



Wessex
Academic Health
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Independent Evaluation of the Mountbatten Coordination Centre



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DISCLAIMER

This report presents the findings of an independent evaluation of the Mountbatten Coordination Centre.

The findings of this independent evaluation are those of the author and do not necessarily represent the views of the Mountbatten Coordination Centre.

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1. BACKGROUND AND OVERVIEW

Of the 1700 people a year who die on the Island, it is thought that 30% currently benefit from the expertise and support of hospice services (approx. 510 patients) and a further 30% should do so.

A redesign of the end of life pathway has resulted in the creation of a new end of life coordination centre, hosted by Mountbatten, Isle of Wight called the Mountbatten Coordination Centre. The hospice is the sole provider of expert end of life care on the Island and as such is leading the pilot project aiming to improve the coordination and delivery of care for end of life patients.

The Mountbatten Coordination Centre provides an out of hours advice and visiting service, staffed by administrators and registered nurses, which is available 24 hours a day 365 days a year. The new service was launched in January 2018 and its stated aims were:

1. Coordinate the care of those people identified in the last year of life earlier and provide better integrated care and case management, ensuring patients are put onto an end of life care register.
2. Lead to a reduction in unplanned hospital admissions for the 70% of patients referred to the service.
3. Focus on reducing hospital admission costs.
4. Reach more people.

At the time of launch the end of life criteria on the Island were revised, with patients able to access the service in the last 5 years of life (previously this was in the last year of life). At this point there were approximately 200 patients identified on the community team workload as being end of life.

The Mountbatten Coordination Centre staffing model is:

Clinical Staff	Administrative Staff
1 x CNS (Band 7) Cover Mon–Sun – 0900 – 1700	1 x 37.5hrs pw (Mon – Fri 0830-1630)
2 x Staff Nurse (Band 5/6) cover Mon–Sun 0730 – 0900 & 1700 – 2100	3 x 20hrs pw (1 person on rota at a time covering weekdays 1530 – 2100 and weekends 0800-2030)
1 x Staff Nurse (Band 5) cover Mon–Sun 2100 – 0730	



2. METHODS & EVALUATION QUESTIONS

Service activity data was collected via an audit process, over a 3-day period in October 2018, which identified 22 patients that the service received calls about on these days. These patients were then reviewed in December 2018 and their use of services and outcomes over the two intervening months recorded.

Additionally, 5 longitudinal audits were completed in December 2018, reviewing patients' use of health and social care services in the 12 months prior to their referral to the Mountbatten Coordination Centre and for at least 6 months after their first contact with the service.

One focus group, lasting 1.5hrs, with 8 Mountbatten Coordination Centre staff members was conducted in December 2018. This focus group sought to investigate the impacts of the Mountbatten Coordination Centre as perceived by the team and the staff they have worked with. Themes developed (in bold text before the example quotes) from the focus group are included throughout the report and organised underneath broad topics, such as patient impacts and staff impacts.

The evaluation questions sought to understand if the model delivered its intended aims and outcomes for individuals coming into contact with the hub, as follows:

1. What impact does the Mountbatten Coordination Centre have on patient outcomes?
2. Does the Mountbatten Coordination Centre reduce the number of emergency admissions to hospital, and is there a financial benefit?
3. Contribute to the questions "what does a future hospice look like?" and "how should future end of life care be delivered?"

As the evaluation took place at an early stage of implementation (February - December 2018), this report also includes recommendations for an evaluation methodology which could be used by the hospice later in 2019.

3. IMPACTS ON PATIENTS, FAMILIES & CARERS

This section will address aims 1 and 4, and evaluation question 1.

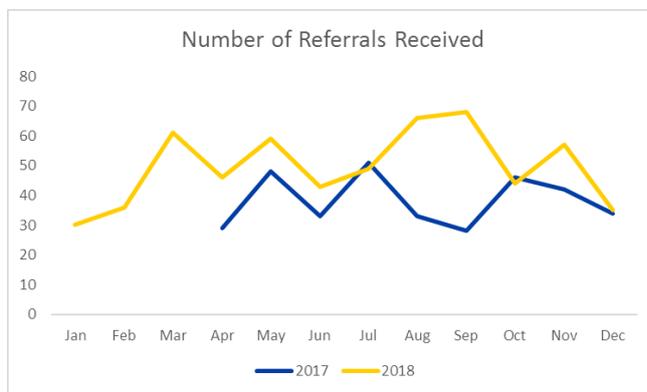
HEADLINES: The number of patients identified as end of life on the island has more than doubled since the service launch, partly due to the work of the service and partially to the change in end of life criteria.

As these patients' health deteriorates they are contacting the Mountbatten Coordination Centre more frequently and are receiving timely advice and interventions, which might otherwise not be available so quickly. There is some evidence that the service is reducing activity in primary care and to a lesser extent secondary care.

The service is also providing practical and emotional support to families and carers; reducing their anxiety and increasing their ability to support their loved ones at home.

Service activity data from the Mountbatten Coordination Centre revealed the number of patients on the Island identified as being end of life was around 200 prior to the launch of the Mountbatten Coordination Centre. By early 2019 this had increased to 444 individuals on the Share my Care register. (This is a database hosted by the Mountbatten Centre, accessible to clinicians via SystmOne, which holds information about the type and location of care patients would like to receive as they approach the end of life).

In total the service has received almost 600 referrals in 2018, an increase over the level of referrals to the hospice in the previous year. The average number of referrals a month has increased from 38 to 50:



This was confirmed in the focus group, it was reported that **proactive care reviews by Mountbatten Coordination Centre staff were conducted**, to the benefit of patients and families:

“The team do Share My Care reviews and off that back of those call the next of kin. They are grateful for our call and quite often, from the call, decide they need to speak to a nurse to review the situation.”

Source: Mountbatten Coordination Centre Staff Member 1

Furthermore, the **share my care system has encouraged wider use of the Mountbatten Hospice:**

“I’ve seen a number of patients come up to the [unit] who are quite well, but deemed to be in their last 5 years, patients have [been] coming for the social activities there [unit] and volunteers have been going to patients’ homes when patients are isolated. This is part of the EoL coordination centre model and uses the Share My Care system.”

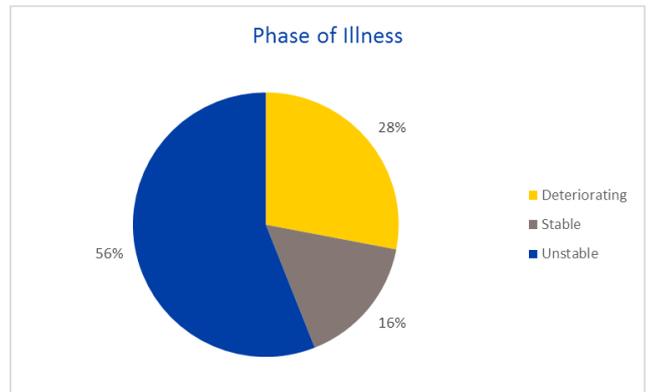
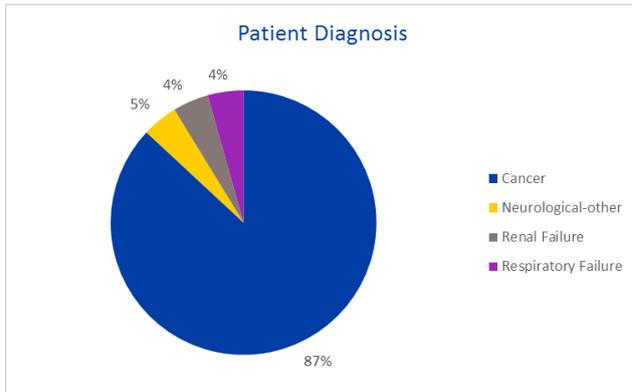
Source: Mountbatten Coordination Centre Staff Member 3

Importantly, conclusions from the audit data about patient impact in this report were based on a specific set of data. Audit data, collected over a 3-day period in October 2018, provided a view on

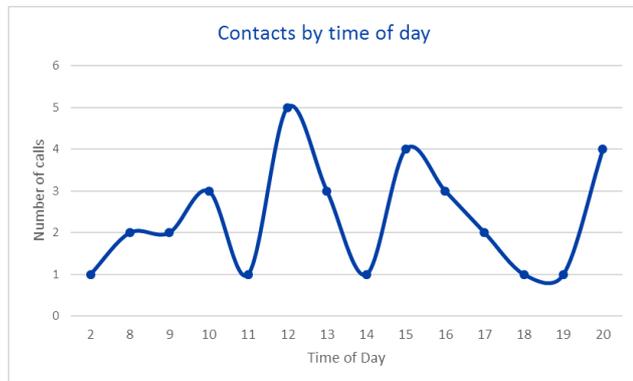
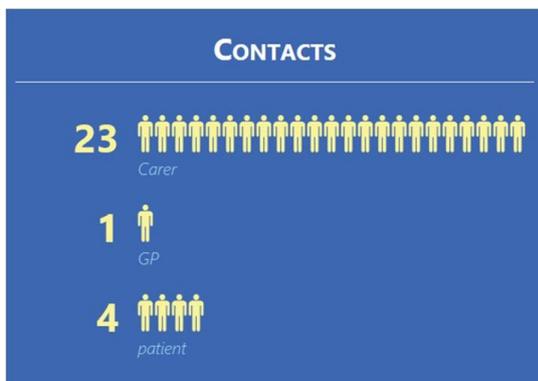


the people contacting the Mountbatten Coordination Centre and what happened to them two months after this. It should be noted that this isn't necessarily two months from their *first* call to the service. This data was based on the results of 34 calls received about 22 patients.

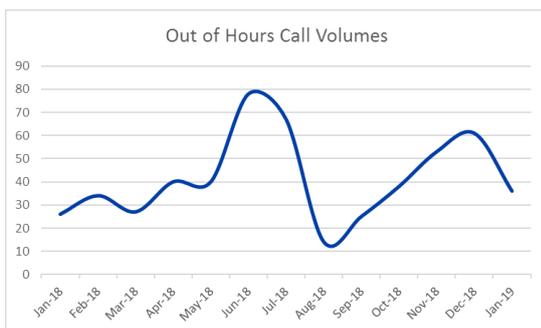
The majority had a cancer diagnosis and were in an unstable or deteriorating phase of their illness:



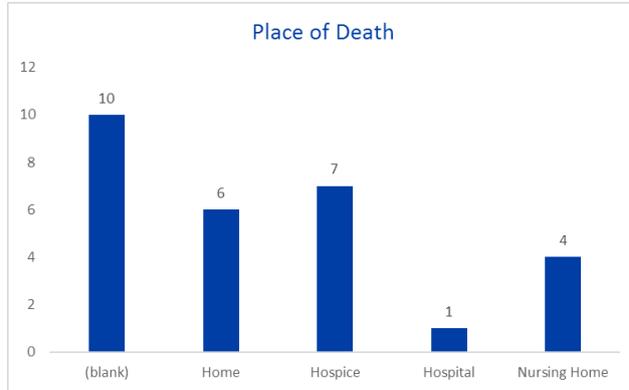
In terms of use of the service, most calls came from carers and were made within the normal working day, with 73% of calls between 9am-5pm. However, the service was accessed from 2am through to 8pm during the audit period. All telephone calls, apart from one, to the Mountbatten Coordination Centre were about patients already known to the service.



