NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NHS England

Case-mix adjusted 30 day mortality post Systemic Anti-Cancer Therapy (SACT) rates

A toolkit to support the CMAR data releases

About the NDRS

The National Disease Registration Service (NDRS) is part of NHS Digital (NHSD). Its purpose is to collect and quality-assure high-quality, timely data on a wide range of diseases and provide robust surveillance to monitor and detect changes in health and disease in the population.

The NDRS includes:

- the National Cancer Registration and Analysis Service (NCRAS) and
- the National Congenital Anomaly and Rare Disease Registration Service (NCARDRS)

Healthcare professionals, researchers and policy makers use data to better understand population health and disease. The data is provided by patients and collected by the NHS as part of their care and support. The NDRS uses the data to help:

- understand cancer, rare diseases and congenital anomalies;
- improve diagnosis;
- plan NHS services;
- improve treatment;
- evaluate policy;
- improve genetic counselling.

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Background

In 2016, the SACT team at Public Health England (PHE) published a paper in the Lancet Oncology[1] providing 30 day mortality post-SACT rates for breast and lung cancer. NHS trusts, NHS England and the clinical community fed back to PHE that this work had been beneficial in terms of setting a national benchmark, identifying variation in clinical practice between trusts and within trusts and identifying areas where patient care could have been improved. This information helped to inform advancements to clinical practice.

In December 2018, the SACT team released a workbook to trusts providing crude rates for 30 day mortality post-SACT[2] for all cancers combined and breakdowns for Acute Myeloid Leukaemia, Breast, Colon, Children's Teenagers and Young Adults (CTYA), Small Cell Lung Cancer, Non-Small Cell Lung Cancer, Upper Gastro-Intestinal and Oesophageal.

Feedback generated from this release highlighted the need for 30 day mortality data which was more timely to support clinical audit, as well as case-mix adjusted rates which would facilitate the comparison of performance between trusts. Unfortunately, these two needs cannot be met in a single data feed. Case-mix adjusted rates cannot be produced soon enough after treatment activity to support clinical audits as it requires linkage to the National Cancer Registration Dataset for England[3] to provide supplementary patient information which operates at an approximate 18-month time lag, and additional analytical time to conduct the work. Furthermore, for rarer cancer sites, case-mix adjustment may only be possible when several years of data have accrued to provide sufficient cohort size to support analysis. The SACT team have therefore met these two needs through two outputs:

- rapid data review (RDR)
- case-mix adjusted rates (CMAR)

The RDR provides a quarterly data feed to all NHS trusts in England providing key information on patients who died within 30 days of receiving SACT at their trust. This aims to inform 'mortality and morbidity' meetings and develop communications between trusts on initiatives undertaken to reduce 30 day mortality. The CMAR produces 30 day mortality post-SACT rates that are adjusted for key variables which means that rates can be compared between trusts and within trusts over time.

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[1] Wallington, Saxon, Bomb et al. (2016). 30 day mortality after systemic anticancer treatment for breast and lung cancer in England: a population-based, observational study. The Lancet. Oncology, 17(9), 1203–1216. https://www.thelancet.com/journals/lanonc/article/PIIS1470-2045(16)30383-7/fulltext

[2] 30 day mortality post-SACT 2015-16 workbook: http://www.chemodataset.nhs.uk/view?rid=283

[3] Henson, Elliss-Brookes, Coupland et al. (2020). Data Resource Profile: National Cancer Registration Dataset in England. International journal of epidemiology, 49(1), 16–16h. https://academic.oup.com/ije/article/49/1/16/5476570

Since August 2020, the SACT team have released several workbooks containing case-mix adjusted 30 day post-SACT mortality rates for adults (aged 18+) for a range of cancer sites. More information and the links to previous releases can be found in Q4 on which cancer sites are covered in the workbooks or on the SACT website[4].

Each workbook was based on data reported by NHS trusts in England through their monthly routine SACT data uploads. In advance of these publications the adult workbooks were sent to the NHS Trusts and the CTYA Acute lymphoblastic leukaemia (ALL) workbook was sent to Principal Treatment Centres (PTCs) for review, giving them the opportunity to provide a statement to accompany their data. These statements have been included in the companion reports released with each CMAR workbook.

The data for these workbooks are now available as an interactive web application at https://www.cancerdata.nhs.uk/sact/cmarreport. This presents all CMAR cancer sites covering ages 18+ in one output and enables new functionality such as: displaying trust name, number of patients treated, and case-mix adjusted 30 day mortality rate when hovering over datapoints on the funnel plot.

For further information on the SACT data reports please see http://www.chemodataset.nhs.uk/reports/

Please see the UK Chemotherapy Board (UKCB) morbidity and mortality within 30 days of SACT recommended proforma[5] for information on reviewing current practice.

