

NCEPOD End of Life Care study

Frequently Asked Questions

What is the patient sample?

Patients aged 18 and over that have died in hospital between 1st April 2022 - 30th September 2022 inclusive, with one or more of the following conditions; dementia, heart failure, lung cancer and liver disease.

Patients aged 18 and over that have been discharged to the community between 1st April 2022 - 30th September 2022 inclusive who have subsequently died within six months with one of the above conditions are also included.

What is the study period for this study?

Hospital deaths between 1st April 2022 - 30th September 2022 inclusive, with one or more of the
Community deaths: Patients aged 18 and over that have been discharged to the community between 1st April 2022 - 30th September 2022 inclusive who have subsequently died within six months.

Which hospitals should be participating in this study?

All acute and community hospitals in England, Wales and Northern Ireland that treat patients aged 18 and over, with the following conditions, dementia, heart failure, lung cancer and/or liver disease can take part in this study.

Should Mental Health trusts be participating in this study?

Mental health trusts are eligible to participate in the end of life care study that we are running, although we appreciate that a small number of patients may be identified.

Are deaths in the Emergency Department included in this study?

Yes, please include all patients that die in the emergency department with the following conditions dementia, heart failure, lung cancer and liver disease.

Are there any exclusions for this study?

Yes, the following cases will be excluded from this study:

- Deaths due to suicides, homicides, or self-harm related
- Deaths due to trauma, drowning, drug overdose or poisoning

What will happen once we have submitted our data collection spreadsheet?

NCEPOD will import the information you have sent into our study database; we will then randomly select several patients per hospital to be looked at in more detail. For each of these selected patients we will upload a clinician questionnaire to our online system and ask the Local Reporter to invite the clinician who was involved in the patients care to complete this. We will also request case notes relating to the patient's admission to be sent to us for peer-review.

What case notes should I return to NCEPOD?

Please see the case note extract list which can be found here [Case note request](#)

For the community deaths, please send all correspondence from the final hospital discharge up until the time of the patient's death in the community. This may include letters from the hospital to the GP/ patient, outpatient appointment attendances and community services involvement.

How do I return case notes to NCEPOD?

NCEPOD accepts **photocopied** case notes in both paper and digital formats.

Sending paper photocopied notes to NCEPOD:

On request, we will provide freepost (up to 1kg) tamperproof envelopes to your Trust which allows for safe delivery to the NCEPOD office by post

Sending digital case notes to NCEPOD:

NCEPOD can accept digital case notes send as a PDF to ncepod@nhs.net, these will need to be password protected and not embedded in a word document.

We also use online platforms such as Egress, SharePoint and Centricity, which also need to have password protection. When sending files digitally, please do not include patient identifiable information such as name, DoB, NHS/hospital number in the file titles.

Please do not include the passwords in an email – instead, call the NCEPOD office on 0207 251 9060 where someone will take the password for you.