13,925 calls were resolved by the Goldline team and did not require onward referral, and 57% were referred on to another professional.

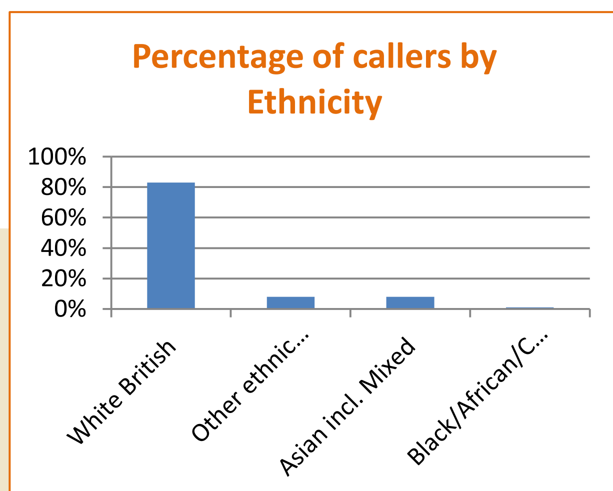
| Onward referral | Number of calls | % |
|---|---|---|
| District Nurse | 4,759 | 34% |
| OOH GP | 1,549 | 11% |
| In Hours GP | 1,110 | 8% |
| Palliative Care CNS | 290 | 2% |
| Multiple referrals | 151 | 1% |
| ACCT/CCCT (outreach team) | 37 | < 1% |
| Community Matron | 64 | < 1% |
| Palliative Care Consultant | 12 | < 1% |
| Social services | 4 | < 1% |
| No onward referral | 5,949 | 43% |
| **Total** | **13,925** | |

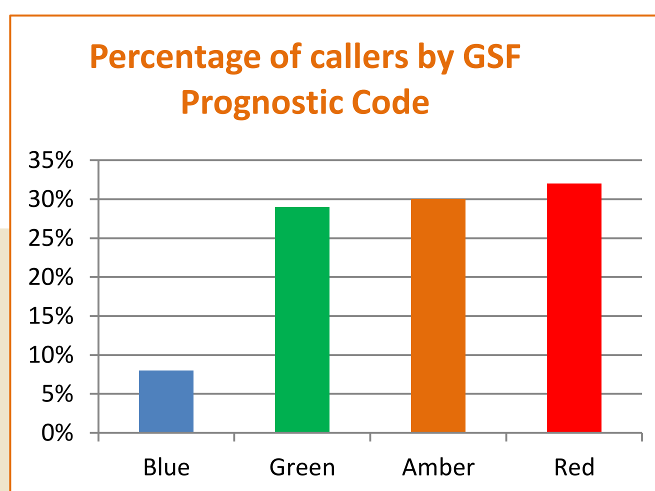


## 2.10 Characteristics of callers to Goldline (all BAWC CCGs)




## 2.11 Place of death

- 2,354 patients died with Goldline support in the year ending 31st March 2019
- 2,318 had a place of death recorded

| Place of Death | Goldline | England (Dec 2018) |
|---|---|---|
| Home | 727 (31% of 2,318) | 23.7% |
| Care Home | 859 (37% of 2,318) | 22.5% |
| Hospice | 335 (15% of 2,318) | 5.8% |
| Hospital | 397 (17% of 2,318) | 45.5% |
| Total | **2,318** | |

| Place of Death with GL by CCG | AWC | Bradford | Other |
|---|---|---|---|
| Home | 232 (25% of 925) | 484 (35% of 1,364) | 11 |
| Care Home | 428 (46% of 925) | 418 (31% of 1,364) | 13 |
| Hospice | 112 (12% of 925) | 221 (16% of 1,364) | 2 |
| Hospital | 153 (17% of 925) | 241 (18% of 1,364) | 3 |
| TOTAL | **925** | **1,364** | **29** |
| Deaths in usual place of residence | 660 (71% of 925) | 902 (66% of 1,364) | |

## 2.12 Preferred versus actual place of death

- 1,293 of the people on Goldline who died in the year had a documented preference place of death (PPOD - home, hospital, care home, hospice)
- In addition, for 261 patients there was documented evidence of: were unable to discuss (n=85), declined a discussion (n=24), discussion was not appropriate (n=130), were undecided (n=22) or their decision was ambiguous (n=0)
- 800 patients had no information about preference recorded
- **954 (74%) people who expressed a preference achieved their preference**

| Preference as recorded on EPaCCS (the last known preference recorded before death) | | Actual place of death known and matches PPOD |
|---|---|---|
| Home | 638 (of these, we know the actual place of death for 636) | 422 (66%) |
| Hospital | 23 | 21 (91%) |
| Care home | 338 | 301 (89%) |
| Hospice | 294 | 210 (71%) |
| Discussion not appropriate | 130 | N/A |
| Patient declined discussion | 24 | N/A |
| Patient unable to express preference | 85 | N/A |
| Patient undecided | 22 | N/A |
| Ambiguous | 0 | N/A |
| No entry on EPaCCS | 800 | N/A |
| Total | **2,354** | **954** |

Of the 36 who we do not know the place of their death, 8 had an expressed PPOD recorded: home (n=4) / hospital (n=0) / care home (n=2) / hospice (n=2).

## 2.13 Other key recorded EOL information

The frequency of other relevant information recorded within the patient electronic record is provided below. This shows that the majority of patients have key information recorded within their EPACCS template, including preferred place of care, RAG coding for prognosis and resuscitation status.