This use of the service out of hours was supported by activity data collected by the service since launch:



Returning to the audit data, more calls were made to the service as patients' end of life approached, with 18 of the 22 patients dying within the audit period. Only one patient passed away in the acute setting. This could be an early indicator that patients were more likely to be in their preferred place of death but further data would be required to verify this.

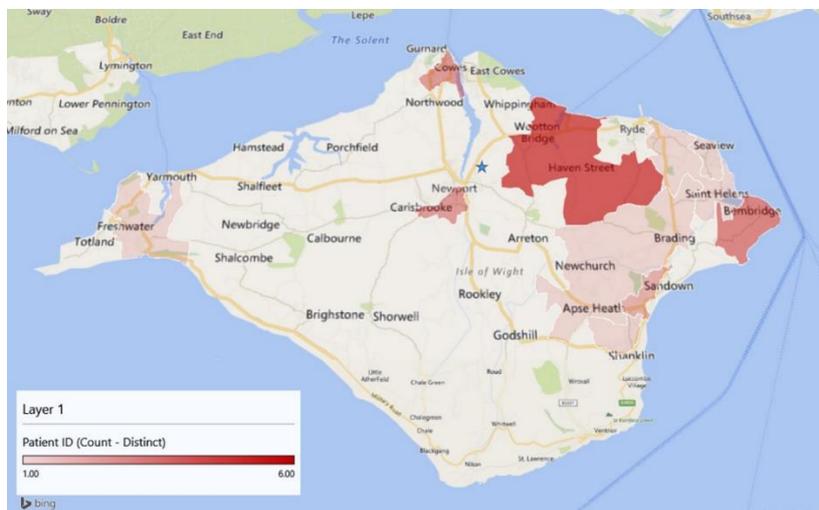


This finding was supported by the focus group analysis. **Organising work to ensure even complex cases were in their preferred place at end of life** was a theme from the focus group.

“One patient deteriorated quickly, we went out with a clinical team and put a plan in place. The care at home team and clinical team were there to help manage the difficult symptoms, we did all that was needed, and kept the patient at home, which is where they wished to be, with their family. This case was at the top of the pyramid, the patient needed intensive to manage the symptoms at home. The consultant, clinical nurse specialist, clinical team, and care at home team were involved.”

Source: Mountbatten Coordination Centre Staff Member 1

Telephone calls were received from across the island, with larger volumes from the area nearest to the hospice, possibly due to a higher level of awareness of the Hospice within the local community.

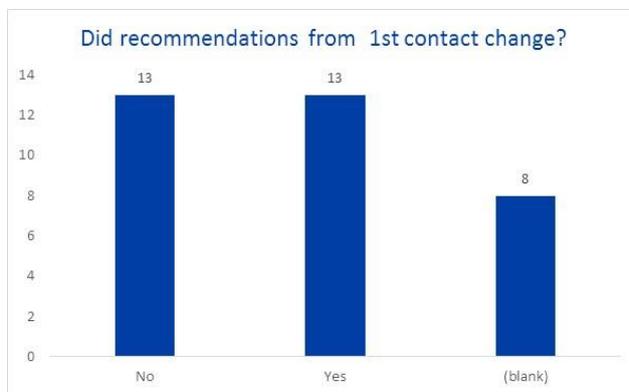


On average, the service received 1.5 telephone calls about each patient in the audit period, but this was variable with one patient (carer) making 6 calls and another 4.

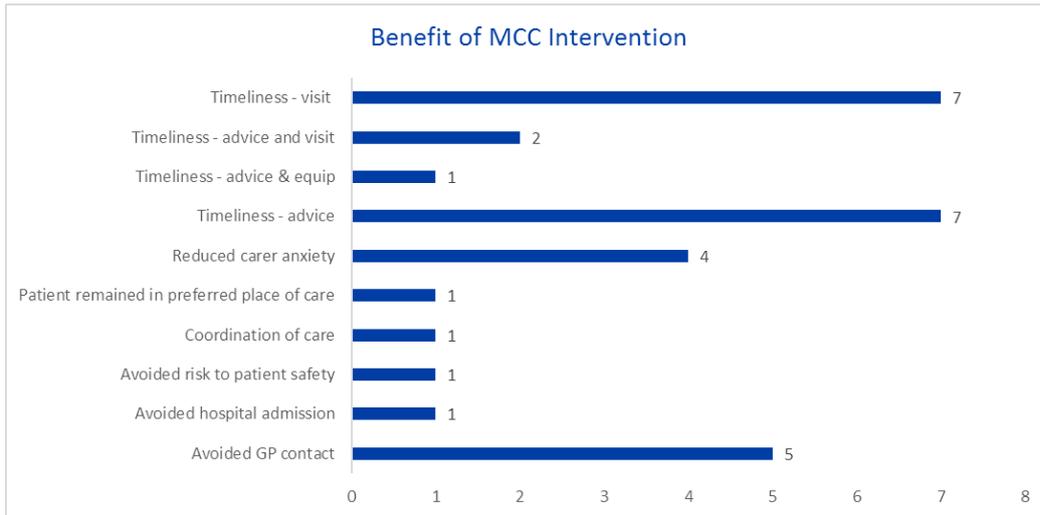
The audit also provided information about the outputs of the contacts with the Mountbatten Coordination Centre, analysed below. Most received either symptom management advice or a visit from the team:



When these recommendations were revisited two months later, around half of them had changed. It is unclear if this is because the original recommendations were incorrect or if it might be related to the rapidly changing health status of this group of patients.



When categorising the benefits that came from the service's interventions, they can be grouped as follows:

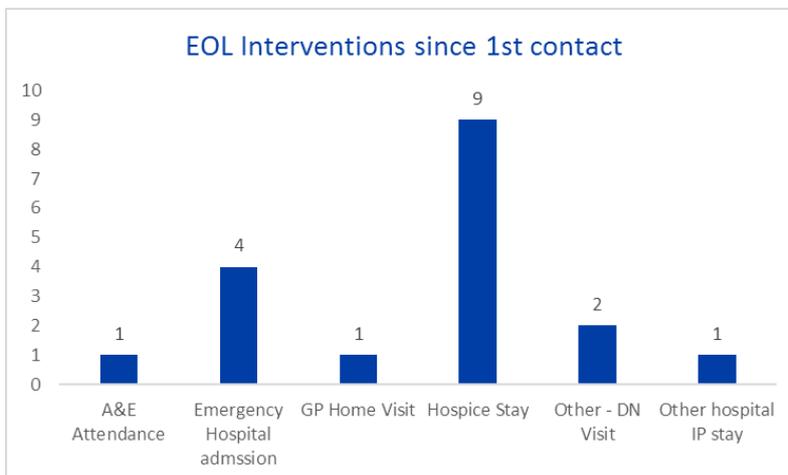


It was clear that **timeliness** was the major benefit which the service was offering. They were responsive to patients' needs, provided advice or visited more quickly than otherwise might have. Support was also extended beyond the patient to the family and carers, with practical and emotional advice given.

"Mike needed emotional support in caring for his mum, he had already had a long phone call earlier with staff. I do not know if he could have rung anyone else for emotional support"

Source: Mountbatten Coordination Centre Staff Member

Since the first contact with the service, patients went on to experience the following secondary and primary care interventions:



It is possible that the improved timeliness of advice for symptom management could be one factor reducing the use of primary care by these patients. Potentially, without the Mountbatten Coordination Centre, these queries would probably be directed to either a GP or Nurse. The longitudinal audits show some evidence to support this, with primary care contacts generally reducing after first contact with the service.

Additionally, Mountbatten Coordination Centre advice and support coupled with the ability to provide rapid home visits may have avoided a health crisis requiring acute care (ambulance conveyance, A&E attendance or emergency admission).

In support of the audit findings above, findings from the staff focus group highlighted several patient/family impacts in terms of the support they received.

Increased access to end of life support was reported:

"I think it's about relatives knowing there is someone they can call, particularly out of hours, because once the GP surgery is closed at 6pm, you only have the hospital system to go to. Now relatives have a service [EoL coordination centre] they can call to get support."

Source: Mountbatten Coordination Centre Staff Member 6

An expanded scope of support was reported:

"The EoL coordination centre has advertised the Steps To Wellbeing programme, about eating, drinking, fatigue, breathlessness...patients and carers can come to that and it's a chance to interact with other people and works well."

Source: Mountbatten Coordination Centre Staff Member 3

Earlier intervention in patients' plans at end of life was reported:

"We are making sure we meet patients earlier in their end of life journey. Having the conversations earlier means we can get work going to help people stay at home and respect their wishes."

Source: Mountbatten Coordination Centre Staff Member 2

Work by the Mountbatten Coordination Centre provided coordinated support:

"One relative told us about her experience of the coordination centre...how she didn't call hospital services overnight, how the centre worked to organise staff to provide medications as needed...the patient died at home, and staff were organised from the centre to go out and verify the death. We've done a lot of that and it's a positive place to be."

Source: Mountbatten Coordination Centre Staff Member 7

Reduced stress for families at end of life was reported:

“One patient had a brain tumour and had been going ok for a year but then there was a rapid deterioration. We worked with district nurses and GPs...the patient had a syringe driver set up but then it needed changing due to the patient’s symptoms changing and I was there to do that...later that day the patient died...as I was there I was able to phone the EoL coordination centre...we did the last offices verification needed...for the family this easy communication and work took some of the stress out of the event.”

Source: Mountbatten Coordination Centre Staff Member 3

Reassurance for families was reported:

“They know they can call us during and after the death of their loved one, we can advise, we can go to their home...we can verify the death, we can do last offices, and coordinate with the care at home team and clinical team.”

Source: Mountbatten Coordination Centre Staff Member 4

4. IMPACTS ON STAFF & HEALTH CARE SYSTEM

This section will address aims 2 and 3, and evaluation question 2.

Findings from the focus group highlighted four relevant impacts. A key benefit for health care staff was the **Mountbatten Coordination Centre provided advice and training to health care professionals**. A wide range of advice and support was apparent and exemplified below:

“One nursing home asked us for EoL training, so I’ve gone out there and done some work with them about end of life advanced care planning. I’ve followed that up with helping them to identify patients to join to the Share My Care register.”

