

"A Good Send-Off?" Patients' and Family's Experiences of End of Life Care

One year on March 2021



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1. Background

- 1.1 In September 2020, Healthwatch produced <u>"A Good Send-Off"</u> based on conversations with patients who were at the very end of their life and with their families. Healthwatch had talked to 15 patients on the oncology ward at the Royal Sussex County Hospital about their discharge from hospital between November 2019 and January 2020 and followed up with them once discharged. We wanted to gain better insight into why so many people died in hospital when most said they preferred to die at home. We looked at whether there was anything in the systems and processes, cultures and practices being followed when people were discharged from hospital that helped or hindered this wish.
- 1.2 The work took place at the end of 2019 and early 2020 and was written up in March. We delayed publication until September 2020 because of the coronavirus pandemic. This report follows up our recommendations after a year and looks generally at what is happening around end of life care in hospitals and the community.
- 1.3 In 2018, the National Audit of End of Life study (NACEL)ii drafted recommendations about the systems, processes and the capacity that was needed across all sectors hospital, community, primary care and care homes to deliver good care. Their results showed in patient documents reviewed- that for only a quarter of patients, hospital was the preferred place of death. The majority of people would like to die at home. In Brighton and Hove, in half of all deaths, people die in their usual residence (2016). This is a higher proportion than for England and has increased from 40% in 2006. It is however still a way from meeting people's wishes. Brighton and Hove Joint Health and Wellbeing Strategy includes an element on Dying Well.
- 1.4 The original intention of our study was to talk to a wide range of people who were at the end of their life, including frail older people. The Brighton and Sussex University Hospitals NHS Trust (BSUH) (as of 1st April 2021, this is now called University Hospitals Sussex NHS Trust) has greater than national average of deaths in very old people (aged 85-94) and those with frailty and dementia (NACEL, above). Our starting point was whether it might be possible to improve the chances of older people dying outside a hospital environment if this was their expressed wish.
- 1. 5 This study looked at patients who were being discharged from the oncology ward at the Royal Sussex County Hospital (RSCH). This was because the Palliative Care Team at the hospital and the oncology ward were *also interested* in how people fared at home when discharged. It was a pilot project, intended to lead to wider work to include frail older people. We spoke to patients and families on the ward and after discharge, sometimes several times, in their homes and by telephone.



1.6 We found that people experienced enormous churn during the last few days and weeks of their life, often being admitted in and out of hospital. Care and support at home was of variable quality with resources not always in place to support them. There were several instances of 'failed discharges' with people going back into hospital very soon after their discharge. Follow-ups of community health services appeared to families to be 'hit and miss'. GPs were invariably not involved after discharge with the patients we interviewed. Many families felt they were not appropriately involved, even though they were likely to be the main carers when the person was discharged. No one had heard of ReSPECT (Recommended Summary Plan for Emergency Care and Treatment) or remembered early conversations about planning the end of their life or death, even though staff said discussions had taken place. People who had been discharged through the specialist Palliative Care Team at the hospital or were linked into Martlets Hospice fared better, with their care plan being coordinated by specialists.

2. One year on - the context

- 2.1 Since our fieldwork, COVID-19 has totally dominated the agenda and prevented Healthwatch from continuing to interview people. In our report, we described a 'good death' as 'a good send-off', a remark made by a bereaved relative. For her, this meant all the family being around, with caring support and a peaceful end. Sadly, COVID-19 has meant that many people have died without that close support from their families, with last messages being delivered by phone or FaceTime, and although staff had done everything they could to support patients and families, it was a far cry from what most people say they would want to die at home, without pain with their family and close ones.
- 2.2 Our report necessarily takes this context into account. Some planned improvements in end of life care have stalled. Notwithstanding, COVID-19 has highlighted how important it is to have a good send-off: and the impetus to deliver this remains with staff in services most closely involved in end of life care.



What impact has our report had to date?

Some formal processes have taken place to embed our report findings into strategy and policy, which provides confidence that having quality end of life care and dying well remains high on statutory agencies agendas.

1. On 3rd September 2020, the Clinical Commissioning Groupⁱⁱⁱ (CCG) formally responded to the Healthwatch report, accepting that all of our recommendations were appropriate and reasonable.