| Patients | 931 Deceased pts (AWC CCG) | | 1,377 Deceased pts (Bradfd.CCGs) | | Total (n=2,308) |
|---|---|---|---|---|---|
| Referral to pall. care code (XaAex) | 491 | 53% | 879 | 64% | 1,370 (59%) |
| GSF register code (XaRFG) | 928 | 100% | 1,358 | 99% | 2,286 (99%) |
| Cancer diagnosis | 373 | 40% | 720 | 52% | 1,093 (47%) |
| Non-cancer diagnosis | 597 | 64% | 709 | 51% | 1,306 (57%) |
| - Parkinson's disease | 17 | 2% | 12 | 1% | 29 (1%) |
| - Motor neurone disease | 4 | 0% | 6 | 0% | 10 (0%) |
| - Dementia | 221 | 24% | 219 | 16% | 440 (19%) |
| - Cirrhosis of liver | 9 | 1% | 23 | 2% | 32 (1%) |
| - End stage renal failure | 11 | 1% | 25 | 2% | 1 (2%) |
| - Degen. nervous system diseases | 47 | 5% | 27 | 2% | 74 (3%) |
| - Heart/circulatory disease | 80 | 9% | 71 | 5% | 151 (7%) |
| - Other non-cancer diagnosis | 132 | 14% | 215 | 16% | 347 (15%) |
| - Chronic respiratory disease | 60 | 6% | 94 | 7% | 154 (7%) |
| - Multiple | 16 | 2% | 17 | 1% | 33 (1%) |
| Prog. Indicator stage A (blue) | 48 | 5% | 68 | 5% | 116 (5%) |
| PI stage B (green) | 152 | 16% | 379 | 28% | 531 (23%) |
| PI stage C (yellow) | 248 | 27% | 456 | 33% | 704 (31%) |
| PI stage D (red) | 468 | 50% | 420 | 31% | 888 (38%) |
| No PI stage recorded | 15 | 2% | 57 | 4% | 72 (3%) |
| Pref. place of care res./nur. home | 242 | 26% | 220 | 16% | 462 (20%) |
| PPC own home | 383 | 41% | 601 | 44% | 984 (43%) |
| PPC hospice | 42 | 5% | 93 | 7% | 135 (6%) |
| PPC hospital | 22 | 2% | 38 | 3% | 60 (3%) |
| PPC discussion not approp. | 21 | 2% | 53 | 4% | 74 (3%) |
| PPC pat. declined to participate | 2 | 0% | 7 | 1% | 9 (0%) |
| PPC pat. unable to express pref. | 38 | 4% | 53 | 4% | 91 (4%) |
| PPC unknown | 181 | 19% | 312 | 23% | 493 (21%) |
| For CPR | 15 | 2% | 39 | 3% | 54 (2%) |
| DNACPR | 889 | 95% | 1,123 | 82% | 2,013 (87%) |
| DNACPR discussion not approp. | 8 | 1% | 41 | 3% | 49 (2%) |
| Resuscitation status unknown | 19 | 2% | 174 | 13% | 192 (8%) |
| Place of residence (PR) Care home | 409 | 44% | 393 | 29% | 802 (35%) |
| PR Own home | 474 | 51% | 883 | 64% | 1,357 (59%) |
| PR Sheltered housing | 17 | 2% | 31 | 2% | 48 (2%) |
| PR Unknown | 31 | 3% | 70 | 5% | 101 (4%) |

Goldline 24/7 Patient Care

## 2.14 Goldline referrals as marker for recognition of patients in the last year of life

Recognition that patients may be approaching the end of life is the first step to offering care coordination and discussion regarding individual preferences. Referral to Goldline requires that patients are offered a conversation about their serious illness. We are hoping to increase recognition of patients who may be in the last year or so of life so that conversations can be started and plans made to offer best support. We are hoping that Goldline referrals will continue to increase until the majority of people who die following a period of illness will have been offered this service.

Assuming that 25% of deaths occur unexpectedly (Ref. Predicting Death, Estimating the proportion of deaths that are *'unexpected'*. National End of Life Care Intelligence Network), 47% of *'expected'* deaths across BAWC had a Goldline referral in place when they died. If GP practices use the EPaCCS template to generate the patients to discuss at GSF meetings, and hold meeting regularly, all Goldline patients will also be getting regular, proactive review of their care and needs. There is some variation in recognition and therefore referral to Goldline across the three CCGs – see table below

| CCG | Number of Deaths in 2018 (National EOL Intelligence) | 75% of deaths (i.e. approx. no. of 'predictable deaths') | Number of deaths who had Goldline referral in place March-April 2018/19 | % Predictable Deaths on Goldline Caseload | % All deaths in the CCG on Goldline case load |
|---|---|---|---|---|---|
| AWC CCG | 1661 | 1246 | 931 | 75% | 56% |
| Bradford City CCG | 458 | 343 | 150 | 44% | 33% |
| Bradford Districts CCG | 2744 | 2058 | 1,227 | 60% | 45% |
| Totals | **4863** | **3647** | **2,354** | **63%** | **47%** |

## 3.0 Governance

A range of measures are being used to provide robust governance of the service:

- Professional and service user feedback is encouraged, all feedback received is reviewed, calls listened to when needed, and action taken to address concerns and review any learning
- Call management system to record all calls – every quarter approx. 35 calls are reviewed by the nurse consultant and hub manager. Calls are listened to and checked for the quality in terms of communication and appropriate and safe advice. The written SystmOne record of these calls is also checked for accuracy. A copy of the latest report is available in **Appendix 3**.
- Clinical supervision for the Goldline Clinical team through action learning sets commenced in 2016
- Various audits, for example, audit of patients who had been on Goldline for more than 18 months, audit of calls where Goldline requested a GP visit.

### 3.1 Professional feedback

Professionals can give feedback via a form on the EPaCCS template, or contact the Goldline directly by telephone or email. All concerns raised are investigated by the service manager and discussed at the monthly governance and operational team meetings to ensure communication and shared learning.

14 concerns were received in the year (April 2018 - March 2019) which equates to <0.1% of 13925 calls received:

1. Concern re hub advice for patient on methadone and in pain. On review of written records of calls, all advice seemed to be appropriate.
2. Concern re advice given regarding commencing a syringe driver. On review of case, advice appeared to be correct.
3. Concern re advice given to paramedic to involve police in an expected death. This advice was not correct as patient was fast tracked to care home from hospice. To follow up with education for hub staff re expected vs unexpected deaths.
4. Patient reported Goldline service was not explained to them when given written information at referral
5. Patient not referred to service but given Goldline number, also issue complicated by IT problem at practice meaning patient got sent text meesages with verification code - this IT issue for practices has now been resolved
6. Delay in Goldline passing on a request for a District Nurse (DN) to Single Point of Access SPA for 1 hour. Service very busy but importance of calling for DN reiterated to hub team.
7. Caller to Goldline wanted a return of call but didn't leave contact details so no call able to be returned
8. Concern re delay in visit by Out of Hours (OOH) GP and GP did not seem to understand the background of the patient. Notes reviewed and all info was passed to OOH service and several calls made to follow up why the visit was delayed. No issues with Goldline identified.
9. Concern re delay in visit from DN and when did arrive appeared fairly unsympathetic and pressurised. Review of Goldline calls show immediate referral to SPA and follow up calls.
10. Concern re advice from Goldline to a care home to call 111 rather than requesting GP. This was poor practice and team have been reminded they should call 111 themselves rather than asking patients/carers to do this.
11. Concern re Goldline nurse having poor knowledge of brand names of common palliative care drug. Staff member was new to role and agreed to update her knowledge.
12. Concern re blunt approach of Goldline nurse, team discussed using other ways to explain someone is dying
13. Concern that patient was admitted inappropriately to hospital and died soon after admission. GSF code was green and no advance care plan in place to suggest close to end of life. Goldline felt reversible cause. Goldline reminded to call for support from palliative care consultants if unsure about appropriateness of hospital admisisons
14. Patient in a care home with an advance care plan to prevent all future hospital admisisons, Goldline requested GP visit, but GP arranged 999 ambulance. Goldline felt unable to challenge GP but did not contact Palliative Care Consultant. Patient had an advance decision to refuse treatment including hospital admission. Being followed up with GP OOH service and team reminded to contact Consultant on call for support at all times.

No serious incidents or formal complaints were reported.

## 3.2 Patient/Carer Feedback

Patients are given a feedback form as part of the information leaflet they receive at the time they are referred to the service.

During the year, the team received 37 messages of thanks sent from patients or their families to Goldline via cards, phone calls, feedback forms (13 forms) and donations. Examples of the feedback received by Goldline are shown above in Section 1.0 Patient and carer feedback.

Many more anecdotal compliments were received.

## 3.3 Staff training and competencies

Since Jan 2019, the following competencies have been agreed as mandatory for all staff taking Goldline calls, to be completed within 9 months of commencing the post, and annually thereafter:

3.3.1 Completion of elearning moduels on the e-ELCA system, introductory session on the following topics:

**Introduction sessions**

- 00_01 - Introduction to e-learning for End of Life Care (e-ELCA)
- 00_02 - Relationship between palliative Care and End of Life Care (EOL).

**Advance Care Planning sessions**

- 01_01 - Introduction to principles of Advance Care Planning (ACP).
- 01_02 - Cultural and spiritual considerations in Advance Care Planning.
- 01_03 – Benefits and risks of ACP in patients, families and staff.

**Assessment**

- 02_01 – Introduction to principles of assessment in EOL care – part 1.
- 02_02 – Introduction to principles of assessment in EOL care – part 2.
- 02_03 – Assessment of physical symptoms
- 02_04 – Assessment of physical function.
- 02_05 – Assessment of psychological well-being.
- 02_06 - Assessment of social and occupational well-being.
- 02_07 - Assessment of spiritual well-being.
- 02_08 - Context of assessment cultural and language issues.

**Communication skills**

- 03_01 - The importance of communication.
- 03_02 - Principles of communication.
- 03_03 – Communicating with ill people.
- 03_07 – Self- awareness in communication
- 03_12 – telephone communication
- 03_14 – Dealing with challenging relatives.

**Symptom management**

- 04_01 – General approach to assessment of symptoms.
- 04_02 – Agreeing to a plan of management and care.
- 04_06 – Recognising own limitations in symptom management.
- 04_07 – Assessment of pain.
- 04_08 - Principles of pain management.
- 04_09 - Drug management of pain and core knowledge.
- 04_02 - Assessment of breathlessness.
- 04_13 – Drug management of breathlessness.
- 04_15 - causes of nausea and vomiting.
- 04_ 18 – Assessment of constipation.

- 04_22 - Recognising and managing malignant spinal cord compression.
- 04_23 – Recognising the dying phase, last days of life and verifying death.

**Spirituality**

- 08_01 – Spirituality and the philosophy of EOL care.
- 08_02 - Understanding and assessing spiritual need and spiritual distress.
- 08_06 - Spirituality in the Community.

**Priorities for the Care of the Dying Person.**

- Priorities for care of the Dying Person Learning Path for Nurses ( CORE SESSIONS )

100% of our clinicians are on target to complete all the modules by July 2019.

3.3.2 Attendance at the local End of Life trianing course
(2 day course provide by Bradford, Airedale, Wharfedale and Craven Managed Clinical Network for Palliative Care) 100% of staff have completed or are booked on to courses this year. Staff who have done the course more than 5 years ago will be offered to repeat the course.

3.3.3 Additional topics of interest or promoting learning from cases by Palliative Care Consultant attending team meetings

3.3.4 Development of case scenorios using actors to call Goldline and recording calls for learning

## 3.4 Audit of calls to Goldline

Our regular audit of 30 calls to Goldline in each quarter of 2018/19 demonstrated the following overall results:

| Competency achieved | Yes |
|---|---|
| Controls the flow and pace of the call appropriately | 98% |
| Conveys questions skillfully, including own summary questions for purposes of validation | 100% |
| Ensures adequate information is obtained to enable safe and effective clinical triage | 90% |
| Listens carefully throughout the call and retains information | 100% |
| Demonstrates active listening to the caller | 100% |
| Information and advice is provided skillfully and accurately | 100% |
| Referred to the correct service if applicable | 98% |
| Systmone accessed and call documented | 100% |
| Goldline call sheet used | 100% |
| **Type of call** | |
| 53% of the calls audited resulted in a visit<br>37% were advice calls<br>10% were for prescription requests | |

Appendix 3 includes full details of this 2018/19 audit, and the recent audit of quarter 1 2019/20.