Source: Mountbatten Coordination Centre Staff Member 1

“The community nurses often call for advice and we’ve been working more closely with them.”

Source: Mountbatten Coordination Centre Staff Member 2

“I was talking to the memory service last week and they’re still surprised they can refer patients with dementia to the hospice for support. There is still a sense that the hospice is just about patients who have cancer or motor neurone disease. To them [memory service], the coordination centre was something new to refer to.”

Source: Mountbatten Coordination Centre Staff Member 7

“In terms of the crisis response team...we’ve needed their input and advice as much as they’ve welcomed our advice. The relationship development between the two teams has been a really positive step.”

Source: Mountbatten Coordination Centre Staff Member 6

Secondly, Mountbatten Coordination Centre staff indicated **care homes were starting to avoid using the GP referral route:**

“In the residential care and nursing homes, they are starting to be empowered and pick up the phone or complete the Share My Care form and avoid using the GP. Care homes can refer direct to us.”

Source: Mountbatten Coordination Centre Staff Member 5

Thirdly, **Mountbatten Coordination Centre staff were expanding their working contact with other services:**

“At the Integrated Locality Services meetings, I’ve met staff from sheltered housing services and many of their clients should be on the Share My Care register.”

Source: Mountbatten Coordination Centre Staff Member 2

“We’ve received referrals from Care Navigators...we’re working with them now as they’re based in the community. They’ve often heard of Share My Care and wanted to get patients onto that. That’s also the same for the Integrated Localities Staff who we’re starting to accept referrals from and coordinate with too.”

Source: Mountbatten Coordination Centre Staff Member 1

“We’ve had hospital ward nurses calling us for advice about patients who have deteriorated. It’s usually symptom management or advice to help a relative or a new diagnosis that’s changed things. In some cases, we’ve travelled to the wards to speak to the nurses face to face.”

Source: Mountbatten Coordination Centre Staff Member 1

Fourth, staff at the focus group also perceived an important system benefit of **avoided hospital admissions from residential care homes:**

“We know we’ve reduced the number of patients being conveyed from residential care homes to hospital in their final hours to die in A&E wards, where the patient often doesn’t want to be. Care home staff do phone 111 and that can often result in an ambulance coming out and the patient being conveyed. Now, the care homes can call here [Mountbatten Coordination Centre] instead and our duty nurse can go out and support the care homes with decisions.”

Source: Mountbatten Coordination Centre Staff Member 4

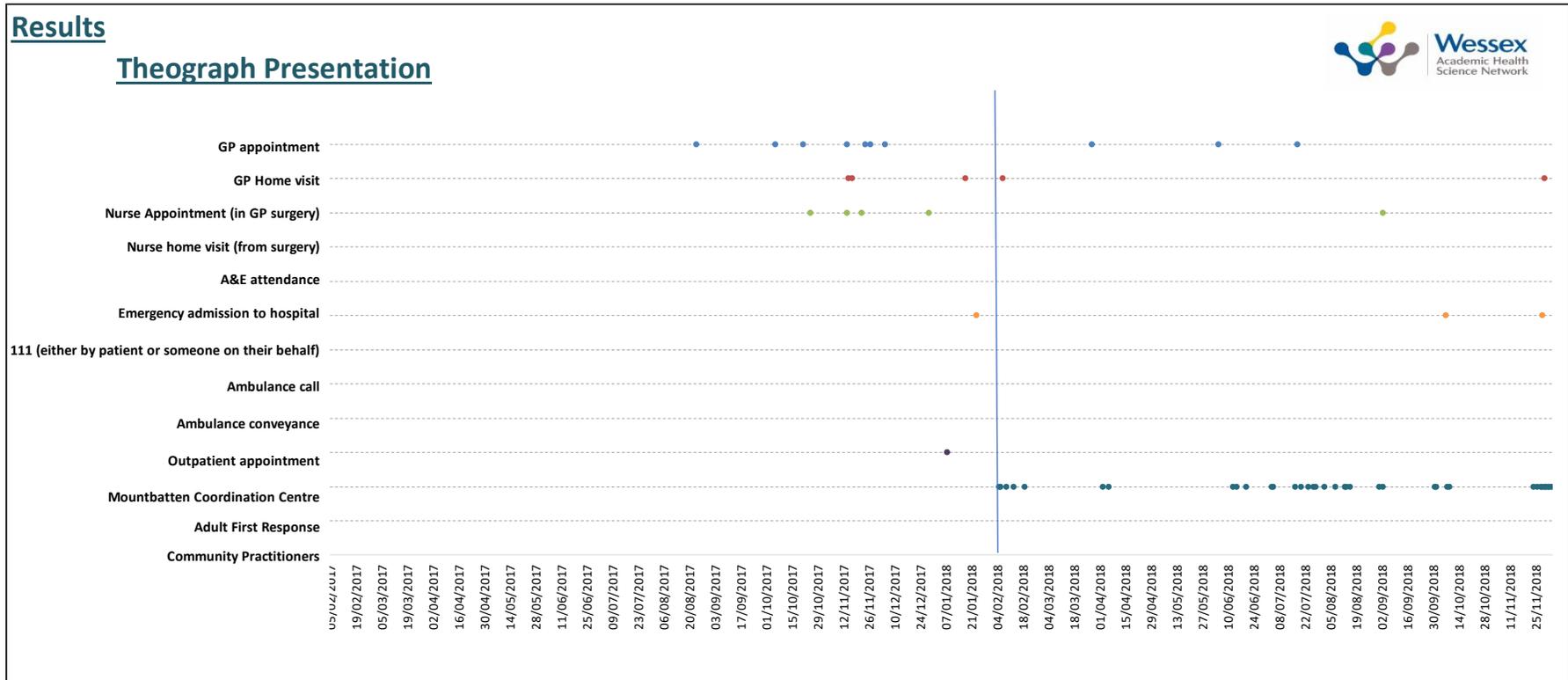
Following on from these qualitative findings, the five longitudinal audits indicated:

HEADLINE: *The audit data collected by the service shows some evidence that the intervention of the Mountbatten Coordination Centre may reduce activity in other parts of the system, particularly in primary care, for the patients concerned.*

In all five longitudinal audits there was a reduction in the number of GP or Nurse interventions once the patient had contacted the Mountbatten Coordination Centre. In 4 of the 5 audits there was limited evidence that acute activity (either emergency or OP) had reduced as well. Given the small sample size and the complexity of the patients' health, it was difficult to establish a direct link between the service and these reductions.

As an example, below is the longitudinal audit result for one patient (shown as a theograph), which shows over time their use of health services before and after their referral to the service. It demonstrates the shift in system activity which occurs once the patient is on the end of life pathway. Each line of the chart relates to a different health/social care interaction, with the markers showing when the patient has accessed this service. The vertical blue line shows the point at which first contact with the service was made, so comparing the use of services to the left and right sides of this line is a 'before and after' comparison;

(See appendix 1 for copies of all 5 patient theographs)

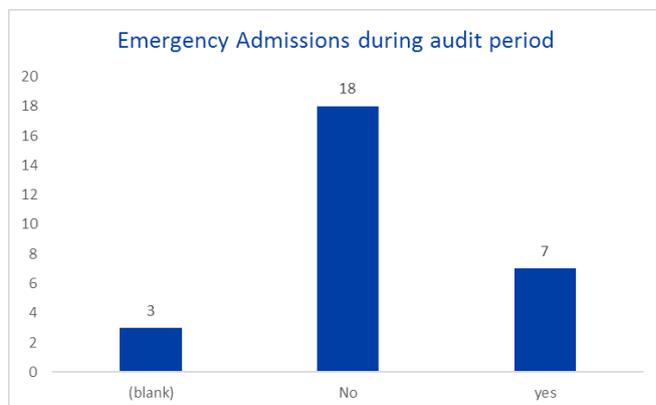


A summary of the changes shown by the longitudinal audits points to the service reducing activity in primary care. The following table summarises the change in each activity line since the patients' first contact with the Mountbatten Coordination Centre.

The shift in activity is coded as: green = reduction, grey = no change, red = increase

	Primary Care				Secondary Care						Mountbatten Coordination Centre Contact	Adult First Response	Community Practitioners
	GP appointment	GP Home visit	Nurse Appointment (in GP surgery)	Nurse home visit (from surgery)	A&E attendance	Emergency admission to hospital	Call to 111 (either by patient or someone on their behalf)	Ambulance call	Ambulance conveyance	OP appointment			
1	reduction (7 pre 3 post)	3 pre and 2 post	reduction (4 pre 1 post)	none	none	1 just before referral and 2 end of audit	none	none	none	reduction 1 pre and 0 post	44 contacts	none	none
2	no change	none	reduction (4 pre 1 post)	only a spate at end of period	2 after	reduction (3 pre and 1 post)	0 pre 2 post	none	none	reduction 3 pre 0 post	38 contacts	none	none
3	reduction (5 pre 3 post)	1 post	none	reduction 2 pre 0 post	none	1 at time of referral	reduction 2 pre 1 post	none	none	reduction 3 pre 1 post	12 contacts	none	reduction 1 pre
4	reduction (4 pre 0 post)	reduction (12 pre 7 post)	reduction (1 pre 0 post)	none	reduction (1 pre 0 post)	reduction (2 pre 1 post)	reduction 2 pre 1 post	none	none	none	9 contacts	none	none
5	reduction (5 pre 0 post)	reduction (4 pre 1 post)	reduction (2 pre 0 post)	none	none	none	none	none	none	no change (1 pre 1 post)	5 contacts	none	none

Returning to the two-month audit, of the 22 patients reviewed, most did not have any emergency admissions in this period. However, we do not have the data to understand these patients' use of acute services prior to their use of the Mountbatten Coordination Centre, nor the use of acute services by palliative care patients before the introduction of the new service as a comparison. It is therefore not possible to draw conclusions from this one data point.



The two-month audit data showed that in the service's opinion, 1 hospital admission was avoided and a further 5 GP contacts were avoided through the intervention of the service across the 22 patients.

Due to the small sample size in both the two-month and longitudinal audits, it was not possible to extrapolate financial value for the change in the use of health services since the introduction of the Service. Please see the 'Ongoing Monitoring & Evaluation' section of this report for recommendations around this.

5. IS THE MODEL CONTRIBUTING TO HOW FUTURE HOSPICE CARE SHOULD BE DELIVERED?

The World Health Organisation describe palliative care as *"an approach that improves the quality of life of patients and their families facing the problem associated with life threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual."*

A working paper of the commission into the future of hospice care (2013) highlighted the challenges and opportunities for hospices to be 'fit for the future'. A key recommendation is that hospices should be central to the coordination of care, with the capability to coordinate and respond to need 24 hours a day with a broader use of triage based on patient assessment, leading to consistency and coordination as well as meeting what is important to patients and carers.