[4] SACT website: http://www.chemodataset.nhs.uk/

[5] UK Chemotherapy Board (UKCB) Morbidity and Mortality within 30 Days of Systemic Anti-Cancer Therapy - Review pf Current Practice - Standardised Review Process main page: https://www.ukchemotherapyboard.org/morbidity-and-mortality-within-30-d
UK Chemotherapy Board (UKCB) morbidity and mortality within 30 days of SACT recommended proforma: https://4bd2316d-e45d-4e90-96b5-431f1c12dd3e.filesusr.com/ugd/638ee8_e5a2706d61124ae18f5a6e40e7e451af.pdf

Workbook

Q1. How are workbooks produced?

The workbooks are produced as part of the NHS Digital (NHSD)/NHS England-Improvement (NHSE-I) SACT partnership and are based on routine data submitted by NHS trusts to the SACT Dataset[6]. They include patients diagnosed with cancer in England between 2010 and 2018 or 2020 (for more recent CMAR workbooks) and treated with SACT in all NHS trusts in England for a specified period, depending on site. Patients were only included if they received their latest treatment during the treatment period of interest. Each patient was allocated to the trust where they received their final treatment, regardless of any prior treatment received at other trusts. Please see Table 1 for the period of interest for each cancer site. For follicular lymphoma and the 2nd bowel, breast and lung release we consider any patient having treatment in the relevant years irrespective of whether they had completed treatment or not.

Q2. Where is the data included within the workbooks derived?

The National Disease Registration Service (NDRS), part of NHS Digital, is the population-based cancer registry for England. It receives data from across the National Health Service (NHS) and produces the National Cancer Registration Dataset for England. The SACT Dataset collects Systemic Anti-Cancer Therapy (SACT) activity from all NHS providers. For the purposes of the analysis, patients were selected from the National Cancer Registration Dataset. For the 2nd bowel, breast and lung reports we used the Rapid Cancer Registration Dataset[7], for diagnoses from 2019 onwards. This cohort of patients was then linked to the SACT Dataset on NHS number in order to retrieve the latest treatment records for these patients. Certain restrictions were applied to the data to ensure the appropriate patients and treatments were selected for each cancer site. These restrictions mean that some trusts may have no data included in the workbook because their patients and patients' treatment activity did not fit the criteria applied. The restrictions applied to the data are outlined below and in the companion briefs for each release.

[6] Bright, Lawton, Benson et al. (2020). Data Resource Profile: The Systemic Anti-Cancer Therapy (SACT) dataset. *International journal of epidemiology*, *49*(1), 15–15l. https://doi.org/10.1093/ije/dyz137

[7] Rapid Cancer Registration Dataset: http://www.ncin.org.uk/collecting_and_using_data/rcrd

Q3. Where do the dates of death come from?

The dates of death come from the Office for National Statistics via NHS Digital's Demographics Batch Service Bureau[8].

Q4. Which cancer sites are covered in the workbooks?

Table 1 below displays the cancer site, ICD-10 code, diagnosis period and treatment activity period covered within each CMAR release including links to the workbooks and companion brief.

The data for these workbooks are now available as an interactive web application at https://www.cancerdata.nhs.uk/sact/cmarreport. This presents all CMAR cancer sites covering ages 18+ in one output and enables new functionality such as: displaying trust name, number of patients treated, and case-mix adjusted 30 day mortality rate when hovering over datapoints on the funnel plot.

[8] NHS Digital Demographics Batch Service Bureau webpage: https://digital.nhs.uk/services/national-back-office-for-the-personal-demographics-service/demographics-batch-service-bureau

Table 1. Cancer site, ICD-10 code and treatment activity covered for each release[9]

Cancer site	Update frequency	ICD-10 code	Report release	Period of diagnosis	Period of treatment activity	Published report workbook	Published report companion brief
Acute lymphoblastic leukaemia (ALL) for children, teenagers and young adults (CTYA)	One-off	C91.0	First report	2010 - 2018	Jan 2017 - Dec 2019	May 2021 ALL CTYA workbook	May 2021 ALL CTYA companion brief
Acute lymphoblastic leukaemia (ALL)	One-off	C91.0	First report	2010 - 2018	Jan 2017 - Dec 2019	May 2021 ALL and AML workbook	May 2021 ALL and AML companion brief
Acute myeloid leukaemia (AML)	One-off	C92.0, C92.4, C92.5, C92.6, C92.8, C93.0, C94.0, C94.2	First report	2010 - 2018	Jan 2018 - Dec 2019	May 2021 ALL and AML workbook	May 2021 ALL and AML companion brief
Bowel	Annual	Bowel cancer: C18-C20 Rectal cancer: C21.8	First report	2010 - 2018	Jan 2019 - Dec 2019	Nov 2020 workbook	Nov 2020 companion brief
			Second report	2010 - 2020	Jan 2020 - Dec 2020	Feb 2022 workbook	Feb 2022 companion brief
Breast	Annual	C50	First report	2010 - 2018	Jan 2019 - Dec 2019	Nov 2020 workbook	Nov 2020 companion brief
			Second report	2010 - 2020	Jan 2020 - Dec 2020	Feb 2022 workbook	Feb 2022 companion brief
Cancer of unknown primary (CUP)	Biennial	C77-C80	First report	2010 - 2017	Jan 2017 - Dec 2018	Aug 2020 workbook	Aug 2020 companion brief