# 4.0 Discussion points

## 4.1 Current considerations

- The team providing Goldline come from a wide variety of backgrounds including Community Nursing, Palliative Care (Hospice at Home), Urgent Care (A&E, AAU, Acute and critical care), Tissue Viability, Care of the Elderly, and Surgical wards. The team provide other services alongside Goldline including telemedicine to care homes across the country.
- Referral numbers and calls taken by the Goldline continue to increase
- Goldline is addressing some of the known inequity in EOL care support services for patients (those with non-cancer and those not known to specialist palliative care services)
- Goldline patients are significantly more likely to die out of hospital compared to both national and local data
- Data on achieving preferred place of death is difficult to compare as there is little data available for comparison. We know that Goldline patients who expressed a preference achieve their PPOD at least 74% of the time.
- The Goldline sits within an end of life program across the districts with an array of services and support which work together to support patients and carers in their preferred place.
- Support in the form of education, training, coaching and facilitation provided by specialists in palliative care, EOL facilitators and GP End of Life leads to primary care services and hospitals has been, and will continue to be, key to enabling more patients and carers to access this service.

## 4.2 The Future

- Continued support, education and development of hub staff responsible for Goldline.
- Engaging with external stakeholders where possible to spread the use of Goldline into other areas, particularly to areas already served by AGH such as East Lancashire
- Continuation of spreading and embedding use of Goldline service aiming to offer the service to more of those eligible.
- Move to offer a video call service in addition to phone for all Goldline patients who wish to use this
- Ongoing work in promoting of the End of Life Care program and integration of this approach into existing and evolving programs of care by:
  - Use of end of life facilitators
  - Working with primary care leads to find ways to improve identification of patients in a timely manner, e.g. using tools already available such as frailty index and other risk stratification tools, also piloting the serious illness conversations program within Airedale.
  - Using local district wide data to identify practices to offer additional support in this approach to care.
  - Work within both acute trusts lead by specialist palliative care services to promote identification and care planning using GSF or last year of life approach.
  - Working with care homes to identify those residents who would benefit form end of life conversations and planning
  - Reviewing patient and public engagement and awareness.

## 4.3 Data trends

The National End of Life intelligence network is hosted by Public Health England and reports on place of death for all deaths. See **Appendix 1** for graphs.

Based on the most recent data produced to March 2018 here is how the 3 CCGs are performing against the England figures.

| Place of death year ending March 2019 | England (%) | AWC CCG (%) | BC CCG (%) | BD CCG (%) |
|---|---|---|---|---|
| Usual place of residence | 46.8 | 57.3 | 47.4 | 48.4 |
| Home | 23.7 | 22.6 | 29.5 | 26.9 |
| Care Home | 22.5 | 34 | 17.9 | 21.2 |
| Hospital | 45.5 | 33.5 | 46.2 | 42.4 |
| Hospice | 5.8 | 7.6 | 4.0 | 7.2 |

- Deaths in hospital: AWC continues to have the lowest % hospital deaths across all CCGs in England.
- The % of people dying in hospital in Bradford Districts is reducing very slowly, City CCG is not really changing but have a very different demographic and a smaller number of overall deaths
- Deaths in care homes have not shown significant changes since last year
- Deaths at home have risen slightly in all three CCGs. AWC has a very high % of patients dying in care homes compared to England as a whole
- Deaths in hospice: are fairly stable, City CCG having a significantly lower death rate in hospice than the other areas

Identification of more patients likely to be in the last year of life, looking with them at their preferences, and proactively planning care, usually results in a referral to Goldline as a part of this agreed plan. Therefore even if patients don't use Goldline we can use the fact they were referred as a marker of identification, care planning, and involvement of other appropriate services to support patients and carers. Patients on Goldline are more likely to die out of hospital which is likely to fit more with patients' preferences. Goldline contributes to a system of care services required to achieve these plans of care and preferences.

It is interesting to note that local data upon the uptake of Goldline (which we can use as a proxy for EOL care planning) is low in practices in Bradford City and most recent national data indicates a rise in hospital deaths in this area.

Most recent trends in all three CCGs demonstrate the need to continue to support and promote the end of life care program of which Goldline is a key service.

## FURTHER INFORMATION AVAILABLE FROM:

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✉ linda.wilson8@nhs.net

Sophie Brown, Head of Business Development:
✉ sophie.brown@anhst.nhs.uk ☎ 01535 294 545

Or take a look at our website: http://www.airedaledigitalcare.nhs.uk/our-services/goldline/

## Appendix 1: National Data from National End of Life Intelligence Network

### 1.1 Airedale, Wharfedale and Craven (AWC) CCG deaths by place of death

| Quarterly % of deaths by place of death (rolling 12 month periods) in AWC CCG | | | | | |
|---|---|---|---|---|---|
| | Usual Place Residence | Home | Hospital | Hospice | Care Home |
| 2012/13 Q3-Q2 | 51.9 | 20.5 | 37.8 | 9.3 | 32.2 |
| 2013/14 Q3-Q2 | 53.4 | 19.4 | 36.6 | 8.4 | 33.1 |
| 2014/15 Q3-Q2 | 53.2 | 21.1 | 35.3 | 9.3 | 31.7 |
| 2015/16 Q3-Q2 | 54.6 | 21.2 | 35.4 | 8 | 32.7 |
| 2016/17 Q3-Q2 | 53.9 | 22.5 | 34.9 | 8.9 | 30.7 |
| 2017/18 Q3-Q2 | 53.7 | 22.5 | 34.9 | 7.9 | 31 |
| 2018/19 Q3-Q2 | 56.8 | 22.2 | 34 | 7.3 | 34 |

AWC CCG % deaths by place of death (rolling 12 months)

53
45
37
29
21
13
5
UPR
Hospital
Care Home
Home
Hospice
2012/13 Q3-Q2
2013/14 Q3-Q2
2014/15 Q3-Q2
2015/16 Q3-Q2
2016/17 Q3- Q2
2017/18 Q3-Q2
2018/19 Q3-Q2

Goldline 24/7 Patient Care

## 1.2 Bradford City (BC) CCG deaths by place of death

| Quarterly % of deaths by place of death (rolling 12 month periods) in BC CCG | | | | | |
|---|---|---|---|---|---|
| | UPR | Home | Hospital | Hospice | Care Home |
| 2012/13 Q3-Q2 | 43.4 | 22.0 | 49.2 | 4.3 | 19.5 |
| 2013/14 Q3-Q2 | 40.7 | 24.1 | 49.9 | 5.4 | 21.1 |
| 2014/15 Q3-Q2 | 46.8 | 23.7 | 46.7 | 4.8 | 21.1 |
| 2015/16 Q3-Q2 | 42.4 | 20.8 | 49.7 | 5.5 | 20.2 |
| 2016/17 Q3- Q2 | 43.3 | 25.4 | 49.9 | 6.2 | 21.7 |
| 2017/18 Q3-Q2 | 44.1 | 25.8 | 45.8 | 5.4 | 21.1 |
| 2018/19 Q3-Q2 | 47.1 | 28.9 | 47.9 | 2.7 | 17.9 |