Based on the evidence provided, the Mountbatten Coordination Centre. is providing round the clock access to specialist advice and care to carers, patients and professionals. Most of the patients dealt with by the service received multiple telephone calls and home visits in the course of their care, moving activity out of primary care in the first instance.

Timely provision of services (which may have either not been available otherwise, or which would have taken longer to access) is making a real difference to the quality of care being experienced.

This support is being extended to families and carers, increasing their resilience and ability to care for their loved ones in their chosen care setting.

During the focus group, despite a focus on impacts, participants were keen to share some of the key aspects and challenges of the service. Describing these helped to understand what was required and what to be wary of when setting up a service like the Mountbatten Coordination Centre.

The Mountbatten Coordination Centre was subject to two key factors considered important to running the service. Firstly, **having an administrator available at the weekend:**

“The admin team manning the phone at weekends and whilst we’re [Nurses] out and that has made the coordinated centre much slicker.”

Source: Mountbatten Coordination Centre.
Staff Member 4

Secondly, **using SystemOne to manage work.** (The electronic patient record used across the Island)

“We’re on SystemOne, same as the GPs, and the community nurses are on it now too. This is really useful as we can send them a task and they can pick it up easily.”

Source: Mountbatten Coordination Centre. Staff Member 3

To date, two key challenges were reported. Firstly, the **boundaries of administrator responsibility:**

“Where to draw the line with the admin responsibility is an issue. We don’t have an algorithm for non-clinical staff to use and not sure if we want to go that route anyway. I think we want to in a more personal way and avoid algorithms. Our centre is different compared to a 111 or 999 call centre with structured algorithms and a directory of services to signpost toward.”

Source: Mountbatten Coordination Centre. Staff Member 3

Secondly, **working processes with social services was a challenge:**

“We tend to butt up against social services a lot, we often disagree about the appropriate timings for when to introduce our care work. This can be quite challenging. If someone’s been referred to us, even at end of life, sometimes from a social work perspective they think end of life cases meet Fast Track criteria, but this isn’t the case as with Fast Track you must have evidence of a step down. Sometimes there isn’t a change to the patient’s situation and because they [social services] know the patient is known to us, we should sort out the care. It’s a grey area.”

Source: Mountbatten Coordination Centre. Staff Member 5

6. ONGOING MONITORING AND EVALUATION

HEADLINE: *Given the evidence from this evaluation, a focus solely on reductions of acute activity would not accurately reflect the impact of the Mountbatten Coordination Centre. service on the system. Our early findings show that activity may be avoided in primary care and consideration should be given as to how this change can best be captured in the longer term.*

The service could repeat both the longitudinal audits and the two-month audit to increase the sample size, which would allow a more robust analysis to take place. This would provide further evidence around any change to the use of community health services by patients on the end of life pathway.

To validate the impact of the service on acute care, particularly emergency admissions and admission costs it will be necessary to utilise Secondary Uses Service (SUS) data. This section of the report reviews how end of life patients are currently identified in the acute setting, and how this could be used to track their secondary care activity in the longer term:

6.01 ACUTE CARE DATA:

South, Central and West Commissioning Support Unit (CSU) have explored the data fields and flags in SUS data which would enable the monitoring of the use of urgent and emergency care by palliative care patients on an ongoing basis. A full report of their findings is attached as an appendix to this evaluation report.

In summary, whilst in principal there is coding available which could allow the utilisation of services in the acute setting to be monitored, the way that this is applied on a day to day basis would need to be improved to give meaningful data. In addition, many of the diagnosis, treatments, specialties and Healthcare Resource Group (HRGs) coded for patients with palliative care needs are not specific enough to identify palliative care activity.

Coding of inpatient data is more complete than for A&E or Outpatient activity, as diagnosis coding in the latter is poorly recorded with A&E using a coding scheme with no obviously relevant codes to palliative care.

In the inpatient setting the ICD10 code “Z515 – Palliative Care” is currently used by all providers in Hampshire and the Isle of Wight (HIOW). It is the nationally recommended code to identify which palliative care/specialised palliative care has been administered and is almost always used as a secondary diagnosis code. It appears to be most commonly applied when a member of the palliative care team has been involved in a patient’s care. However, it’s clear that acute activity for these patients will frequently be for symptom management or diagnosis rather than directly for palliative care, and this may mean that the Z515 code is not being applied in a way which guarantees patient identification.

Recommendations to improve tracking of palliative care patients' acute activity:

- **Closer liaison between Clinical Coding Departments and their Trusts' palliative care team to identify when palliative care/specialised palliative care has been given.**
- **The use of Z515 diagnosis code purely as a palliative care code and a check on its current application to ensure consistency and standardisation across specialties and care settings**

additionally

- The use of 315 Treatment Function Code should be specific to palliative care and should be utilised by IoW Trust (it is not currently used)
- The use of Z518 diagnosis code could be used for end of life patients
- Use of the HRG codes SD01 to SD05 (which are specialist palliative care codes), which aren't currently used in HIOW, would provide the ideal markers to identify palliative care.

If these coding issues were addressed, then we would suggest the following methodology to look at the use of acute care for palliative patients:

1. Cohort comparison.
 - a. A comparison of acute activity for a cohort of patients with the Z515 code and a comparator group who did not have this code.
2. Tracking of acute activity for patients with a Z515 code
 - a. Comparison of activity before and after hospice involvement/application of the Z515 code

An additional option would be to use the NHS numbers of patients accessing the Mountbatten Coordination Centre, which would allow their hospice activity to be linked to their acute activity and analysed. This would need appropriate data sharing arrangements to be in place and would require CSU data linking facilities to undertake this piece of work.

7. CONCLUSIONS

This evaluation was carried out early in the service's life and as such there are limitations to the conclusions that are able to be drawn.

Regarding service aim 1, to coordinate care and ensure patients were put onto the end of life register, the evaluation found that the service provides a single point of access for end of life patients and is being accessed across its 24/7 operating hours. The service is offering timely advice and support to end of life patients, with an approach which eases access for patients and their families to the help they need.

There is evidence that the system is identifying more patients as they reach the last 5 years of life, who are then able to access the support offered by the Mountbatten Coordination Centre. This is being supported by how the service is integrating with existing services, although challenges remain around working with colleagues from Adult Social Care.

Regarding service aim 4, to reach more people, the evaluation found that the service is receiving more referrals to the hospice than in the previous year, which coupled with the increase in the number of patients on the Share my Care register demonstrates the increased access to specialist end of life care on the Island.

Regarding evaluation question 1, about impacts on patients, the evaluation found that the Mountbatten Coordination Centre is offering practical advice around symptom management and are visiting patients quickly on a responsive basis. The service becomes more involved with patients the nearer to end of life they become and there is indirect evidence that preferences for place of death are being facilitated.

Whilst this support is centred around the patients, many of the telephone calls received by the service are from families and carers. They are directly benefiting from the Mountbatten Coordination Centre and are being supported (practically and emotionally) to care for their loved ones.

Regarding to service aims 2 and 3, and evaluation question 2, about hospital admission and associated costs the evaluation found that there is very limited evidence that the Mountbatten Coordination Centre is reducing secondary care activity, however the coding of patients receiving palliative care is currently poor and doesn't allow for accurate tracking of these patients.

There is more evidence that GP and Nurse appointments and home visits being avoided, with the system activity shift being felt more in primary care.

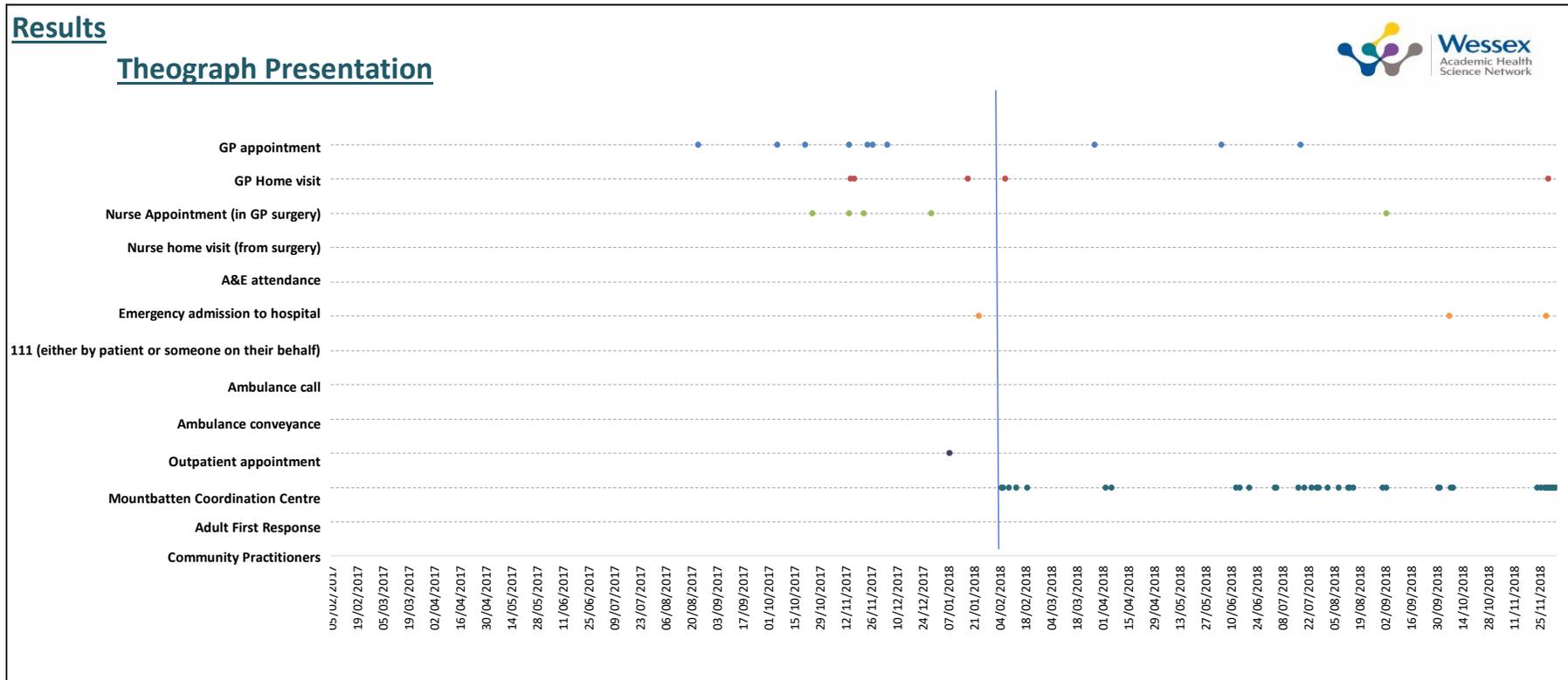
Whilst it will be challenging to measure the impact of the service on primary and community care activity, the findings from this evaluation point to these being the settings where impacts will be most apparent.