- 2. In October 2020, the report was presented to the Patient Experience Panel and the Quality Assurance Board at the BSUH, which is a strategic forum attended by senior Trust departmental leads. The Board agreed "to improve the care pathway and correct the elements of personal insensitivity and absence of care planning that (Healthwatch) found when talking to patients and families". A formal response from the Trust can be read on page 4 of our initial report.
- 3. In November 2020, the <u>Health and Wellbeing Board</u> received the report and proposed that it formed part of their 'Dying Well' Joint Health and Wellbeing Strategy delivery plan. They asked for it to be brought back to the Board to monitor progress on the 23rd March 2021.

RESOLVED -

- (1) That the Board request that the recommendations of the report are delivered through the Brighton and Hove Joint Health and Wellbeing Strategy, by all the relevant partners to the strategy. Particularly Dying Well and Ageing Well.
- (2) That the Board request partners to the JHWS to devise and implement an action plan to address the recommendations of the report. That action plan should include service users and their families as equal partners in service re-design and co-production of improved end of life care services; and
- (3) That there be a report back to the HWB on progress in 12 months' time.
- 4. In March 2021, a report was brought back to the Health and Wellbeing Board by the CCG updating the committee on actions emanating from the Healthwatch recommendations. The update included work in place to avoid unnecessary hospital admissions, fast track domiciliary care, future commissioning intentions and work on training of staff and building networks on end of life care. The report was noted, and can be found here.
- Our report has also been presented twice to the CCG GP practice leads End of Life Gold Standards Framework Coordinators meeting: and to the research team at <u>The Shore-C Cancer Research Centre at Sussex University</u>, a centre of excellence on cancer



3. Healthwatch recommendations and follow-up

In this section we revisit the ten recommendations made in our report <u>"A Good Send-Off"</u> and the progress which has been made against these so far. We also explore some of the national context around improving end of life care.



Recommendation One: A greater focus on patients at the end of their life to improve their experience, and also hospital performance.

Data shows that people at the end of their life often have many admissions to hospital in the last year of their life. They stay in hospital longer and often have complex and delayed discharges. They are frequently re-admitted to A&E, sometimes shortly after discharge (this data was shared at an End of Life Conference, November 1999, hosted by CCG and Public Health Brighton and Hove.)

At the time Healthwatch carried out its study (end of 2019 and early 2020) with 15 patients, some serious concerns emerged. These issues included the number of attendances at A&E and the time people spent waiting to be seen; and people's discharge being delayed when they were clinically ready to go home from hospital. Some patients spent long periods in hospital (these patients are referred to as being 'stranded' when they remain in hospital longer than a week. Patients tend to deteriorate the longer they remain in hospital especially over 3 weeks, when they are regarded as 'super-stranded'.)

Supporting people at home on discharge requires the involvement of NHS community services and local authority social services. These are complex systems for patients to navigate and often under-resourced, so some concerns continue, despite efforts of the wider health and social care system to address these. Many patients affected by them are at the end of their life. It was - and remains - the Health-watch contention that providing extra resources for patients at the end of their life would not only improve the quality of life for patients but would also address some of the hospital performance issues.

Most of the people we interviewed had cancer, but some had other conditions such as chronic respiratory disease. By definition, people with end of life care needs are very ill and they may be having active therapies, have side-effects from treatments and/or new symptoms, so will need clinical oversight. However, the number of admissions and the amount of time that end of life patients spent in hospital does open up the question as to whether - if more support was available in the community - some admissions could be avoided. Our study shows that being readmitted through A&E is particularly distressing for patients and families. Any service that would prevent that experience would be valuable.

We did find that some family members and paid carers, often at the front line of care, felt obliged to phone 999 when the patient had a problem because they did



not know what else to do. This sets up a potential care pathway that leads to the hospital. The ambulance service works hard to avoid admissions where they can. The reasons for conveying patients to hospital are widely known. They include the push of not having staff or carers to provide optimum care in the community or care homes and not having documented information on the person's wishes and end of life plan being available at the point of crisis. This happens especially overnight where medications may not be prescribed or available, staffing levels are low, families are more worried, specialist advice not being on hand and a rapid response not being available.

In addition, when training is being considered, our study indicated that care workers need to be included, not just those in care homes but also in the community as their reactions and ability to care for the person at home, and the risks associated, can make the difference between a person being hospitalised, or not.

Update

There are some new initiatives in their early stages of development that have the potential to address unnecessary admission to A&E. The <u>Sussex and Kent Ambulance Service (SECAmb)</u> have a pilot aiming to appropriately reduce conveyancing/transporting people at the end of their life to hospital. This is an important area as sometimes family, and even care staff in people's own homes or a care home, are fearful of not calling emergency services. The necessary back up in the community, such as a night sitter is rarely there. This scenario certainly chimes with our study where sometimes family members and even care staff in people's own homes or a care home, think they are doing the best by calling the ambulance, especially if it is out of normal hours. At present, the out of hours sitting service does not operate between midnight and 6am, when many emergencies occur. More investment in the Night Sitting Service could avoid hospital admission out of hours.