Bradford City
% of deaths by place of death (rolling 12 month periods 2012-2019)

60
50
40
30
20
10
0

Hospital
UPR
Home
Care Home
Hospice

2012/13 Q3-Q2 2013/14 Q3-Q2 2014/15 Q3-Q2 2015/16 Q3-Q2 2016/17 Q3- Q2 2017/18 Q3-Q2 2018/19 Q3-Q2

## 1.3 Bradford Districts (BD) CCG deaths by place of death

| Quarterly % of deaths by place of death (rolling 12 month periods) in BD CCG | | | | | |
|---|---|---|---|---|---|
| | UPR | Home | Hospital | Hospice | Care Home |
| 2012/13 Q3-Q2 | 45 | 25.5 | 45.7 | 7.5 | 19 |
| 2013/14 Q3-Q2 | 43.3 | 24.9 | 47 | 8.1 | 20.2 |
| 2014/15 Q3-Q2 | 45.3 | 23.9 | 43.9 | 8.4 | 20.2 |
| 2015/16 Q3-Q2 | 45.4 | 24.4 | 45.1 | 8.2 | 20.5 |
| 2016/17 Q3- Q2 | 45.8 | 24.8 | 45.2 | 8 | 20.6 |
| 2017/18 Q3-Q2 | 48.1 | 26.8 | 42.1 | 8 | 21.1 |
| 2018/19 Q3-Q2 | 48.2 | 26.4 | 42.9 | 7.2 | 21.5 |

Bradford Districts % of deaths by place of death
(rolling 12 month periods 2012-2019)

60
50
40
30
20
10
0
UPR
Hospital
Home
Care Home
Hospice
2012/13 Q3-Q2
2013/14 Q3-Q2
2014/15 Q3-Q2
2015/16 Q3-Q2
2016/17 Q3- Q2
2017/18 Q3-Q2
2018/19 Q3-Q2

## 1.4 England data

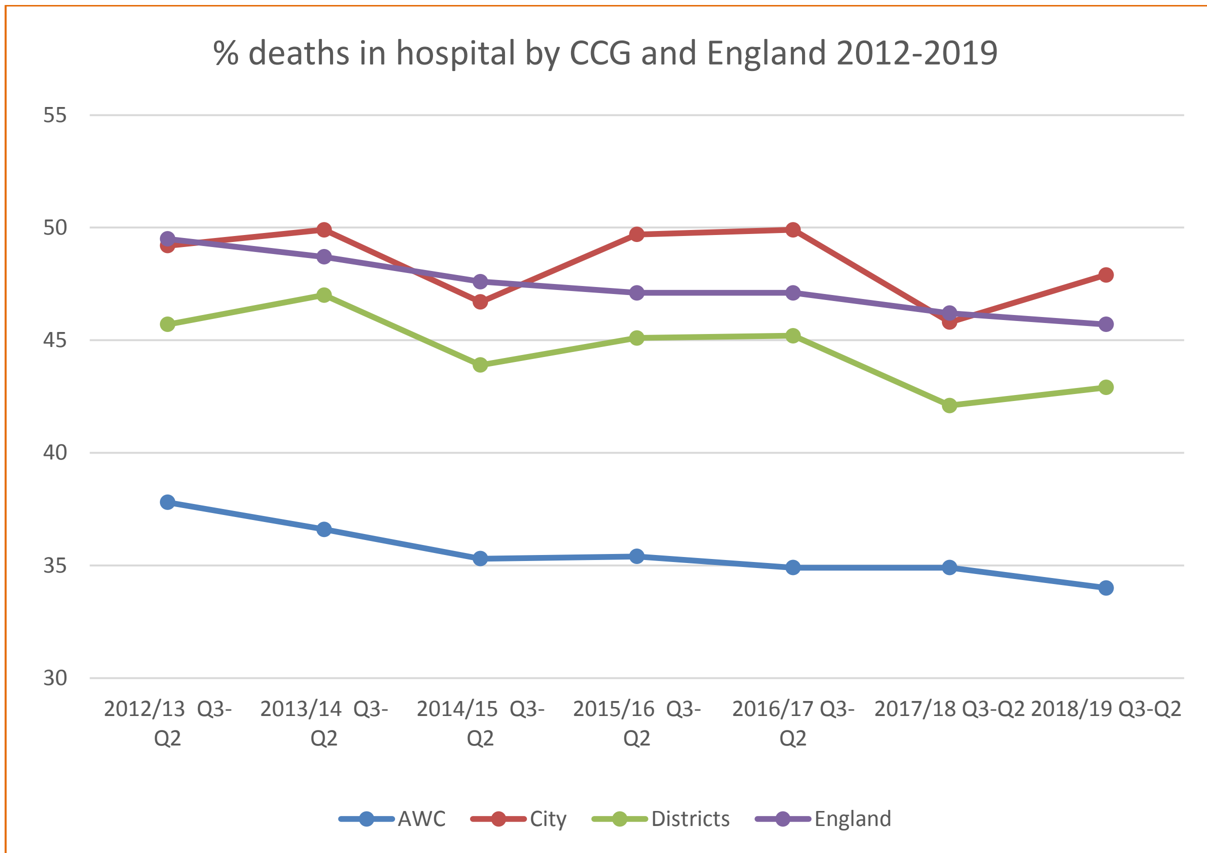
| Quarterly % of deaths by place of death (rolling 12 month periods) in England | | | | | |
|---|---|---|---|---|---|
| | UPR | Home | Hospital | Hospice | Care Home |
| 2012/13 Q3-Q2 | 43.3 | 22.0 | 49.5 | 5.7 | 19.4 |
| 2013/14 Q3-Q2 | 44.3 | 22.1 | 48.7 | 5.6 | 19.9 |
| 2014/15 Q3-Q2 | 45.1 | 23.0 | 47.6 | 5.7 | 20.7 |
| 2015/16 Q3-Q2 | 45.9 | 23.0 | 47.1 | 5.5 | 21.5 |
| 2016/17 Q3- Q2 | 45.7 | 23.3 | 47.1 | 5.7 | 21.4 |
| 2017/18 Q3-Q2 | 46.4 | 23.6 | 46.2 | 5.8 | 22.3 |
| 2018/19 Q3-Q2 | 46.8 | 23.6 | 45.7 | 5.8 | 22.6 |