With regard to the Commission's key recommendation that hospices should be central to the coordination of care, the early evidence is the Mountbatten Coordination Centre is fulfilling this activity. Patients, carers and professionals can access the service around the clock and receive timely advice and support. Patients' care is being co-ordinated, with clinical interventions provided by the service rather than by primary care clinicians.

APPENDIX 1

Theographs from 5 longitudinal audits

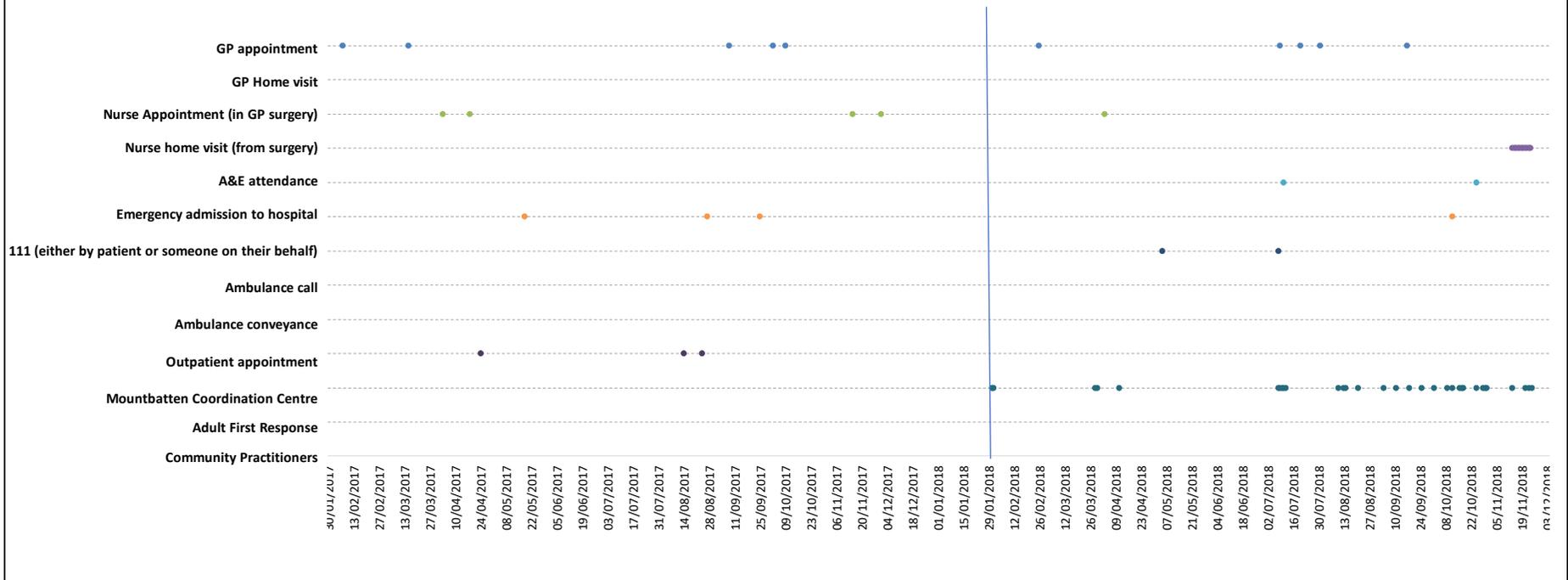
Patient 1: referred 5/2/18



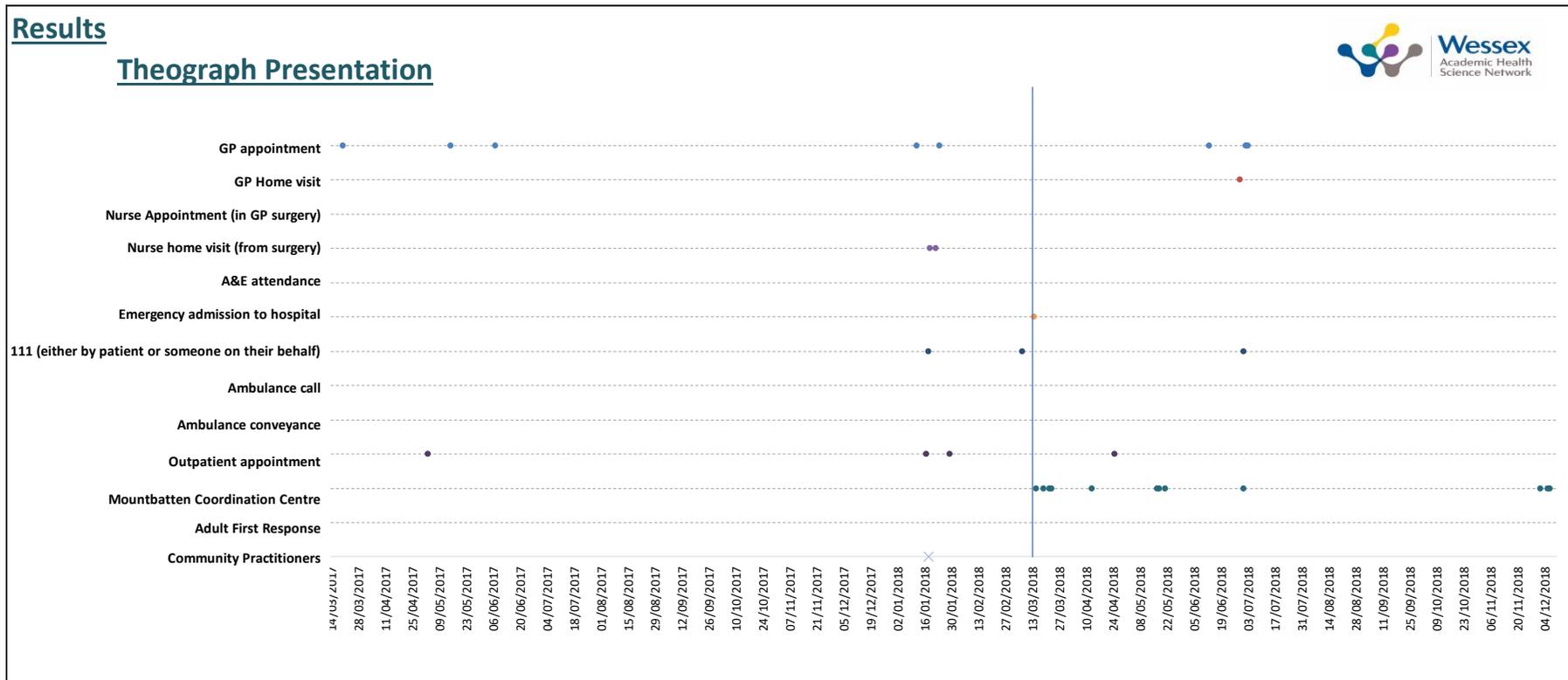
Patient 2: referred 30/1/18

Results

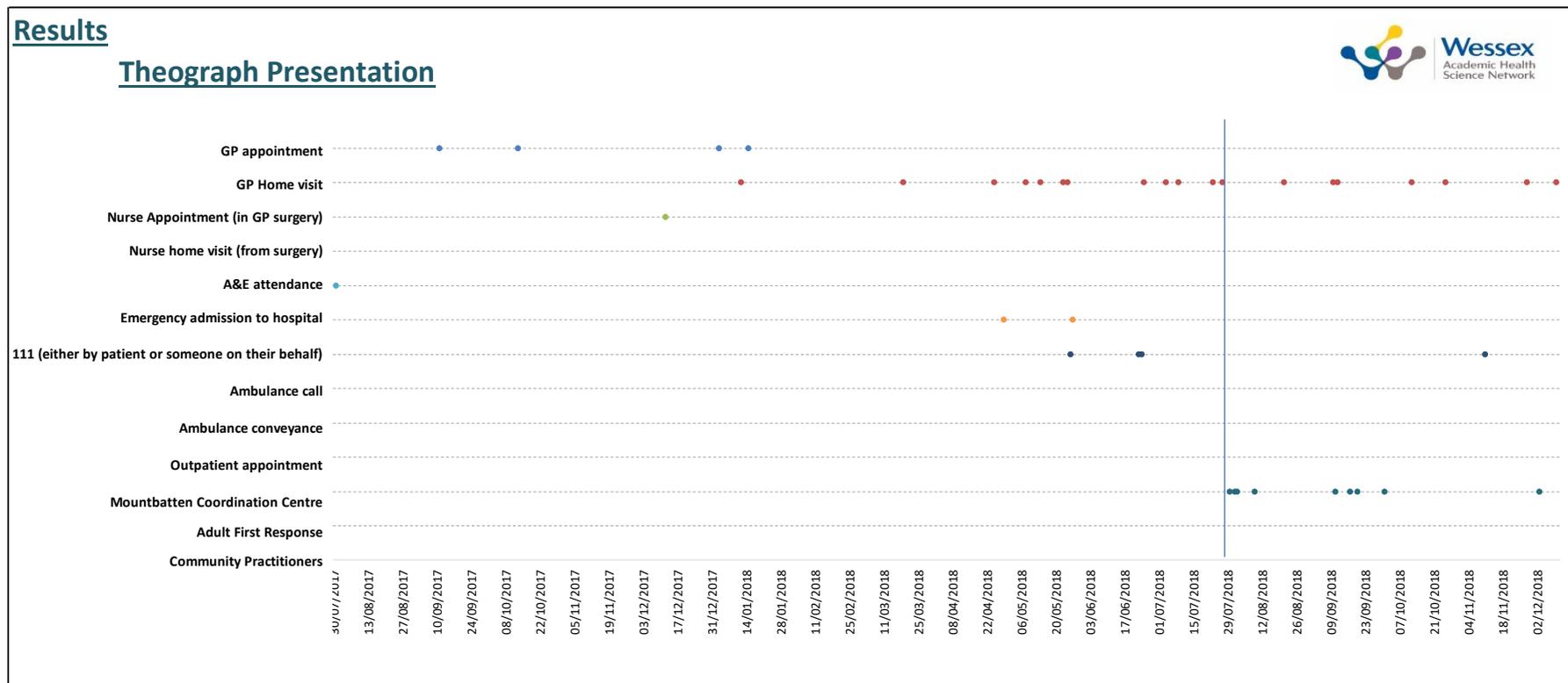
Theograph Presentation



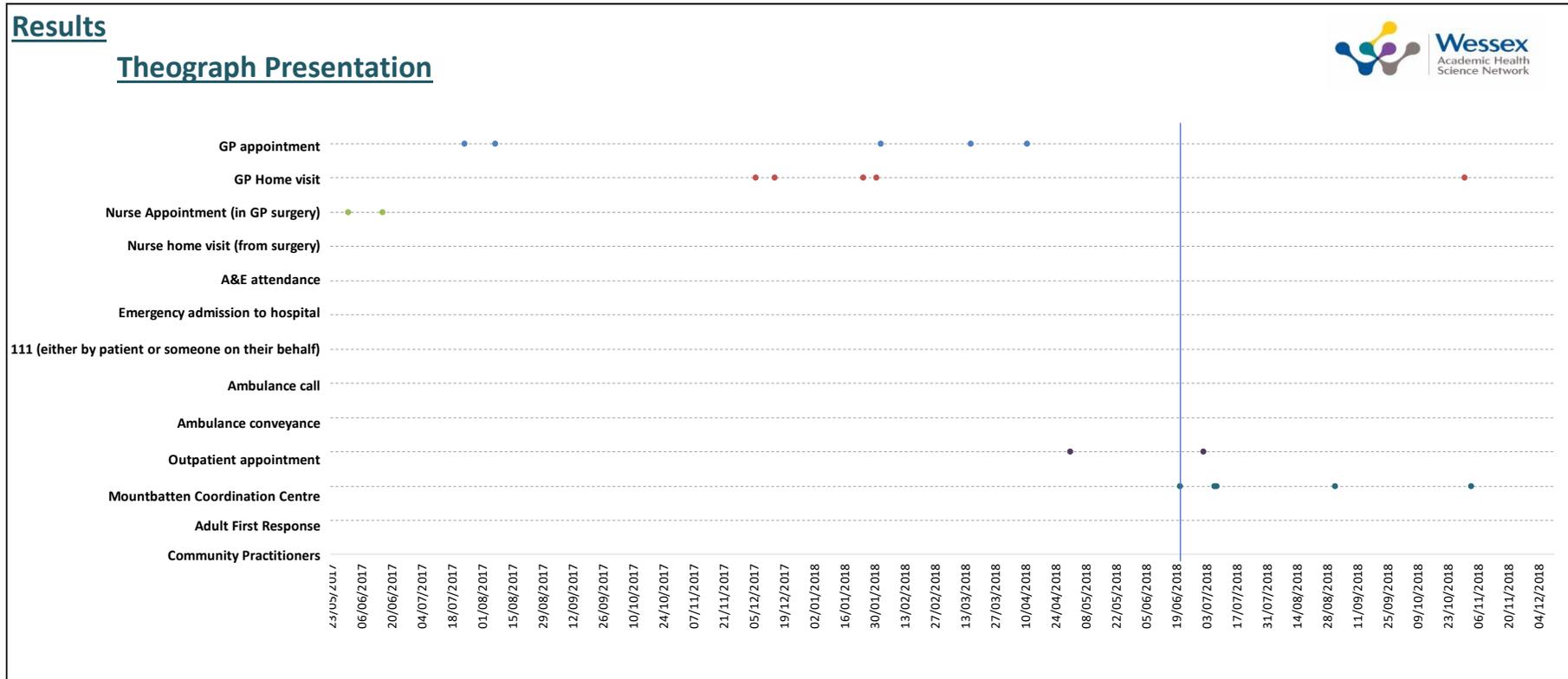
Patient 3: referred 14/3/18



Patent 4: referred 30/7/18



Patient 5: referred 23/5/18



SCW CSU Report on Identification of Palliative Care Activity (Alison Taylor, January 2019)

1. Request/Context

The Wessex Academic Health Science Network (Wessex AHSN) has been asked to evaluate the Mountbatten Coordination Centre. In their description of the evaluation, Wessex AHSN describe “The Isle of Wight has an aging population whose palliative care needs are going to increase rapidly over the coming years. Mountbatten has proposed to redesign the end of life pathway on the Isle of Wight. This is to be achieved through the development of a new End of Life Care Coordination Centre, to include an out of hour’s advice and visiting service together with the development and maintenance of an Island End of Life Register”.

As part of their evaluation process Wessex AHSN have asked South, Central and West Commissioning Support Unit (SCW) to explore Secondary Uses Service data (SUS) to look at what palliative care markers might be available and to recommend what/how these could be tracked by the service going forward to assist this evaluation.

2. Background

WHO Definition of Palliative Care

Palliative care is an approach that improves the quality of life of patients and their families facing the problem associated with life-threatening illness, through the prevention and relief of suffering by means of early identification and impeccable assessment and treatment of pain and other problems, physical, psychosocial and spiritual.

NHS England refers to progressive life-limiting illness. Examples of life-limiting illnesses include advanced cancer, motor neuron disease (MND) and dementia. However, a wide range of conditions can qualify.

3. Process/Methodology

Investigation started with a review of code lists used with Secondary Care data.

- International Classification of Disease (ICD10)
- Office of Population Censuses and Surveys (OPCS) Classification of Surgical Operations and Procedures Fourth Revision (OPCS4)
- Healthcare Resource Groups (HRGs)
- Source of Admission
- Discharge Destination
- Organisation codes

Additional searches included:

- NHS Data Dictionary
- NHS England website
- Public Health England website
- National End of Life Care Intelligence Network

Each of these was explored for potential palliative care markers.

Secondary Uses Service data (SUS) for April 2017 to the end of November 2018 was then explored for activity against these markers for Isle of Wight (IoW) CCG and across all the Hampshire and Isle of Wight CCGs (HIOW) to see if they were used, where and in what context, and how specific they might be to palliative care.

Additional advice was obtained from the SCW Clinical Coding & Clinical Audit Advisory Team.

As diagnosis is very poorly recorded by providers in outpatient SUS data, and A&E uses a different diagnosis coding scheme (with no obviously relevant codes to palliative care), investigation of potential markers within these areas of care was carried out by analysing care in outpatients and A&E received by the cohort of IoW CCG patients who had a hospital admission, including a palliative care diagnosis, during the period April 2017 to the end of November 2018.

4. Findings

4.1 HOSPITAL ADMISSIONS

A. ICD10 Diagnosis Codes

Z515	Palliative care
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Most ICD10 'Z' codes are used as secondary diagnoses rather than the main - primary diagnosis – reason for admission. On paper this code appears the perfect metric to identify palliative care but was investigated to see how it was used for IoW CCG and HIOW.

Analysis revealed:

- The Z515 code is used by all HIOW providers – with highest use at University Hospital Southampton (UHS), both at Countess Mountbatten House (CMH) and Southampton General Hospital. Therefore, Southampton and West Hampshire CCGs had the highest rate of use of the code per 100,000 population.
- IoW CCG had the fourth highest rate of use in HIOW, with the majority recorded at IoW Trust.
- The majority of hospital admissions were non-elective.
- Patient age was mostly aged 50 years plus, with IoW CCG having a higher proportion over 65 years of age than across HIOW.