Whilst it was not a main focus of our original report, the way in which <u>Advance</u> <u>Care Plans</u> (a declaration of patients wishes at the end of life including where they want to die, what sort of death, and how they want to live their last days) are shared between agencies - ambulance services, out of hours services, the hospital and care homes - could help to avoid unnecessary admission and coordinate care. Launched in the primary and community care setting, the aim is to work towards these plans being more readily available in the Trust. The ReSPECT process creates a summary of personalised recommendations for a person's clinical care in a future emergency in which they do not have capacity to make or express choices. Healthwatch will remain interested as to how that works to improve patient care.

See also recommendation 5 below.





Recommendation Two: An increased, or improved, use of specialist support teams both on End of Life Care and Discharge Planning and recognition that most discharges of people with terminal care are complex for the patient and family.

In hospitals, discharges are defined by the complexity of the service response needed as is perceived by discharging ward staff. If someone just needs a care package reinstated or a small piece of equipment, this is usually regarded as a simple discharge. We found that for all the people we spoke to at the very end of their life, the discharge was complex for *them and their family* irrespective of what services needed to be set up. This was because there was the likelihood of deterioration and worries about dying and impending death. This emotional aspect needs to be incorporated into the planned discharge process.

Update

The NACEL audit report recommends end of life teams be available 9am - 5pm, seven days a week. Their data shows that more people die at the weekends and in the night when specialist services are not readily available. When we did our study, the Palliative Care Team at BSUH was in place only Monday to Friday and only during the day. We understand that a proposal to extend the service to 7-days a week is being considered by commissioners and Healthwatch would support this as it would provide a significant improvement to patients' care and family support.

Timely discharge remains on the top of the BSUH agenda. A specialist discharge nurse manager has also been appointed for a year. This role is intended to assist staff in having early conversations with patients and families about their end of life care. Training and support is planned to provide all levels of staff with the confidence to have a dialogue. This should go some way to addressing issues in Recommendation Three below.

A discharge checklist for good practice has been developed by BSUH. The discharge handbook "Let's get you Home' which should be available to patients as soon as possible after admission and was not being used, but has subsequently been revamped and is to be relaunched soon. There will be a greater emphasis upon multi-disciplinary working. On one of the older people's wards, an interdisciplinary piece of work is in place to improve discharge (called "ELECT").



Recommendation Three: Better information and active early involvement of patients in planning their care and routine inclusion of their families; and implementation of the 'Let's get you home 'policy.

In our study, very few people had really thought about what would happen at the very end of their life, even though they had terminal diagnoses. ReSPECT was being



launched in the primary and community care setting but no patient or family member surveyed recognised the term or were aware that treatment was within its principles.

All of the people we spoke to had been in hospital more than once in the previous year, some many times. This means there were multiple opportunities to talk about what people wanted at the end of their life. People did not seem to have Advanced Care Plans, or to have documented their wishes. Although staff may have initiated this conversation, patients did not remember these discussions. Multiple and different ways of approaching an individual's situation are probably needed - and the timing of conversations will certainly make a difference. This is not easy in a busy hospital when some people may be unrealistic about their future or be in denial. This was identified by Healthwatch as an area that needed more exploration. We concluded that conversations need to be tailored to accommodate the differing attitudes to death and dying that people have, and which also recognise different cultural and religious beliefs.

The NACEL report showed that across the country most people did have a 'Do not attempt cardiopulmonary resuscitation' (DNRCPR) in place, but we found that in a number of circumstances, patients and their families were not aware of this. This is a very sensitive area, and the experience of COVID-19 has highlighted the stresses to patients, families, and staff of having to have the most delicate discussion, often remotely. Ideally, the topic needs to be addressed at an earlier stage in illness and not at the point of death.

Update

Less than a half of the NACEL audit group had an individualised care plan. The same study found that many families and 'nominated' persons tended not to be positive about the end of life experience and found communications poor and felt they were not being listened to.

A recent report published in March 2020 by the <u>Care Quality Commission</u>, '<u>Protect</u>, <u>respect</u>, <u>connect</u>''^{iv} echoed our findings. The report found there was variability about when and how conversations about DNRCPR were raised and these were not always personalised. The CQC recommended more staff training and support and a consistent approach to advanced care planning: emphasising that this is a human rights issue.