[9] Each release covers ages 18+ apart from the children, teenagers and young adults (CTYA) acute lymphoblastic leukaemia (ALL) output which covers ages 0-24. ICD-10 codes for future releases may be subject to change upon further sensitivity analysis and clinical feedback

Cancer site	Update frequency	ICD-10 code	Report release	Period of diagnosis	Period of treatment activity	Published report workbook	Published report companion brief
			Second report	TBC	TBC	2022	2022
Follicular lymphoma	One-off	C82	First report	2010 - 2018	Jan 2017 - Nov 2020	Feb 2022 workbook[10]	Feb 2022 companion brief
Gastric	Biennial	Small Intestine Cancer: C17 Stomach Cancer: C16	First report	2010 - 2017	Jan 2017 - Dec 2018	Aug 2020 workbook	Aug 2020 companion brief
			Second report	TBC	TBC	2022	2022
Lung **Please see footnote for list of lung morphology codes[11]**	Annual	C33-C34, C37-C39	First report	2010 - 2017	Jan 2018 - Dec 2018	Aug 2020 workbook	Aug 2020 companion brief
			Second report	2010 - 2020	Jan 2019 - Dec 2020	Feb 2022 workbook	Feb 2022 companion brief
Myeloma	Biennial		First report	2010 - 2018	Jan 2018 - Dec 2019	Nov 2020 workbook	Nov 2020 companion brief

[10] In February 2022 we revised the CMAR for follicular lymphoma to replace the September 2021 version.

[11] Lung morphology was used for the 1st lung CMAR report but not the 2nd lung CMAR report as morphology was not sufficiently complete in the Rapid Cancer Registration Dataset to permit this. The lung morphology used for the 1st lung CMAR report is detailed below.

Lung cancer (Non-Small Cell Lung Cancer): ICD10: C33-C34, C37-C39; Morphology: M8012/3, M8013/3, M8046/3, M8050/3, M8070/3, M8070/6, M8071/3, M8072/3, M8074/3, M8075/3, M8140/3, M8140/6, M8200/3, M8240/3, M8246/3, M8249/3, M8250/3, M8253/3, M8255/3, M8260/3, M8263/3, M8310/3, M8370/3, M8470/3, M8480/3, M8481/3, M8490/3, M8520/3, M8550/3, M8560/3, M8574/3, M8575/3.

Lung cancer (Small Cell Lung Cancer): ICD10: C33-C34, C37-C39; Morphology: M8002/3, M8041/3, M8042/3, M8044/3, M8045/3.

Lung cancer (unknown morphology): ICD10: C33-C34, C37-C39; Morphology not recorded.

Cancer site	Update frequency	ICD-10 code	Report release	Period of diagnosis	Period of treatment activity	Published report workbook	Published report companion brief
		Multiple myeloma: C90.0 Plasma cell leukaemia: C90.1	Second report	TBC	TBC	2022	2022
Ovarian	Biennial	C48.1 C56-C57.4	First report	2010 - 2018	Jan 2018 - Dec 2019	Nov 2020 workbook	Nov 2020 companion brief
			Second report	TBC	TBC	2022	2022
Pancreas	Biennial	C25	First report	2010 - 2017	Jan 2017 - Dec 2018	Aug 2020 workbook	Aug 2020 companion brief
			Second report		TBC	2022	2022
Prostate	One-off	C61	First report	2010 - 2018	Jan 2018 - Dec 2019	May 2021 prostate workbook	May 2021 prostate companion brief

Q5. How is the last SACT treatment obtained and how is the treating trust allocated to each patient?

The last known treatment date in SACT is used – in most cases this is the latest administration date (date of the SACT drug administration or the date an oral drug was initially dispensed to the patient). However, if this is missing, then the latest start date of cycle for that patient is taken, and failing that, the latest start date of regimen is used.

For workbooks released up to May 2021 only patients who had their last treatment during the time period of interest were included. Therefore, patients still receiving treatment after the period of interest were not included in the analysis. Please see Table 1 for the period of interest at each cancer site.

For follicular lymphoma, and the 2nd bowel, breast and lung reports, we consider any patient having treatment in the relevant years irrespective of whether they had completed treatment or not.

Each patient was allocated to the trust where they received their final treatment, regardless of any prior treatment received at other trusts.