England % of deaths by place of death
(rolling 12 month periods 2012-2019)

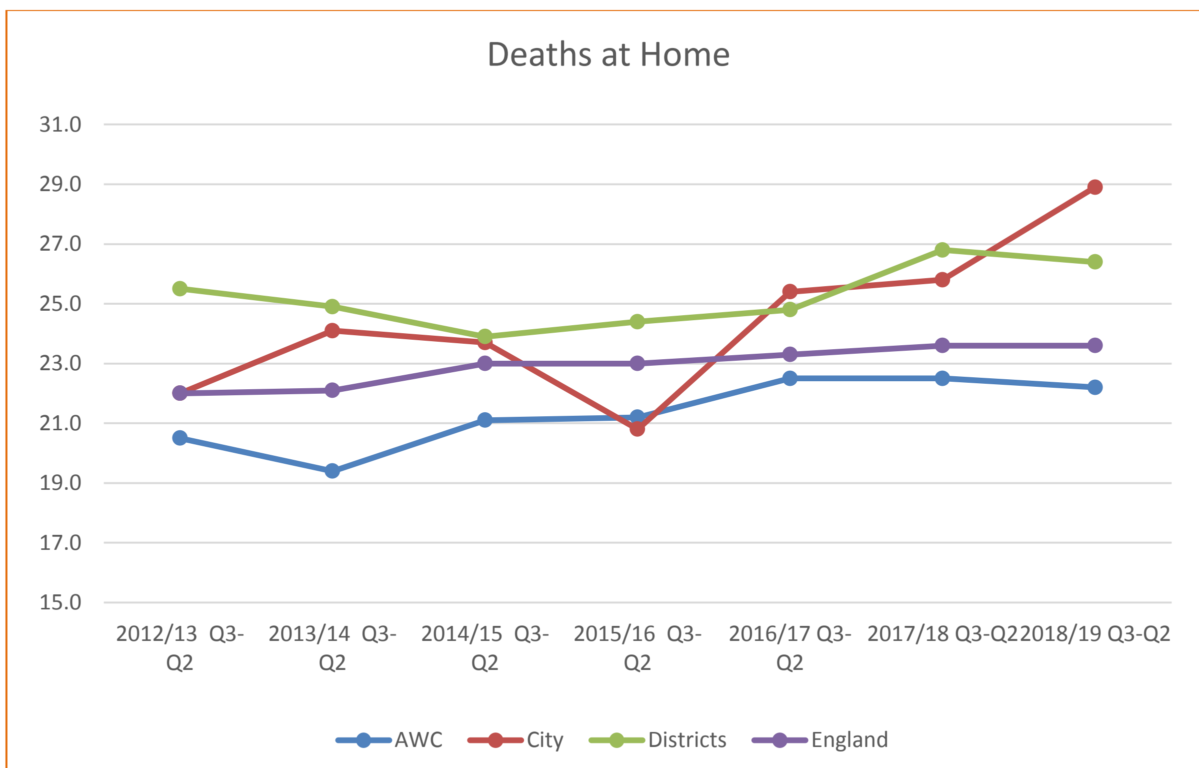
60
50
40
30
20
10
0
UPR
Hospital
Home
Care Home
Hospice
2012/13 Q3-Q2 2013/14 Q3-Q2 2014/15 Q3-Q2 2015/16 Q3-Q2 2016/17 Q3- Q2 2017/18 Q3-Q2 2018/19 Q3-Q2

## 1.5 Comparative data between the CCGs and England

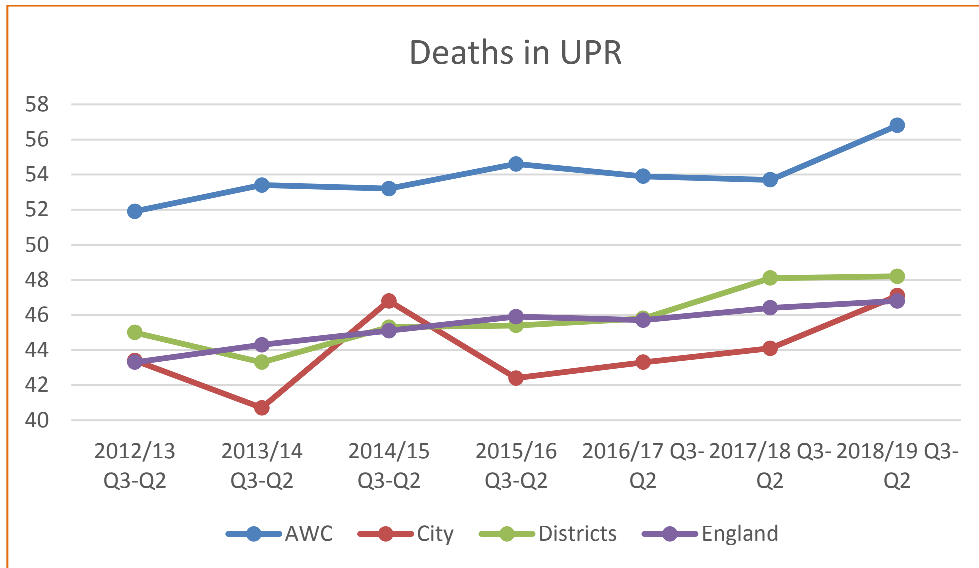
### 1.5.1 Hospital deaths by CCG/England 2012-2019