The aspiration to roll out ReSPECT training to all BSUH staff is welcomed. ReSPECT is important as, done appropriately, it requires an informed discussion and decision that is personalised. The Recommended Summary Plan for Emergency Care and Treatment is recorded so that it can be shared with different services and practitioners so that unnecessary repetitive conversations do not arise. Most importantly, it identifies the prior wishes of the patient and family about what the person wants in their life and about treatment at the end, especially if they are not in the position to express those wishes. Delivering ReSPECT will help to ensure that the person dies in the place and in the way they wish - to have 'a good send- off'.



In addition, a non-care home Frailty and End of Life Locally Commissioned Service (LCS) has been developed. This allows for a Sussex-wide process to encourage and support the offer of a care plan to all people with moderate frailty (**Rockwood scale 6**), including an Advance Care Plan or ReSPECT, where appropriate, for all people with severe frailty (**Rockwood scale 7**). This is being launched on 1st April 2021.

The next step needs to be training and support for patients and families about what these policies mean and how they can influence the plan and to inform and start a debate with the public to be thinking ahead.



Recommendation Four: Reconsideration of the quality of care that can be given in the Discharge Lounge for patients who are terminally ill and will not be discharged in a short time.

The discharge lounge at the Royal Sussex County Hospital (RSCH) is small, and inadequate for a large hospital. It is also located at the very front of the hospital down long corridors, situated away from lifts, and away from the oncology ward. Problems with it have been identified in other Healthwatch reports. It is recognised that it needs replacing but any significant changes have been postponed awaiting the total rebuild of the RSCH.

Update

We have not been able to assess patients' experiences of the lounge during the coronavirus pandemic. We are assured by the RSCH that patents who are at the end of their life are rarely admitted to the Discharge Lounge. This is an area we intend to revisit once it becomes possible to do so.



Recommendation Five: A review of the practice of readmitting patients through A&E within days of hospital discharge, and a consideration of a patient fast-track continuity plan (rather than the admission being seen as an episode of care) to avoid this if their condition deteriorates.

Update

Some progress was made on this recommendation in late September 2020. A team was set up in A&E with a doctor and specialist nurses to pick up people with treatable but non-curative malignant and non-malignant disease (the Supportive Oncology Team). Their purpose is to pick up patients at the 'front door' of the hospital and help them and staff to have a holistic approach to their care in the context of their end of life plans. This approach avoids unnecessary and invasive tests and treatments and subsequent side effects, being completed when they are not what the patient wants. Staff concentrate on 'what matters most to the patient'. The team have intrinsic specialist expertise and can mediate with other specialists and help to avoid patients remaining in hospital longer than is essential. It helps them get



home when they do not want to die in hospital. This project is now being evaluated. Healthwatch would support this approach to avoiding unnecessary hospital admissions which patients we spoke to found most distressing.



Recommendation Six: Involving patients and families in training programmes on End of Life.

Update

Because of the coronavirus pandemic, there has been little progress made on this recommendation. See also Recommendation Three above.

There are many staff training and orientation events in the city, highlighting the interest and commitment to this area. They are not always cross organisational so that staff can inform other agencies and develop more patient centred approaches. Patients and families do not seem to be involved in shaping those events, though it seems this is planned. There is still a need for more information for patients and families at the point they are asking for it, which means access to trusted people on an ongoing basis.

Language remains problematic. It slips from 'end of life care', 'terminal care', 'palliative care' and so on - seemingly being used interchangeably or differently on websites and documents. Some of these terms are clinically specific and being categorised as such may lead to eligibility for a service (such as Fast Track Continuing Care) but patients and families do not always understand them or their implications. There is also a plethora of acronyms. Consideration needs to be given for agreeing how terms are used across agencies and ensuring all staff use the appropriate terms and ensuring that patients and families know what is being referred to in conversations.

Communications packs are being developed for patients around ReSPECT forms and this is welcome, especially as multiple languages will be available. We would recommend that people with personal experience around end of life and those who understand cultural issues should be involved at an early stage in their design, production, and dissemination. Healthwatch volunteers already review patients' leaflets produced by BSUH - feeding back from the patients' perspective - and we would recommend their involvement in all material produced.