For the CTYA (Children Teenager and Young Adult) acute lymphoblastic leukaemia (ALL) release, each patient was allocated to a trust and this trust was then mapped to its corresponding Principal Treatment Centre (PTC). The trusts and caseloads included for each PTC are shown in the 'List of trusts included' tab in the CTYA ALL workbook.

Q6. Why does the data in the workbook differ from our trust monthly SACT submissions for the same period?

The SACT data used in the workbook has been linked to the National Cancer Registration Dataset or Rapid Cancer Registration Dataset to provide accurate diagnosis and morphology codes. This may result in a patient being reassigned to a different cancer site, based on the National Cancer Registration Dataset or Rapid Cancer Registration Dataset, or excluded due to an inability to accurately link the patient's cancer site in the two datasets.

Q7. How many trusts are included in the workbook?

Analysis of CMAR includes trust mergers which had taken place up to July 2021. The latest information from this period shows that there were 130 trusts in England who submit SACT data, but not all trusts have been included in the analysis. Trusts were not included if they did not meet the data completeness criteria or if there were no patients treated at the trust for the cancer site of interest during the time period selected.

For the CTYA (Children Teenager and Young Adult) acute lymphoblastic leukaemia (ALL) workbook, data for 50 trusts were mapped to 17 Principal Treatment Centres (PTCs).

Data Restrictions

Q8. What tumour diagnosis restrictions were applied to the data?

- The cohort was restricted to cancers diagnosed between 2010 and 2018 for CMAR releases up to September 2021, and to cancers diagnosed between 2010 and 2020 for later CMAR releases.
- Patients whose most recent cancer diagnosis for the relevant cancer site being analysed were selected.
    - This means, for example, if a patient was diagnosed with another cancer following the cancer site of interest and both cancers were diagnosed between 2010 and 2018 (or between 2010 and 2020 for later releases), the patient would be excluded because the cancer site of interest was not their latest diagnosis.
- If patients had more than one cancer diagnosed on the same day, the relevant tumour or cancer was selected.

It is important to note that in some cases, the cancer diagnosis recorded in the National Cancer Registration Dataset or Rapid Cancer Registration Dataset may differ from that recorded by the trust.

If you would like support in improving the quality of the data feed into the NCRAS then please contact ndrs.datasets@phe.gov.uk.

Q9. What data completeness restrictions were applied to the data?

Trusts with less than 70% completeness for the key variables of co-morbidity score; grade[12]; performance status; and stage at diagnosis[13]; were excluded from the analysis. Please note that these variables were sourced from the SACT Dataset and National Cancer Registration Dataset. For the 2nd bowel, breast and lung report we also used the Rapid Cancer Registration Dataset.

[12] Grade was only included within the key variables criteria for the follicular lymphoma CMAR analysis using the C82 (follicular lymphoma) ICD-10 code. For further information please see the WHO ICD-10 C81-C96 page

[13] Stage at diagnosis was excluded from the key variables criteria for cancer of unknown primary (CUP), acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML) and myeloma due to lack of staging data for these sites. It was excluded from follicular lymphoma due to poor data completeness. For further information on stage at diagnosis please see the National Cancer Registration Dataset in England, Data Resource Profile

For the majority of CMAR reports, cancer sites were selected for analysis on the basis that less than 20% of trusts would be excluded using the 70% completeness threshold. The following cancer sites excluded a higher percentage of trusts (~30%) based on the 70% completeness threshold during the project design stages, and were therefore set as 'one-off' releases:

- acute lymphoblastic leukaemia (ALL)
- acute myeloid leukaemia (AML)
- follicular lymphoma
- prostate

Q10. What is the impact of excluding data that does not meet the 70% completeness threshold?

Trusts that did not meet the threshold across key variables (see above) were not considered further in the case-mix adjusted analyses. This exclusion may have introduced bias but we believe the impact of this to be minimal. We have let trusts know when their low data completeness prevented them from being included in the analysis and these trusts have been listed in the workbook. When trusts met this threshold but still had missing data for one or more key variables and/or for other variables used in the risk-adjustment process, a separate 'missing' category was used for each variable, for the data modelling. For example, the performance status data were grouped as 'Performance status 0', 'Performance status 1', 'Performance status 2+', and 'Unknown'.

Q11. What data consistency restrictions were applied to the data?

- The trust at which final SACT treatment was completed is important for calculating the CMAR. Any patients whose final SACT treatment in the treatment activity period was recorded at two different trusts on the same day have therefore been removed from the analysis.
- Any patients who had a record of SACT treatment after death were removed from the analysis.
- Any patients where we had inconsistent death data were removed from the analysis.

These were not common events in the data.

Q12. What age restrictions were applied to the data?

For the majority of the workbooks, the cohort was restricted to those aged 18+. A separate workbook was published which was restricted to those aged 0-24. Please see background section for more information.

