



Our role on NACEL



National Audit of Care at the End of Life

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The statutory activities of Healthwatch South Tyneside

Healthwatch South Tyneside (HWST) is one of 148 local Healthwatch organisations across England launched in April 2013 to give users of health and social care services a powerful voice.

As set out in the Health and Social Care Act of 2012, Healthwatch South Tyneside has the following statutory activities:

- Promoting and supporting the involvement of local people in the commissioning, the provision and scrutiny of local care services.
- Enabling local people to monitor the standard of provision of local care services and whether and how local care services could and ought to be improved.
- Obtaining the views of local people regarding their need for, and experiences of, local care services and importantly to make these views known.
- Making reports and recommendations about how local care services could or ought to be improved. These should be directed to commissioners and providers of care services and people responsible for managing or scrutinising local care services and shared with Healthwatch England.
- Providing advice and information about access to local care services so choices can be made about local care services.
- Formulating views on the standard of provision and whether and how the local care services could and ought to be improved; and sharing these views with Healthwatch England.
- Making recommendations to Healthwatch England to advise the Care Quality Commission to conduct special reviews or investigations (or, where the circumstances justify doing so, making such recommendations direct to CQC); and to make recommendations to Healthwatch England to publish reports about particular issues.
- Providing Healthwatch England with the intelligence and insight it needs to enable it to perform effectively.

As an independent Community Interest Company (CIC), it is a dedicated consumer champion, working with users of local National Health Service (NHS) and social care services to hear about their experiences, identify any issues or problems and help generate improvements.

Healthwatch South Tyneside has the power to enter and view services, can influence how services are set up and commissioned by having a seat on the local Health and Wellbeing Board, and provide information, advice and support about local services.

It also produces reports which influence the way services are designed and delivered and can pass information and recommendations to Healthwatch England and the Care Quality Commission.

Prologue

In early 2019 the much-loved hospice in our borough went into voluntary liquidation. As you can imagine this caused much consternation to the local residents so Healthwatch South Tyneside (HWST) made it a priority to become involved. We started taking part in the system of palliative and end-of-life care across South Tyneside. In July we attended a local meeting on the service. At the meeting the NACEL report for 2018/19 was discussed. After the meeting the report and appendices were considered and it was noted that the appendix which referred to staffing was only rated 5 out of 10 for the local Trust. This was raised with the local consultants in palliative and end of life care and the reasons for the scoring explained.

After the feedback the NACEL website was visited and it was noted that many organisations were involved in advising the audit process but Healthwatch was not represented. This was raised with the NACEL Team and discussed by their clinical leads and it was thought to be a good idea to have Healthwatch involved. We referred the offer to Healthwatch England and over the period between August to November 2019 arrangements were made for HWST to represent Healthwatch England on the NACEL Advisory Group.

Foreword

Taken from the current NACEL report: “The one certainty in life is that we will die. Wherever that might be, we should expect to receive the best possible care, according to our needs and wishes. National policy guidance in both England and Wales reflects the high priority that we as a society give to good end of life care.”

Background

The background describes NACEL (National Audit of Care at the End of Life) for people over 18, its purpose, key metrics and partners.

The NHS Benchmarking Network - www.nhsbenchmarking.nhs.uk - has been commissioned by the Health Quality Improvement Partnership (HQPI) - www.hqip.org.uk - to carry out the National Audit of Care at the End of Life (NACEL). Three cycles of the audit have been commissioned to be undertaken over three consecutive years which started in 2018/19. Due to COVID-19, however, the scheduled audit for 2020 has been deferred, therefore round three is rescheduled for 2021.

The aim of the audit is to improve the quality of care of people at the end of their life. The audit focuses on the quality and outcomes of care experienced by those in their last admission to acute, community and mental health hospitals throughout England and Wales.

Outputs from this project will be of interest to those who receive, deliver, commission and monitor care so they will have a far-reaching audience. The current report represents the findings of the second round of the audit. It is a national comparative audit of the quality and outcomes of care experienced by the dying person and those important to them during the last admission leading to death in acute, community hospitals and mental health inpatient facilities.

The audit is supported by:

- Two joint Clinical Leads: Dr Suzanne Kite, Consultant in Palliative Medicine and Elizabeth Rees, Lead Nurse for End of Life Care (Joint Chair of NACEL).
- A 24 strong Steering Group (SG) which is a mix of clinicians, academics, member of the faith community, a lay member, a body representing patients and central organisations which includes NHS England and the CQC.
- A 34 strong Advisory Group (AG) which represents over 25 organisations across health, academia and partners in the third and voluntary sector; many clinical members also have academic responsibilities. NICE and the GMC are represented on the group as is the Association of Directors of Adult Social Care. Healthwatch sits on this group.
- Six staff from NHS Benchmarking support the audit as part of their portfolio of work.