A recent study of bereaved relatives at St Bartholomew's Hospital early during the COVID-19 pandemic^{vi} described the distress caused by a lack of face-to-face visits, no family bedside support, underdevelopment of virtual visiting, belongings being quarantined, misplaced, or lost, and funerals being delayed or restricted. The distress was worse for people from Black, Asian, Minority Ethnic Communities (BAME) communities. One outcome was to suggest new visual communications skills training for all staff levels, especially around difficult conversations, and consistent communications to relatives. There could be some pointers in this study as to how



to develop initiatives in Brighton and Hove. It is also noted that having a multi-faith chaplaincy helped St Bartholomew's in this area.



Recommendation Seven: Open and sensitive discussion of end of life care planning and a consideration of revising the agenda that would have been addressed in Dying Matters Week which was postponed (in 2020) due to COVID-19.

Update

In May 2021, Dying Matters Week will be held. This year, the theme is 'the importance of being in a good place to die'. This chimes with the questions in our study, and implicit within the theme is not just the physical place but also an emotionally and spiritually supportive place, which is what we have addressed in our report.

Healthwatch would particularly like to see a focus on BAME communities, and cultural and religious issues addressed.

Dying Matters Week is an opportunity to initiate a debate about end of life care and to have a dialogue with the public about thinking and planning ahead. It can help address Advance Care Planning and ReSPECT. It is also an opportunity for those working around end of life to meet to further improve communications and develop collaborative working. It can help people to reflect upon the deaths and experiences people have had in the last year and help to provide a safe space and support.



Recommendation Eight: Proactive involvement of GPs, and other primary care and community health services, and a review of the communications systems between hospital and general practice.

One of the more surprising observations from the patients in our study was that GPs were not involved with their discharge from hospital. In a few cases, care may have been picked up by a community nurse, where families felt better supported.

GPs who have a 'lead' in their surgeries have regular Gold Standard Framework meetings, where we have presented our results twice. We understood that a discharge letter is sent to GPs, but it was not clear what the process is for GPs to regularly see this and then make contact with the patient. Patients and families we spoke to were asking for visits from their GP at the very end of their life.

Update

The new non-Care Home Frailty and End of Life (LCS) for GPs comes into play on 1st April 2021. Its focus should result in earlier discussions with patients, and better recording of people's wishes at the end of their life and better and more formal coordination with Multi-disciplinary teams.



We understand that there are no reviews of deaths in primary care as there are in hospitals and we suggest that introducing a similar process could help to evaluate how the new contract was affecting people's lives and addressing their preferences.

A new service has been developed between Martlets and general practice to share records (System One) which should bring improvements with those patients supported by Martlets. Martlets also has a 24-hour access hub for their patients.

Many people are, however, in the system and having a central point of access, particularly out of hours, would be a solution to many of the issues and concerns of patients and families - and even service providers. Extending the End of Life Care Hub (ECHO) which operates in West Sussex and coordinates end of life care and operates an access point would address this unmet need and we are pleased to see this is being actively explored.



Recommendation Nine: Improved coordination of the services that already exist, including those in the voluntary and charitable sectors and chaplaincies.

There are a number of well-established voluntary and charitable organisations who support people with terminal illnesses, and their families: Martlets, MacMillan, and other organisations like the Carers Centre, Age UK and ToGether Co and others who provide support from specialist treatment and advice to befriending and general support. There may be opportunities for greater coordination and signposting between these groups and statutory organisations. During the COVID-19 pandemic, for instance, MacMillan enhanced their financial support services and took many services online and signposted to other voluntary groups. These experiences throughout the voluntary sector give a good platform for greater collaboration in the future.



Recommendation Ten: Rapid provision of resources and care where there are gaps to assure 'A Good Send-Off'.

Update

Since our report, we are advised that a Fast-Track Continuing Care home care package scheme, devised and delivered by Martlets Care, is in place. This could ensure that patients at the end of their life have access to specialist services at their hospital discharge and would go a long way to ensuring that discharge processes and plans for people who are at the very end of their life are comprehensively met. The issues people face are not just practical but emotional and extend beyond physical care. People may need help and support in considering what they want for the rest of their lives and how to manage death and its consequences for those left behind.



It would however appear that the model of care for people at the end of their life needs to be turned on its head and to assume that people want to die at home unless otherwise advised and in order to achieve that, the services in the community need to be organised differently and resources shifted to the community.

Summary and next steps

From our study and other work, dying well means that people are in their place of choice, usually their own home, but sometimes a care home or a hospice; comfortable and without pain, in receipt of spiritual as well as practical help, with the familiar faces of family, friends, and staff around them. That so many people, when asked, dispassionately say they want to be at home when they die, seems to indicate that they do not want invasive treatments if their end is inevitable but people need to be asked about this in advance so they can indicate their wishes and get the death they want.