For all other CMAR releases, the cohort was restricted to those aged 18+. As these covered an adult cohort, the following children's hospitals were excluded from the analysis:

- Alder Hey Children's NHS Foundation Trust
- Birmingham Women's and Children's NHS Foundation Trust
- Great Ormond Street Hospital for Children NHS Trust
- Sheffield Children's NHS Foundation Trust

For the CTYA (Children Teenager and Young Adult) acute lymphoblastic leukaemia (ALL) workbook the cohort was restricted to patients aged 0-24, and children's hospitals outlined above were included in the analysis.

Q13. What 30 day SACT mortality restrictions were applied to the data?

We count deaths (for any reason) within 30 days of the date that the last SACT treatment was prescribed.

Following feedback from NHS trusts, an oral treatment rule was applied on the CMAR public releases from May 2021 to September 2021 to follow the approach used when using SACT to evaluate treatments in the Cancer Drugs Fund (CDF), Cancer Drugs Fund (CDF) methodology document[14]. For oral treatments this entailed adding days relating to the typical prescription length to the last administration date recorded in the SACT Dataset. 28 days was found to be a reasonable proxy for most treatments. Therefore, we added 28 days to the last administration date for all oral treatments. This is then taken into account when retrieving the final treatment date for each patient. This may differ from methodologies used within trusts themselves. For the 2nd bowel, breast and lung CMAR workbook we reverted back to the original method used for the CMAR workbooks which was not to add any days to oral treatment administration dates to proxy prescription length as a result of trust feedback on varying prescription lengths available.

Q14. Does the report exclude deaths that were within 30 days post-SACT but were from causes unrelated to the patient's cancer?

No, it includes all deaths. This is because cause of death can be misclassified[15],

[14] Appendix links for the CDF methodology document: Appendix A (oral treatment duration calculations) and Appendix B (caveats associated with oral treatment duration calculations)
[15] Sarfati, Blakely et al. (2010). Measuring cancer survival in populations: relative survival vs cancer-specific survival. *International journal of epidemiology*, 39(2), 598–610. https://doi.org/10.1093/ije/dyp392

especially those relating to deaths from cancer treatment[16], therefore the decision was made to take an inclusive approach to cause of death for this report.

Q15. What treatment restrictions were applied to the data?

For the purposes of the analysis, and to ensure treatment data was relevant to the cancer site of interest, the following rules were applied when linking SACT data to the cohort of patients identified from the National Cancer Registration Dataset or Rapid Cancer Registration Dataset:

1. For those patients with only one cancer diagnosed, all treatment records within the relevant time frame were selected.
2. For those patients with more than one cancer diagnosed, treatment records were selected if they met the following criteria:
    a. Within the relevant timeframe
    b. The first three characters of the primary diagnosis (ICD-10) recorded in SACT, matched the first three characters of the cancer site identified in the National Cancer Registration Dataset or Rapid Cancer Registration Dataset.
3. For those patients with treatment records that did not fall within categories 1 and 2 outlined above, treatment records were selected if they were
    a. Within the relevant timeframe
    b. Within 31 days before and 'x' days after the diagnosis of interest (dependent on the cancer site). Please see Table 2 for the range of post-diagnostic time periods relating to each cancer site. The decision to restrict based on the time between treatment and diagnosis is in accordance with the 'Linking treatment tables – chemotherapy, tumour resections and radiotherapy' standard operating procedure. The timeframes used ensure that treatment given soon after diagnosis is included for those patients where the diagnosis codes recorded in the National Cancer Registration Dataset (and Rapid Cancer Registration Dataset where applicable) are not an exact match to those recorded in SACT. This is particularly relevant for some cancers where coding of the cancer site sometimes differs between data sources.

       Please note that the ICD-10 and morphology codes selected may differ from the standard operating procedure referenced. The codes used for this work were selected in accordance with previous releases of 30 day mortality rates.

4. Following clinical advice, treatments that were not treatment options for the cancer sites covered in these reports were also excluded.

[16] Welch & Black. (2002). Are Deaths Within 1 Month of Cancer-Directed Surgery Attributed to Cancer? *JNCI: Journal of the National Cancer Institute,* 94(14), 1066–1070. https://doi.org/10.1093/jnci/94.14.1066

Table 2: Treatment restriction timeframes for each CMAR cancer site[17]