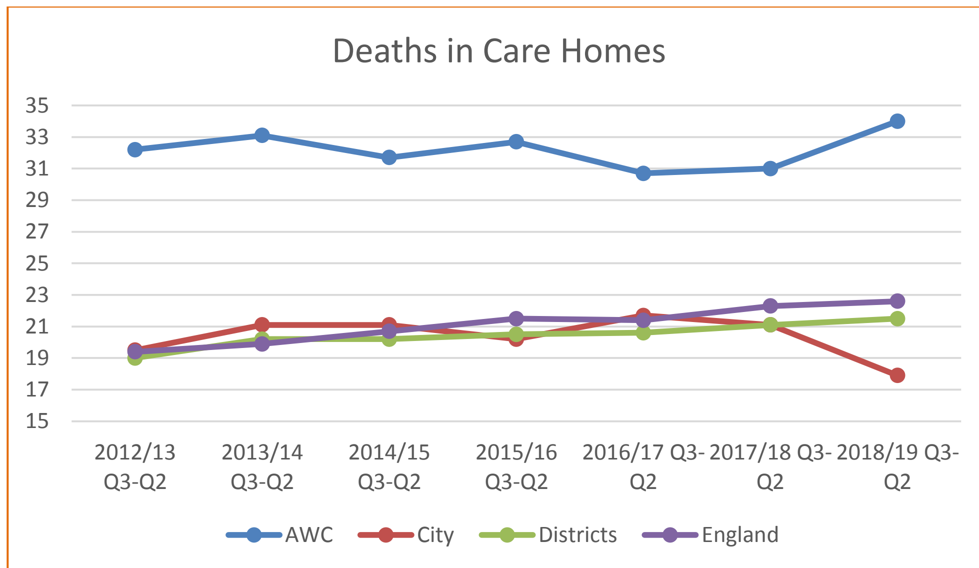

### 1.5.2 Deaths at home by CCG/England 2012-2019



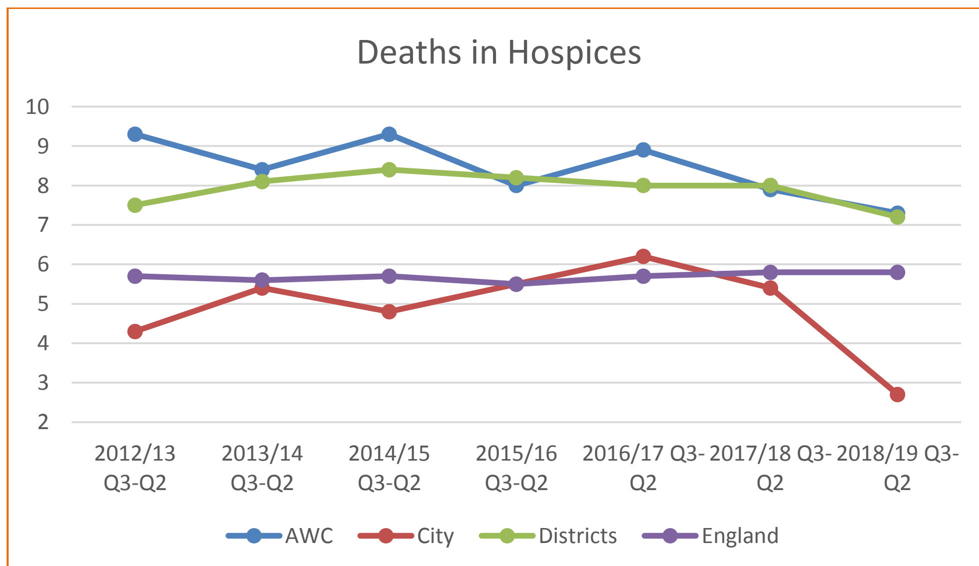
### 1.5.3 Deaths in UPR




### 1.5.4 Deaths in Care Homes




### 1.5.5 Deaths in Hospice



## Appendix 2: Goldline Patient Leaflet.

Goldline
24/7 Patient Care

# 01535 292768

## Our team are here to give you advice and support when you really need it.

Airedale Digital Care Hub

Goldline 24/7 Patient Care

NHS Airedale NHS Foundation Trust

**The doctor or nurse caring for you may have talked about your health problems and how they affect you day to day. Although your condition is not reversible we want to help you and those close to you to have the best quality of life possible. We can do this by using a way of working known as The Gold Standards Framework (GSF).**

**The GSF is for people who have a serious illness and may be in their last year of life. It is a way of working which helps professionals to give better care to you and your family. GSF is widely used across the country to enable people to live as well as possible until they die – Goldline is one of the services available to you as part of your care under this framework.**

## What is Goldline?

**This is a service for patients with a GP in Bradford, Airedale, Wharfedale or Craven. It is a round-the-clock telephone support line for you and your carer to use when:**

- **your GP surgery is closed**
- **you are finding it difficult to get help during the day or night, and you need some advice**
- **you are feeling anxious or frightened at any time.**

**During normal working hours you should, if possible, continue to use your normal point of contact for advice, for example your district nurse or GP.**

## Who will answer my call?

**A qualified and experienced health care professional will answer your call. They are available 24 hours a day, 7 days a week. If the phone line is busy you will hear a recorded message that will ask you to either hold or leave your name and phone number and one of the team will call you back.**

## How can the Goldline team help me?

We can give advice, support you, and contact other services on your behalf. By providing extra advice and support in your own home you may be able to avoid going into hospital. However, if needed, admission to hospital or hospice can be arranged.

With your permission, the team will be able to access your health record on the computer so they are able to see your current situation and medication. They will enter the details of your call into your health record so that your usual care providers can see this information. The Goldline team work closely with all other people involved in your care, and endeavours to co-ordinate other services, such as District Nursing and out of hours GPs, to support you at home.

Ask us for more details on how we use your information, or go to http://www.airedale-trust.nhs.uk/about-us/how-we-use-your-information/

**Call us on 01535 292768**

## How will I benefit from being part of the GSF?

The services you use will be better coordinated. Your doctors and nurses will meet regularly to discuss your care. Your needs and wishes will have greater priority, and your care will be planned with you.

Our aim is for you to get the kind of care you want, in the place that you prefer. Details of what is important to you can be added to your health record such as:

- where you want to be cared for
- decisions you have made about your care, including resuscitation
- where you would like to spend your final days
- who you wish to speak for you if you are unable to make decisions in the future.