Healthwatch therefore supports activities and services that help to avoid hospitalisation, which provide safe alternatives at home, and access to a 24/7 specialist service. When it is necessary for people to attend the hospital, all efforts need to be in place to make that stay is as short as clinically necessary, and safe. vii

The golden thread coming out of this review of end of life care is that there needs to be more opportunities for open dialogue by everyone. Conversations about death are difficult and the differing personal, cultural, and religious contexts and language used mean they need to be tailored and nuanced. Timing is of the essence. They are not easy, and it is good to see this is being recognised with support and training in services. That support also needs to be spread to patients, families and to communities.

Interagency work appears to be improving. There are lots of new initiatives which look promising, but many are short term or pilots for what appear to be long term care issues and ones which are an integral part of mainstream health and social care provision.

Crises occur at night. People die at weekends. So, we particularly support the need for ECHO, the End of Life Coordination Hub, which coordinates end of life care across services and acts as a single point of access for patients and families; and a seven days a week Palliative Care Team in hospitals. These services would go a long way to meeting people's needs.

Healthwatch will continue to review and compare progress made against our recommendations. Whilst some headway has been made, and there has been a recognition of the issues, in most areas, work is in its infancy or in process rather than embedded.

We will in particular monitor the impact of:



- the ReSPECT roll out: the effect it has on patient experience
- the impact of the new GP contract: how it helps with better advanced decisions for people at the end of their life
- the Fast-Track Service Home Care Service: how it helps people to be cared for at home
- the Supportive Oncology Service: its impact on patient experience and admission avoidance
- the pilot SECAmb's supportive admissions avoidance service: impact on unnecessary hospital admissions
- the system and use of shared records: their value to patients
- the development of services in the community, especially out of normal hours to support families and carers and to help in the coordination of care
- the extension of specialist support on palliative care in hospital
- and how training programmes and information with cultural content is available for patients and families.

Once we can resume face-to-face contact, Healthwatch will continue its programme on end of life with a focus on frail older people.

In the meantime, we continue to reflect views of patients and families on the End of Life Steering Group.

Thanks to everyone who has helped Healthwatch compile this report.

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Appendix 1

Report references

Brighton and Hove Joint Strategic Needs Assessment 'Life and Death' http://www.bhconnected.org.uk/sites/bhcon-nected/files/Life%20and%20death%20in%20Brighton%20and%20Hove%20-%20topic%20summary%202018.pdf

Brighton & Hove Joint Health & Wellbeing Strategy 2020-2030 https://www.brighton-hove.gov.uk/sites/default/files/health/brighton-hove-health-wellbeing-strategy-2019-2030-26-july-19.pdf

Health service use in the last two years of life https://www.strategyunitwm.nhs.uk/publications/health-service-use-last-two-years-life

Footnotes

28/%E2%80%9C-good-send-%E2%80%9D-patients%E2%80%99-and-familys-experiences-end-life-care

ii National Audit of Care at the End of Life First round of the audit (2018/19) report

https://www.hqip.org.uk/wp-content/uploads/2019/07/National-Audit-of-Care-at-the-End-of-Life-National-Report-2018-FINAL.pdf

iii NHS Brighton and Hove Clinical Commissioning Group is a GP led statutory NHS body responsible for commissioning the majority of health services for local people. https://www.brightonandhoveccg.nhs.uk/about-us/

^{iv} Care Quality Commission: "Protect, respect, connect - decisions about living and dying well during COVID-19", March 2021 https://www.cqc.org.uk/publications/themed-work/protect-respect-connect-decisions-about-living-dying-well-during-covid-19

v "Let's Get You Home" - Hospital Discharge Report, February 2019 https://www.healthwatchbrightonandhove.co.uk/report/2019-02-09/let%E2%80%99s-get-you-home-hospital-discharge-report

"Leaving Royal Sussex County Hospital", October 2014 https://www.healthwatchbrightonandhove.co.uk/report/2014-10-08/leaving-royal-sussex-county-hospital



vi What bereaved relatives told a trust with 1,300 covid deaths https://www.hsj.co.uk/coronavirus/what-bereaved-relatives-told-a-trust-with-1300-covid-deaths/7029325.article 11/02/21

vii N**HS Outcomes Framework** https://digital.nhs.uk/data-and-information/publications/statistical/nhs-outcomes-framework