- Source of admission was usually recorded as the “Usual place of residence”. Not surprisingly, IoW CCG had a higher proportion of admissions from “51 - NHS other hospital provider - ward for general patients or the younger physically disabled or A & E department” for patients transferred off the island to another provider or transferred back to IoW Trust.
- Almost no admissions had the source of admission coded “88 – Non-NHS run Hospice”.
- Discharge destination – a large proportion of HIOW patients were coded “79 – Not applicable – Patient died”. The proportion was smaller for IoW CCG patients.
- Compared to HIOW, IoW CCG and IoW Trust had a higher proportion of patients with a discharge destination coded as “88 – Non-NHS run Hospice”.
- Treatment Function Code/Specialty – although there is a code for Palliative Medicine (315 – see below), patients with a palliative care diagnosis were admitted under a very wide range of specialties. Across HIOW highest numbers were admitted under General Medicine, followed by Palliative Medicine, Medical Oncology, Geriatric Medicine, Respiratory Medicine, and Clinical Oncology.

- Isle of Wight Trust had no admissions recorded as Palliative Medicine, Medical Oncology, Geriatric Medicine or Clinical Oncology – the majority were under the care of General Medicine.
- Primary diagnosis – a very wide range of primary diagnoses were recorded for these admissions with a secondary palliative care diagnosis, with no individual diagnosis standing out. However, approximately a third had a primary diagnosis of some form of cancer (ICD10 code C*) and a large proportion had a secondary diagnosis of some type of secondary malignancy. Other more common primary diagnosis included sepsis; pneumonia; stroke, cerebral haemorrhage or infarction; heart failure.
- Primary procedure – a large proportion of the admissions involved no procedure. IoW CCG admissions were more likely to have had a procedure than across HIOW as a whole. Where they did, a wide range of procedures were recorded with a high proportion of these being a diagnostic test such as CT or MRI. The most frequent procedures otherwise were catheterisation, drainage of ascites and blood transfusion.

Comment from the SCW Clinical Coding & Clinical Audit Advisory Team was that the use of Z51.5 Palliative Care is mostly used when a member of a palliative care team has been involved. They provided the following national guidance:

“The current ICD10 coding standard **DCS.XXI.9: Palliative Care (Z51.5, Z51.8)** is based on palliative care guidance produced at the request of the Department of Health. As there is no definition of what constitutes as ‘specialised palliative care’, and each Trust’s palliative care services may differ, we strongly recommend that clinical coding departments work closely with their Trust’s palliative care team in order to identify when palliative care/specialised palliative care has been administered. However, if a patient has received specialised palliative care whilst in hospital, and it is clearly documented in the medical record as specialised palliative care, then it would be appropriate to assign ICD-10 code Z515 - Palliative care, regardless of which member of the team has provided the specialised palliative care or the specialty they are admitted under.”

Z518	Other specified medical care
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Investigation of activity revealed that this code was used by all main providers – highest at Portsmouth Hospitals followed by IoW Trust. IoW CCG had the highest rate of admissions per 100,000 population with this diagnosis code, followed by Portsmouth CCG. Almost all IoW CCG patients with this diagnosis were admitted to IoW Trust.

Other findings were that:

- The majority of hospital admissions with this code were non-elective admissions;
- Admissions were under General Medicine, Geriatric or Stroke Medicine specialties.
- The age profile was older than that with the palliative care diagnosis – with almost all patients over the age of 50 years.
- Most patients had a large number of diagnoses/co-morbidities recorded. The most frequent diagnoses were sepsis, pneumonia, stroke/cerebral infarction and heart failure.
- Some of these patients also had a palliative care or secondary malignancy diagnosis.
- The majority of patients had no procedure recorded. Where one was, CT, catheterisation and ventilation were the most frequent.
- A high proportion of these patients died. This proportion was slightly lower for IoW CCG where more patients were recorded as discharged to a hospice or NHS run Care Home.

Comment from the SCW Clinical Coding & Clinical Audit Advisory Team was that code Z518 is classed as an ‘other’ code and is therefore used for a variety of care. It is most often used for identifying care

from a pain service. The ICD10 coding guidance **DCS.XXI.9: Palliative Care (Z51.5, Z51.8)** states that “in Palliative Care (Z51.5, Z51.8), code Z51.8 - Other specified medical care is not restricted to palliative care and may be used to identify other instances of medical care. There is nothing to prohibit the assignment of both Z515 Palliative care and Z518 when the patient has been seen by both specialised palliative care and the pain service teams during their hospital spell.”