Cancer site	ICD 10 code	Months and days included as post-diagnostic time period from linking treatment tables SOP	Months and days included as post-diagnostic time period from CMAR report
Acute lymphoblastic leukaemia (ALL) for children, teenagers and young adults (CTYA)	C91.0	15 months (456 days)	15 months (456 days)
Acute lymphoblastic leukaemia (ALL)	C91.0	15 months (456 days)	15 months (456 days)
Acute myeloid leukaemia (AML)	C92.0, C92.4, C92.5, C92.6, C92.8, C93.0, C94.0, C94.2	15 months (456 days)	15 months (456 days)
Bowel	Bowel cancer: C18-C20	12 months (365 days)	6 months (183 days) for 1st report 12 months (365 days) for 2nd report
	Rectal cancer: C21.8	15 months (456 days)	6 months (183 days) for 1st report 12 months (365 days) for 2nd report
Breast	C50	12 months (365 days)	6 months (183 days) for 1st report 12 months (365 days) for 2nd report
Cancer of unknown primary (CUP)	C77-C80	15 months (456 days)	6 months (183 days)
Follicular lymphoma	C82	15 months (456 days)	15 months (456 days)
Gastric	Small Intestine Cancer: C17	15 months (456 days)	6 months (183 days)
	Stomach Cancer: C16	6 months (183 days)	6 months (183 days)
Lung	C33-C34	6 months (183 days)	6 months (183 days) for 1st report 15 months (456 days) for 2nd report

[17]A post-diagnosis time period of 183 days was set for the first CMAR reports on bowel, breast, cancer of unknown primary (CUP), gastric, lung, myeloma, ovarian and pancreas cancer sites. Some of these differ slightly from the from the linking treatment tables standard operating procedure recommendations outlined above. This means a very small proportion of patients were not included in the analysis for these reports. However, post-diagnosis time periods for future CMAR releases will be reviewed and adjusted to match the relevant sites detailed in the linking treatment tables guidance.

Cancer site	ICD 10 code	Months and days included as post-diagnostic time period from linking treatment tables SOP	Months and days included as post-diagnostic time period from CMAR report
Please see footnote for list of lung morphology codes[18]. These were used for the 1st report but not the 2nd as morphology was not sufficiently complete in the Rapid Cancer Registration Dataset to permit this.	C37-C39	15 months (456 days)	6 months (183 days) for 1st report 15 months (456 days) for 2nd report
Myeloma	Multiple myeloma: C90.0 Plasma cell leukaemia: C90.1	15 months (456 days)	6 months (183 days)
Ovarian	C48.1 C56-C57.4	9 months (274 days)	6 months (183 days)
Pancreas	C25	6 months (183 days)	6 months (183 days)
Prostate	C61	12 months (365 days)	12 months (365 days)

Q16. Why are these treatment restrictions applied?

To get detailed information on the cancer diagnosis, patient and tumour characteristics, tumours recorded in the National Cancer Registration Dataset (or Rapid Cancer Registration Dataset for some reports) are linked to treatment records in the SACT Dataset. This requires analytical decisions to be made. In particular, the recording of primary diagnoses in the SACT Dataset are known to not always exactly match the cancer site recorded in the National Cancer Registration Dataset (the gold standard), so linking records on patient identifiers and tumour site would mean many tumours and their associated SACT treatment could be missed.

[18] Lung cancer (NSCLC): ICD10: C33-C34, C37-C39; Morphology: M8012/3, M8013/3, M8046/3, M8050/3, M8070/3, M8070/6, M8071/3, M8072/3, M8074/3, M8075/3, M8140/3, M8140/6, M8200/3, M8240/3, M8246/3, M8249/3, M8250/3, M8253/3, M8255/3, M8260/3, M8263/3, M8310/3, M8370/3, M8470/3, M8480/3, M8481/3, M8490/3, M8520/3, M8550/3, M8560/3, M8574/3, M8575/3.

Lung cancer (SCLC): ICD10: C33-C34, C37-C39; Morphology: M8002/3, M8041/3, M8042/3, M8044/3, M8045/3.

Lung cancer (unknown morphology): ICD10: C33-C34, C37-C39; Morphology not recorded.

SACT primary diagnosis (ICD-10) is the diagnosis at the start of a patient's SACT treatment. As noted in the SACT Data Resource Profile[19] information in this field is sometimes implausible, and it is recommended to use the ICD-10 site code from the National Cancer Registration Dataset for England. The restrictions detailed in the treatment restrictions section are therefore designed to balance the following risks:

- excluding patients due to errors in primary diagnosis recording or regimen mapping within the SACT Dataset including SACT treatment records that do not relate to the cancer site of interest

Q17. Which treatment regimen values are excluded from the CMAR workbooks?

Regimens that were non-harmful, supportive treatments, hormones and non-chemo treatments were excluded from the CMAR analyses. These treatments were excluded at regimen level rather than drug level. For non-excluded regimens all drug administrations have been retained in the analyses, even those that were, for example, supportive treatments.

The regimens are selected for exclusion following consultation with clinicians and pharmacists and are reviewed on a site-specific basis for every release. Please see Table 3 and Table 4 below for the full list of values from the treatment regimen data fields that have been excluded by cancer site. Table 3 provides the information for the 1st report per cancer site, while Table 4 provides the information for the 2nd report for bowel, breast and lung.

For a small number of reports (follicular lymphoma; 2nd bowel; 2nd breast; 2nd lung) SACT treatment records for patients whose most recent cancer was the cancer interest were extracted, and the number of times each regimen appeared with a particular primary diagnosis in the SACT Dataset was recorded. Any regimens that did not appear on the list with either the relevant primary diagnosis for the cancer site of interest or a close ICD-10 code were excluded from the analyses.