## What happens if my condition changes?

Your preferences can change when your needs change. If this happens, it is important that you tell those caring for you so that your health record can be updated.

Goldline 24/7 Patient Care

**Please give us your feedback…..**

Your experience is important to us. We are interested to hear your thoughts about Goldline, even if you haven't used it. You can submit feedback by completing the form below or speak to a member of the team on ☎ 01535 292768.

**1. Which of the following describes you best?** ☐Patient ☐Carer

**2. If you have called Goldline, did you find it helpful?**

☐Yes ☐No ☐I haven't used it

**3. Please tell us about your experience of Goldline and/or any suggestions for improvement in the box below:**

Please return this form by post to **Goldline, Digital Care Hub, Airedale General Hospital, Steeton, Keighley BD20 6TD** OR email ✉ **goldline.feedback@nhs.net**

Thank you for your feedback. If you would like to be contacted about this, please provide your contact details below:

Name:

Address:

Contact telephone:

## Appendix 3: Audits of Calls to Goldline

### Goldline Audit Report 2018/19

In 2013, a service for patients thought to be in their last year of life was commissioned from the Digital Care Hub at Airedale NHSFT. This service aimed to support patients and their carers 24 hours a day via telephone and video triage, to enable them to remain at home and prevent inappropriate admissions to hospital and attendance at the emergency department.

There are many reasons why people at the end of life are admitted to hospital and the Goldline aimed to help reduce carer strain, co-ordinate services, give information as needed and support community teams using a single point of access.

Since 2013, the number of calls has grown to over 12,000/year and the number of patients has increased.

Consistently >95% of calls result in the patient remaining in their place of residence.

Approximately 60% of the calls result in a referral onwards to a DN or GP. Approximately 20% of which are for a prescription and very few calls result in an ambulance transfer.

Very few of the calls taken are felt to need referral on to the palliative care consultant but the hub staff are able to refer on 24 hours a day if necessary.

Since February 2015, all the telephone calls have been recorded as, due to excessive demand, the hub needed to move the Goldline on to a call management system. As part of the clinical governance process, we are therefore now able to audit calls received and act on any issue that arise.

Each quarter, the Manager of the hub and the Clinical Lead select at random a number of calls to audit. As each call can last up to 50 minutes, a full morning is allocated to this task.

The calls are assessed both subjectively and objectively as parameters such as active listening and control of the pace and flow of the call is considered alongside use of the Goldline call sheet and access of the SystmOne patient record. Each patient record is retrieved and the documentation evaluated to ensure accuracy and follow up arranged as necessary.

In quarter 1 30 calls were audited. Other than “Hello my name is…” not being used consistently there were no other issues to report. The importance of including clinician name at introduction was discussed at the team meeting and an e mail was circulated to stress this. All of the audited calls were answered appropriately and managed skillfully with the pace and flow controlled appropriately although, “hello my name is…” not being used by all clinicians. Adequate information was obtained to ensure a safe and effective clinical triage in all calls and the chemotherapy question was asked when appropriate on 2 occasions.

Unfortunately we were unable to download call data to perform the audit for quarter 2.

In Quarter 3, all of the 30 audited calls were answered appropriately and managed skillfully with the pace and flow controlled appropriately although, “hello my name is…” not being used by all clinicians but this had improved. It was discussed again at the team meeting and agreed that clinicians would remind each other if they heard someone answering a call without using their name. Adequate information was obtained to ensure a safe and effective clinical triage in all calls, although in one call

the clinician did not look at EPaCCS template until ¾ of the way through call where information could have been gathered more quickly and accurately for the patient.
It was noted that;

- All calls were managed in a patient and empathetic manner.
- In one call the clinician did not give the best advice to optimize effect of analgesic medication although her advice on non-pharmacological interventions was excellent. This has been discussed with the assessor and a “review on managing pain in palliative care” is being organized for the team.

In Quarter 4 30 calls were audited. All except two of the audited calls were felt to have been managed skillfully with the pace and flow controlled appropriately although one of the calls was answered by a new member of staff still undergoing supervision and training. In some cases complete patient details were not being checked routinely prior to consultation i.e. name, address, DOB, GP surgery, otherwise adequate information was obtained to ensure a safe and effective clinical triage. The Goldline call sheet was used in all of the calls and the chemotherapy question was not asked in 2 of the calls where the auditor would have deemed it appropriate. It was noted that;

- “Hello my name is…” still not being used consistently by all clinicians and agreed that this is now being monitored by Team Leaders.
- There were long delays on 2 calls due to IT issues leaving the caller on hold.
- In one call the clinician referred a patient for GP visit which was unnecessary, all other onward referrals were appropriate.
- On the whole calls were consistently answered and managed in a skillful, patient and compassionate way.

This quarterly audit has proved invaluable for both staff learning and the identification of issues and concerns.

This regular audit has proven useful in identifying good practice and has allowed us to respond to issues and concerns quickly and accurately.

Recording every call also allows us to investigate complaints and issues quickly.

Audits of Goldline calls continue each quarter and are reported back to the business and governance meeting, together with the quality dashboard, which includes a number of quality and activity data.

This dashboard is reviewed and scrutinised by the executive team at the Trust’s DAG (delivery assurance group) every quarter and then any issues are fed back to the Board.

All concerns and professional feedback are recorded on the issues log and complaints dealt with following the Trust’s policy.

The risk register is kept up to date and reviewed every month at the Telemedicine operational and governance group. Risks rated 12 and over are reported to the Trust Board.

The following table shows the results of the audits carried out in 2019.

## Results Table

| Competency achieved | Yes |
| --- | --- |
| Controls the flow and pace of the call appropriately | 98% |
| Conveys questions skillfully, including own summary questions for purposes of validation | 100% |
| Ensures adequate information is obtained to enable safe and effective clinical triage | 90% |
| Listens carefully throughout the call and retains information | 100% |
| Demonstrates active listening to the caller | 100% |
| Information and advice is provided skillfully and accurately | 100% |
| Referred to the correct service if applicable | 98% |
| Systmone accessed and call documented | 100% |
| Goldline call sheet used | 100% |
| **Type of call** | |
| 53% of the calls audited resulted in a visit<br>37% were advice calls<br>10% were for prescription requests | |