Z519	Medical care, unspecified
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Across HIOW, this secondary diagnosis code was recorded a very small number of times in the time period and was not associated with either a palliative care or secondary malignancy code.

Comment from the clinical coders was that the use of Z519 is discouraged because it is a bucket code and would only be used in circumstances where a local agreement to utilise it for a specific reason is made. It does not indicate palliative care support.

Z755	Holiday relief care
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This secondary diagnosis code was identified in the background details to the palliative care HRGs (see below). However, across HIOW this code was mainly used with a Learning Disability treatment function code at Hampshire Hospitals. A very small proportion of patients with this diagnosis code were recorded under geriatric/general medicine with a dementia diagnosis.

C78	Secondary malignant neoplasm of respiratory and digestive organs
C780	Secondary malignant neoplasm of lung
C781	Secondary malignant neoplasm of mediastinum
C782	Secondary malignant neoplasm of pleura
C783	Secondary malignant neoplasm of other and unspecified respiratory organs
C784	Secondary malignant neoplasm of small intestine
C785	Secondary malignant neoplasm of large intestine and rectum
C786	Secondary malignant neoplasm of retroperitoneum and peritoneum
C787	Secondary malignant neoplasm of liver and intrahepatic bile duct
C788	Secondary malignant neoplasm of other and unspecified digestive organs
C79	Secondary malignant neoplasm of other and unspecified sites
C790	Secondary malignant neoplasm of kidney and renal pelvis
C791	Secondary malignant neoplasm of bladder and other and unspecified urinary organs
C792	Secondary malignant neoplasm of skin
C793	Secondary malignant neoplasm of brain and cerebral meninges
C794	Secondary malignant neoplasm of other and unspecified parts of nervous system
C795	Secondary malignant neoplasm of bone and bone marrow
C796	Secondary malignant neoplasm of ovary
C797	Secondary malignant neoplasm of adrenal gland
C798	Secondary malignant neoplasm of other specified sites
C799	Secondary malignant neoplasm, unspecified site

ICD10 diagnosis codes C78 and C79 (see detail above) are used in both primary and secondary diagnosis positions. Across HLOW approximately half of all hospital admissions with a palliative care diagnosis code (Z515) also had one of the codes above for secondary malignancy.

However, this number was only a small proportion (approximately 1 in 9) of all admissions with a secondary malignancy code. Therefore, these codes would not have the specificity to identify palliative care.

F03X	Unspecified dementia
F009	Dementia in Alzheimer disease, unspecified
F019	Vascular dementia, unspecified
G308	Other Alzheimer disease
G309	Alzheimer disease, unspecified

To be completed if required by Wessex AHSN.

G122	Motor neuron disease
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To be completed if required by Wessex AHSN.

B. OPCS Procedure Codes

There are no procedure codes directly related to palliative care alone – and many patients with a palliative care diagnosis have no procedure.

U212	Computed tomography NEC
U051	Computed tomography of head

Although various forms of CT are some of the most frequent procedures received by patients with a palliative care diagnosis, these admissions are a relatively small proportion of all admissions with a CT primary procedure code. They are therefore not specific enough to identify palliative care activity.

M47-	Urethral catheterisation of bladder
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Similarly, catheterisation and maintenance are some of the more frequent procedures received by patients with a palliative care diagnosis, however these admissions are a relatively small proportion of all admissions with some form of catheterisation recorded as the primary procedure – the vast majority of which do not have a palliative care diagnosis. These codes are therefore not specific enough to identify palliative care activity.

T462	Drainage of ascites NEC
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All admissions with this primary procedure code have either a palliative care/ secondary malignancy diagnosis or liver disease. Therefore, although a palliative care diagnosis is present in only a proportion, it may have some validity in identifying a subset of patients requiring palliative care.

X332	Intravenous blood transfusion of packed cells
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Although one of the more frequent procedures for patients with a palliative care diagnosis, this code is not specific enough to palliative care for use to identify activity.

C. Treatment Function Codes and Specialty

315	Palliative Medicine
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Palliative Medicine would be the obvious specialty for patients to receive palliative care. However, there were **no** IoW CCG admissions recorded under the care of Palliative Medicine. Further analysis showed that neither IoW Trust nor Portsmouth Hospitals coded the Palliative Medicine treatment function code or specialty.

The majority of Palliative Medicine admissions at University Hospital Southampton were based at Countess Mountbatten House (CMH). Approximately half the admissions for Palliative Medicine for all Hampshire were to CMH. Almost all of this activity included a palliative care diagnosis code. However, very few of the admissions under Palliative Medicine to Jubilee House (Solent NHS Trust) included coding for palliative care.

- Almost all patients admitted to Palliative Medicine were over 50 years of age.
- The majority of admissions had a primary diagnosis of cancer.
- The majority of admissions did not have a procedure. Where they did, the most frequent were blood transfusions, catheterisations and drainage of ascites.

370	Medical Oncology
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Although Medical Oncology was one of the main treatment function codes for patients with a palliative care diagnosis across Hampshire (very little for IoW CCG), these patients make up a very small proportion of all admissions for this specialty.

D. Healthcare Resource Group (HRG) Codes

Search of HRG codes revealed the following palliative care specific codes:

SD01A	Inpatient Specialist Palliative Care, 19 years and over
SD01B	Inpatient Specialist Palliative Care, 18 years and under
SD02A	Inpatient Specialist Palliative Care, Same Day, 19 years and over
SD02B	Inpatient Specialist Palliative Care, Same Day, 18 years and under
SD03A	Hospital Specialist Palliative Care Support, 19 years and over
SD03B	Hospital Specialist Palliative Care Support, 18 years and under
SD04A	Medical Specialist Palliative Care Attendance, 19 years and over
SD04B	Medical Specialist Palliative Care Attendance, 18 years and under
SD05A	Non-Medical Specialist Palliative Care Attendance, 19 years and over
SD05B	Non-Medical Specialist Palliative Care Attendance, 18 years and under

However, there was no inpatient activity recorded against any of these SD codes across HIOW.

AA27Z	Medical Care of Patients with Alzheimer's Disease
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To be completed if required by Wessex AHSN.

WD11Z	All patients 70 years and older with a Mental Health Primary Diagnosis, treated by a Non-Specialist Mental Health Service Provider
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To be completed if required by Wessex AHSN

E. Other Codes

Source of Admission

88	Non-NHS (other than Local Authority) run Hospice
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Although there is a code for hospital admission from a hospice, numbers across HIOW and IOW CCG were very small. Only a small number of these admissions had a palliative care diagnosis code, so it could be that when a patient is admitted from a hospice it is generally for care other than palliative care.

Discharge Destination

88	Non-NHS (other than Local Authority) run Hospice
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Analysis of all admissions across HIOW where the destination on discharge from hospital was to a non-NHS hospice revealed a larger number. IoW CCG had the highest rate of discharges to a hospice per 100,000 population of all the HIOW CCGs.

Other findings:

- Although almost all IoW CCG discharges to a hospice were from IoW Trust, not all of these had a palliative care diagnosis during their hospital admission, though the majority did.
- Almost all of these hospital admissions were non-elective admissions.
- The age profile for these patients was similar to that for admissions with a palliative care diagnosis.
- The majority of patients had been admitted to hospital from their usual place of residence.
- Across HIOW patient care in hospital was mainly under General Medicine, Medical Oncology or Respiratory Medicine. For IoW CCG, it was mainly under General Medicine or General Surgery.
- The primary diagnosis for these patients had a similar spectrum to those with a palliative care diagnosis, with a high proportion with a cancer diagnosis. A high proportion had a secondary diagnosis of secondary malignancy.
- The spectrum of primary procedures was also similar to those with a palliative care diagnosis, again with a high proportion of admissions with no procedure, and IoW CCG patients experiencing more procedures than across HIOW as a whole.

Provider Site Codes

Codes were identified for the two main hospices in the area:

R1FCG	Earl Mountbatten Hospice
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No inpatient activity was identified for Earl Mountbatten Hospice on the Isle of Wight. There was also no activity identified using their organisation code "8JM49". In general hospices have an organisation code starting "8-".

RHM04	Countess Mountbatten House
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Countess Mountbatten House (CMH) has a University Hospitals Southampton site code. Inpatient activity was coded to either the Palliative Medicine or Medical Oncology treatment function codes. The majority of their admissions were for either Southampton or West Hampshire CCG patients. Almost all had a palliative care diagnosis code recorded.

4.2 OUTPATIENT ATTENDANCES

Diagnosis is very poorly recorded by providers in outpatient SUS data. Therefore, searches for activity using diagnosis codes such as Z515-Palliative care will not be reliable and will miss most attendances. Investigation of potential markers was carried out by analysing care in outpatients received by the cohort of IoW CCG patients who had a hospital admission including a palliative care diagnosis. Activity for treatment function code/specialty Palliative Medicine was also analysed.



A. Treatment Function Code/Specialty

Not surprisingly, looking at all outpatient attendances for the IoW CCG cohort of patients with an inpatient palliative care diagnosis found activity under a wide range of treatment function codes. These included specialties such as Ophthalmology and Podiatry, reflecting the range of conditions/co-morbidities that these patients may have. However, there were also significant numbers of outpatient attendances under Palliative Medicine, Medical Oncology and Clinical Oncology (previously Radiotherapy), as well as more general specialties such as Respiratory Medicine and Urology.

315	Palliative Medicine
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There was no outpatient activity recorded under Palliative Medicine at IoW Trust. However, some of the IoW CCG palliative care cohort of patients attended Palliative Medicine outpatients at University Hospital Southampton (Southampton General) – utilising half of all the IoW CCG attendances at Palliative Medicine outpatients. None of this was coded as occurring at CMH.

The age profile for patients attending a Palliative Medicine outpatient appointment was slightly younger than the IoW CCG palliative care diagnosis cohort.

None of the Palliative Medicine outpatient activity had diagnosis recorded. The only procedure recorded for some patients was “X622-Assessment by multi-professional team NEC”.

370	Medical Oncology
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Almost half of all outpatient chemotherapy procurement/delivery procedures occurred within Medical Oncology (see codes below). All attendances for this specialty were funded by specialist commissioning. The majority of Medical Oncology outpatients for IoW CCG occurred at IoW Trust. The palliative care diagnosis cohort made up a relatively small proportion of all such outpatient attendances.

B. OPCS Procedure Codes

The majority of the palliative care diagnosis cohort had no procedures during their outpatient attendance.