In addition, for the 2nd bowel, breast and lung report, clinicians reviewed some initial analyses carried out for these sites and helped identify regimens that appeared to relate to cancers other than the cancer site of interest.

However, we are conservative in our approach to excluding treatment regimen values in case any have been incorrectly mapped. This comes with the caveat that SACT treatment outside the cancer site of interest may be included.

[19] Bright, Lawton, Benson et al. (2020). Data Resource Profile: The Systemic Anti-Cancer Therapy (SACT) dataset. *International journal of epidemiology*, *49*(1), 15–15l. https://doi.org/10.1093/ije/dyz137

Table 3: Excluded treatment regimen values for each cancer site – for the 1st report per cancer site[20]

'X' indicates where a regimen value has been excluded, red cells indicate where a regimen value has not been excluded

Regimen	CUP	Gas	Lun	Pan	Bow	Bre	Mye	Ova	CTYA ALL	ALL	AML	Pro	FL
Abiraterone										X	X	X	X
Anagrelide	X	X	X	X	X	X	X	X	X	X	X	X	X
Anastrozole					X	X	X	X	X	X	X	X	X
Anti-Emetics	X	X	X	X	X	X	X	X	X	X	X	X	X
Anti-Histamines	X	X	X	X	X	X	X	X	X	X	X	X	X
Apalutamide										X	X	X	X
APML	X	X	X	X	X	X	X	X	X	X	X	X	X
B12	X	X	X	X	X	X	X	X	X	X	X	X	X
Bicalutamide										X	X	X	X
Bisphosphonates	X	X	X	X	X	X	X	X	X	X	X	X	X
Clodronic Acid													X
Cyproterone										X	X	X	X

[20] Column name abbreviations for each cancer site are as below:
CUP: Cancer of unknown primary
Gas: Gastric
Lun: Lung
Pan: Pancreas
Bow: Bowel
Bre: Breast
Mye: Myeloma
Ova: Ovarian
CTYA ALL: Children's Teenagers and Young Adults for acute lymphoblastic leukaemia
ALL: Acute lymphoblastic leukaemia
AML: Acute myeloid leukaemia
Pro: Prostate
FL: Follicular lymphoma

Regimen	CUP	Gas	Lun	Pan	Bow	Bre	Mye	Ova	CTYA ALL	ALL	AML	Pro	FL
Cyproterone + Goserelin													X
Darolutamide										X	X	X	X
Degarelix										X	X	X	X
Denosumab	X	X	X	X	X	X	X	X	X	X	X	X	X
Dexamethasone										X	X	X	
Enzalutamide										X	X	X	X
Exemestane					X	X	X	X	X	X	X	X	X
Finasteride										X	X	X	X
Flutamide										X	X	X	X
Folinic Acid	X	X	X	X	X	X	X	X	X	X	X	X	X
Fulvestrant										X	X	X	X
GCSF	X	X	X	X	X	X	X	X	X	X	X	X	X
Goserelin					X	X	X	X	X	X	X	X	X
Hepatoblastoma	X	X	X	X	X	X	X	X	X	X	X	X	X
Hormone										X	X	X	X
Hydrocortisone Intrathecal (Any Age)													X
Hydroxycarbamide					X	X	X	X					
Ibandronic Acid	X	X	X	X	X	X	X	X	X	X	X	X	X
Lanreotide	X	X	X	X	X	X	X	X	X	X	X	X	X
Letrozole					X	X	X	X	X	X	X	X	X
Leuprorelin										X	X	X	X
Medroxyprogesterone	X	X	X	X	X	X	X	X	X	X	X	X	X
Megestrol	X	X	X	X	X	X	X	X	X	X	X	X	X
Not Chemo	X	X	X	X	X	X	X	X	X	X	X	X	X
Octreotide	X	X	X	X	X	X	X	X	X	X	X	X	X
Pamidronate	X	X	X	X	X	X	X	X	X	X	X	X	X
Pasireotide	X	X	X	X	X	X	X	X	X	X	X	X	X

Regimen	CUP	Gas	Lun	Pan	Bow	Bre	Mye	Ova	CTYA ALL	ALL	AML	Pro	FL
Progesterone	X	X	X	X	X	X	X	X	X	X	X	X	X
Retinoblastoma	X	X	X	X	X	X	X	X	X	X	X	X	X
Sandostatin	X	X	X	X	X	X	X	X	X	X	X	X	X
Signifor	X	X	X	X	X	X	X	X	X	X	X	X	X
Somatostatin	X	X	X	X	X	X	X	X	X	X	X	X	X
Somatuline	X	X	X	X	X	X	X	X	X	X	X	X	X
Steroid	X	X	X	X	X	X		X	X	X	X	X	X
Stilbestrol	X	X	X	X	X	X	X	X	X	X	X	X	X
Stilboestrol	X	X	X	X	X	X	X	X	X	X	X	X	X
Tamoxifen					X	X	X	X	X	X	X	X	X
Trial	X	X	X	X	X	X	X	X	X	X	X	X	X
Triple Intrathecal	X	X	X	X	X	X	X	X				X	
Triptorelin										X	X	X	X
Vitamin	X	X	X	X	X	X	X	X	X	X	X	X	X
Zoledronic Acid	X	X	X	X	X	X	X	X	X	X	X	X	X