The purpose of each group, taken from the respective terms of reference, is:

- The NACEL Steering Group (SG) is to oversee the design, development and delivery of the National Audit of Care at the End of Life.
- The NACEL Advisory Group (AG) is to assist the NACEL Steering Group with specific areas of the NACEL design, development and delivery.

The current membership of both groups can be found on the NACEL website by using the links on the NACEL Steering Group page.

Report and appendices

As a frame of reference the report is based on

- The NICE quality standard 13: End of Life Care for Adults which in turn is based on 16 quality statements. These can be found at: [Overview | End of life care for adults | Quality standards | NICE](#); and,

- One Chance to get it Right, published by The Leadership Alliance for the Care of Dying People which lists five priorities for care and can be found at: One Chance to Get it Right report

The audit measures seven themes, each based on one source of information from the audit:

1. Recognising the possibility of imminent death (CNR)
2. Communication with the dying person (CNR)
3. Communication with families and others (CNR)
4. Needs of families and others (QS)
5. Individualised plan of care (CNR)
6. Families' and others' experience of care (QS)
7. Workforce/specialist palliative care (H/S)

The following key is used to show the source of each theme:

- H/S = Hospital/site Organisational Level Audit
- CNR = Case Note Review
- QS = Quality Survey

Pages 8 - 16 cover the executive summary and recommendations of the report.

The separate volume of appendices contains the results as well as all the supporting information for the results to be understood. Appendix 5 shows hospital scores by key theme. This brief should be read in conjunction with pages 8 to 16 of the report and Appendix 5 from the volume of appendices.

The documents can be found at: National Audit of Care at the End of Life – NHS
 Except for 'recognising the possibility of imminent death', a summary score, out of 10, is calculated for each theme. They are respectively: 7.8; 6.9; 6.0; 7.2; 7.0 and 7.4. 97% of eligible organisations took part in the audit.

Participation

Work to date

- Preparing for the meeting held on the 15th January 2020 by reading and digesting the draft NACEL report and appendices;
- Participating in the face to face meeting, held on the above date, at Friends House, London;
- Taking part in the virtual meeting held on the 15th July 2020;
- Helping to disseminate knowledge of the report through part of the Healthwatch network and locally through the South Tyneside Palliative and End of Life Care Leaders Group and the Trust's: Patient, Carer and Public Experience Committee.

Meetings

As stated above the meetings were held on the 15th January and 15th July 2020. They involved people from over 25 partnership organisations including national NHS, professional and third/voluntary sector.

15th January meeting

At this meeting the Groups acted like an editorial board commenting and making suggestions on the: readability, clarity, and understandability of the documents and offering additions to and deletions from the report and appendices.

The contribution on behalf of Healthwatch England is recorded on page 3 and the related action is summarised on page 11. The suggestions made were prompted by reading report recommendations 6, 7 and 8 which appear on page 15 of the report for CEOs and Trust Boards.

15th July meeting

This meeting was held using Ms Teams. The meeting was about:

- Consolidating the work for the next round following the publication of the 2019/20 report and allowing time for questions from SG and AG members that may influence the specification for the next round.
- Asking SG and AG members to use their networks to disseminate the messages in the report; especially the infographic on pages 12 and 13.
- Bringing people up-to date on the replacement virtual regional forums, which are in place of the planned conference; a change made due to the pandemic. The regional forum information is in the minutes.
- The unintended but important consequences of the impact of COVID-19 led to SG and AG members being asked to feedback on changes in the practice of caring for dying people; in particular any practice seen as a health improvement and worthy of being passed on. The Team was interested in the following changes:
 - Practices that were introduced which will cease;
 - Practices that were introduced which will continue;
 - Practices that will restart; and,
 - Previous practices that will be let go permanently.

The above was set against the backdrop of “NHS Reset”.

Finally, on a specific note, the Patient's Association was asked to share the results of its COVID-19 survey which has a section on bereavement. This will be made available to SG and AG members.

Benefits

The following are seen as the benefits of taking part in NACEL:

- It enables Healthwatch to make a contribution to and potentially make a difference in an important and highly sensitive area of care which is not only crucial for the care and treatment of the dying person but their family and friends.
- It involves Healthwatch in a health improvement activity.
- It increases the perspective available to NACEL.
- It provides the opportunity to network with a wide range of people of influence in this field, including staff in central roles whose aim is to measure and improve the quality of health and social care.
- Becoming involved, in an in-depth activity, increases understanding in an aspect of NHS care and treatment that is less well known but will affect us all.
- It raises the awareness and increases the knowledge of organisations and people of influence, at national level, to the role of Healthwatch.
- It increases the expertise, with respect to care of the dying, within the Healthwatch family.
- It has enabled Healthwatch South Tyneside to act as a conduit between local organisations, that take part in and those managing the audit.
- It increases Healthwatch's credibility when taking part in local policy forums in this area of care and treatment.
- Being part of the dissemination process and, within Healthwatch, there is the potential for raising the understanding of NACEL by circulating this brief.