X384	Subcutaneous chemotherapy
X701	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 1
X702	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 2
X703	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 3
X704	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 4
X705	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 5
X711	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 6
X712	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 7
X713	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 8
X714	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 9
X715	Procurement of drugs for chemotherapy for neoplasm for regimens in Band 10
X724	Delivery of subsequent element of cycle of chemotherapy for neoplasm
X731	Delivery of exclusively oral chemotherapy for neoplasm

Where there was a procedure recorded in outpatients, procurement and delivery of chemotherapy (see procedure codes above) was recorded in almost a quarter of attendances. Most of these were under the care of Medical Oncology or Clinical Oncology, usually with Specialist Commissioning funding.

L913	Attention to central venous catheter NEC
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This procedure was the most frequent individual procedure for patients with a palliative care diagnosis. However, these patients were a minority compared to all IoW CCG outpatient attendances requiring attention to their central venous catheter.

Almost all of these procedures took place within Clinical Oncology or Medical Oncology, with Specialist Commissioning funding.

C. HRG Codes

The majority of the outpatient attendances for the palliative care diagnosis cohort had the generic outpatient HRG codes “WF01B - Non-Admitted Face-to-Face Attendance, First” or “WF01A - Non-Admitted Face-to-Face Attendance, Follow-up”.

SB97Z	Same Day Chemotherapy Admission or Attendance
YR43A	Attention to Central Venous Catheter, 19 years and over

Where there was a more specific outpatient attendance HRG, the above codes were most frequent – in line with the procedures discussed above.

4.3 A&E ATTENDANCES

The following A&E fields were reviewed for codes that would be applicable to palliative care:

A&E Diagnosis/Conditions
A&E Sub Diagnosis
A&E Treatment Codes
A&E Sub-Treatment Codes

However no distinct palliative care codes were identified - A&E data uses relatively high level codes e.g. “Respiratory conditions”; “Haematological conditions”. Although the new Emergency Care Commissioning Data Set (ECDS; due to replace current dataset from April 2019) includes a much broader range of codes, review of diagnosis and treatment descriptions suggests it may still be difficult to identify attendances related to palliative care.

Activity_Treatment_Function_Code_Decision_To_Admit
Emergency_Care_Referred_To_Service

Review of other fields in ECDS suggest that there may be scope to identify patients by the specialty under which they were admitted or by referral on from A&E to a palliative care service (see fields above). How well these fields are used is yet to be discovered.

To get around these issues and try to identify A&E activity relevant to palliative care, investigation of potential markers within A&E was carried out by analysing care in A&E received by the cohort of IoW CCG patients who had a hospital admission including a palliative care diagnosis, in the time period April 2017 to the end of November 2018.

Almost all of the palliative care cohort attended A&E at least once in the time period. A large proportion attended more than once. A small number had multiple attendances. Almost all of these attendances were within IoW Trust at the main emergency department. Very few were recorded as follow-up A&E attendances (planned or unplanned).

A very large proportion of patients were brought to A&E by ambulance and the majority of patients were admitted. A wide range of diagnoses were made, with the highest being for gastrointestinal conditions, respiratory conditions, infectious disease, haematological conditions and urological conditions. The most frequent treatments received in A&E included observation/monitoring, medication and guidance/advice. None of these are specific enough to identify whether they might be related to the need for palliative care.

4.4 COMMUNITY CARE

The Community Services data Set (CSDS) has been developed and is being tested. The data/statistics are currently classified as experimental with caution advised regarding their use. However, CSDS promises to be a rich source of information on community care – including palliative/end of life care – in the near future.

Data tables and data items that are relevant to palliative care are listed below:

Data Table	Data Item Name	National Code/Description
CYP102 Service Type Referred To	Service or Team Type Referred to (Community Care)	03 - Cancer Service
		14 – End of Life Care Service
		25 - Pain Management Service (excludes mobility)
		36 – Respite Care Service
CYP101 Referral	Primary Reason for Referral (Community Care)	026 – End of Life Support
		049 – Pain/Symptom Control
CYP103 Other Reason Referral	Other reason for referral (Community Care)	026 – End of Life Support
		049 – Pain/Symptom Control
CYP201 Care Contact	Activity Location Type Code	F01 – Hospice
CYP202 Care Activity	Community Care Activity Type Code	03 – Clinical Intervention
		04 – Counselling,
CYP601 Medical History	Previous Diagnosis (Coded Clinical Entry)	Note: may be ICD-10, Read code or SNOMED CT code
CYP607 Primary Diagnosis	Primary Diagnosis (Coded Clinical Entry)	Note: may be ICD-10, Read code or SNOMED CT code
CYP608 Secondary Diagnosis	Secondary Diagnosis (Coded Clinical Entry)	Note: may be ICD-10, Read code or SNOMED CT code

More information can be found at:

<https://digital.nhs.uk/data-and-information/publications/statistical/community-services-statistics-for-children-young-people-and-adults/september-2018>

Of the above data tables, the current monthly reports focus on:

- Referral Details (CYP101)
- Care Contact Details (CYP201), and
- Care Activity Details (CYP202)

5. Recommendations

The analysis above has shown that many of the diagnoses, treatments, specialties and HRGs coded for patients with palliative care needs/receiving palliative care are not specific enough to identify palliative care activity. However, the following recommendations are made on codes/fields to use in order of likelihood to identify palliative care:

Field	Code	Comments
Diagnosis	Z515 – Palliative care	This code should be specific to palliative care and is highly associated with care in Palliative Medicine. It is the nationally recommended code to record to identify when palliative care/specialised palliative care has been administered. It is almost always a secondary diagnosis code.
Treatment Function Code/ Specialty	315 – Palliative Medicine	This TFC should be specific to palliative care, confirmed by its use for the majority of activity at Countess Mountbatten House. However, note that it is not used by IoW Trust.
Diagnosis	Z518 – Other specified medical care	Coding Guidance states that this code “is not restricted to palliative care and may be used to identify other instances of medical care”. However, this suggests that it could be used and the profile of admissions with this code, particularly the high proportion of deaths, suggest that these admissions are “end of life” – but coding may not indicate palliative care.
Discharge Destination	88 - Non-NHS (other than Local Authority) run Hospice	Patients being discharged to a hospice have a requirement for palliative care. Investigation of hospital activity for patients discharged to a hospice showed that many had a palliative care diagnosis. Admissions had a similar profile to those with a palliative care diagnosis in terms of diagnoses, procedures and age profile.
Procedure	T462 - Drainage of ascites NEC	All admissions with this primary procedure code had either a palliative care/secondary malignancy diagnosis or liver disease. Therefore, it may have some validity in identifying a subset of patients requiring palliative care.
HRG	SD01 to SD05 codes for Specialist Palliative Care	In theory these codes should be ideal for identifying palliative care but no activity has been recorded against them in HIOW.

The above recommendations apply to inpatient care. Non-coding of diagnosis in outpatient data and a non-ICD10 diagnosis in A&E make identification of palliative care activity in these settings difficult.

A Palliative Medicine treatment function code/specialty will identify some palliative care activity in outpatients – but probably not all.

An alternative approach for outpatients and A&E is to identify patients receiving inpatient palliative care and to look at their A&E and Outpatient attendances, as investigated for this report. However, it should be noted that this has the risk of missing palliative care for patients who have not been hospitalised, and will pick up additional non-palliative care activity associated with co-morbidities.

The CSDS will provide useful community care activity information in the future. However, the data is currently experimental with caution advised on its use.

It is recommended that IoW Trust is encouraged to use the secondary diagnosis Z515 where palliative care is given. The high rate of use of this code for IoW CCG suggests that IoW Trust may already be coding all relevant activity - but it is impossible to know where such activity has taken place and not been coded.

6. Additional resources, Data and Links

- Palliative Care Currency – new currency being developed by NHS England, based on Setting, Spells and Phases of care, includes age, co-morbidities
 - Developing a new approach to Palliative Care Funding- Final Report 2015/16 Testing. Published 22 March 2017. NHS England.
 - Guidance for using the Adult Palliative Care Currency. Published 22 March 2017. NHS England.
- Atlas of variation for palliative and end of life care in England; November 2018 plus Instant Atlas Tool
 - <http://www.endoflifecare-intelligence.org.uk/view?rid=1038>
 - <https://fingertips.phe.org.uk/documents/Atlas%20of%20variation%20for%20palliative%20and%20end%20of%20life%20care%20Final.pdf>
 - Also includes a list of Palliative and end of life care resources on p101
- National End of Life care Compendium of data sources
 - http://www.endoflifecare-intelligence.org.uk/data_sources/
- Public Health England - Palliative Care clinical dataset
 - www.endoflifecareintelligence.org.uk/resources/publications/pccdseval
- End of Life Care Profiles CCG level snapshots - launched by Public Health England, October 2015 - Focuses on place of death, cause of death, care home use and dementia
- NHSE Resources for commissioners
 - End of Life Care Sustainability Transformation Partnership (STP) Support Packs were produced collaboratively by NHS England, Public Health England (PHE) and the Care Quality Commission (CQC). The packs look at key priorities for STPs around the transformation of services, financial efficiency, and the priorities set out in the Five Year Forward View. They contain a sample of end of life care metrics which could support local decision making.
- NHS England also has:
 - End of Life Care Commissioning Toolkit Updated April 2016
 - Information for Commissioners: specialist level palliative care; palliative care currency; palliative care data set
- The National End of Life Care Intelligence Network (NEoLCIN) profiles provide data on deaths, place of death and deaths by place and cause

- NEOLCIN modelling tools provide a simulation of the likely end of life care needs for an average 200,000 population
- NEOLCIN End of Life Care STP Data Tool 27/10/2017
 - <http://www.endoflifecare-intelligence.org.uk/view?rid=1007>
 - Looks at variation in the proportion of people that died with various causes e.g. cancer, COPD, heart disease or in usual place of residence, hospital, hospice, care home etc.
 - Includes dashboard with individual CCG values as well as STP for comparison.
- Quality and Outcomes Framework (QOF) provides performance on palliative care indicators at GP practice level (use of palliative care registers and regular multidisciplinary meetings to discuss cases)
- Hospital Episode Statistics (HES) hospital mortality data gives the ratio between the actual number of patients who die after hospitalisation at a trust and the number expected to die on the basis of average England figures, given the anonymised characteristics of the patients treated there

REFERENCES

The Commission into the Future of Hospice Care – an evidence-based report. Calanzani, Higginson, Gomes (2013)

VERSION CONTROL

Version	Status	Key Changes	Authorised by
V1	Archived		SH
V2	Archived	Some qual data included	AS
V2.1	Archived	All qualitative data included and some restructuring	AS
V2.2	Archived	Initial conclusions and some restructuring. Reformatting of quotes	SH
V2.3	Archived	AS comments. Addition of references. Amended conclusions	SH
V2.4	Archived	PD Comments	PD
V2.5	Archived	Final edits and amends	SH
V2.6	Archived	Amended following fact check by service	SH
V2.6	Live	FINAL REPORT	SH