Table 4: Excluded treatment regimen values for the 2nd bowel, breast and lung report per cancer site[21]

'X' indicates where a regimen value has been excluded, red cells indicate where a regimen value has not been excluded

Regimen	Bow	Bre	Lun
Abiraterone	X	X	X
Anagrelide	X	X	X
Anastrozole	X	X	X
Anti-Emetics	X	X	X
Anti-Histamines	X	X	X
Apalutamide	X	X	X
APML	X	X	X
B12	X	X	X
Bicalutamide	X	X	X
Bisphosphonates	X	X	X
Clodronic Acid	X	X	X
Cyproterone	X	X	X
Cyproterone + Goserelin	X	X	X
Darolutamide	X	X	X
Degarelix	X	X	X
Denosumab	X	X	X
Dexamethasone	X	X	X
Enzalutamide	X	X	X
Exemestane	X	X	X
Finasteride	X	X	X
Flutamide	X	X	X
Folinic Acid	X	X	X
Fulvestrant	X	X	X
GCSF	X	X	X
Goserelin	X	X	X
Hepatoblastoma	X	X	X
Hormone	X	X	X
Hydrocortisone Intrathecal (Any Age)	X	X	X
Hydroxycarbamide	X	X	X
Ibandronic Acid	X	X	X
Lanreotide	X	X	X
Letrozole	X	X	X
Leuprorelin	X	X	X
Medroxyprogesterone	X	X	X

[21] Column name abbreviations for each cancer site are as below:
Bow: Bowel
Bre: Breast
Lun: Lung

Regimen	Bow	Bre	Lun
Megestrol	X	X	X
Not Chemo	X	X	X
Octreotide	X	X	X
Pamidronate	X	X	X
Pasireotide	X	X	X
Progesterone	X	X	X
Retinoblastoma	X	X	X
Sandostatin	X	X	X
Signifor	X	X	X
Somatostatin	X	X	X
Somatuline	X	X	X
Steroid	X	X	X
Stilbestrol	X	X	X
Stilboestrol	X	X	X
Tamoxifen	X	X	X
Trial	X	X	X
Triple Intrathecal	X	X	X
Triptorelin	X	X	X
Vitamin	X	X	X
Zoledronic Acid	X	X	X

Q18. What are the implications of the methodological approach?

The coronavirus (COVID-19) pandemic has unfortunately led to an increased lag in the availability of National Cancer Registration Dataset data. This meant cancer diagnoses made in 2019 were not available at the time these analyses were carried out. The 2nd bowel, breast and lung reports therefore used 2019 to 2020 treatment data from the Rapid Cancer Registration Dataset in addition to 2010 to 2018 treatment data from the National Cancer Registration Dataset. The Rapid Cancer Registration Dataset contains proxy tumour registrations and some associated events on the cancer patient pathway (e.g. surgery, radiotherapy and chemotherapy) from January 2018 to the most recently available data on cancer diagnoses. A core advantage of using this dataset is that using more timely data means additional patients can be included in the analyses. Some limitations on using the Rapids Data include:

- False Negative (FNE) cases where there is real registration but no proxy registration ("*missing data*") and False Positive (FPE) cases where there is no real registration but proxy registration ("*bad data*")[22]

[22] For further information please see October 2020 Rapid Cancer Registration Dataset webinar: https://www.ndrs.nhs.uk/ndrs-webinar-rapid-registrations-cancer-dataset-october-2020/
The creation methodology and data quality caveats report from the Rapid Cancer Registration Dataset are also available on the NCRAS webpage:

- Lack of lung morphology coding for the Rapid Cancer Registration Dataset to define Non-Small Cell Lung Cancer (NSCLC), Small Cell Lung Cancer (SCLC) and unknown morphology. As such lung morphology was not defined in analysis for the 2nd lung release.

Interpretation of the data

Q19. My trust has a higher caseload than the funnel plot caseload – why is this?

Potential explanations vary depending on the specific workbook, but could include:

- For workbooks released up to May 2021, patients still receiving treatment following the period of interest were excluded. Please see Table 1 for the period of interest for each cancer site. For follicular lymphoma and later releases we consider any patient having treatment in the relevant years irrespective of whether they had completed treatment or not.
- For some workbooks, the diagnosis period used does not cover the full treatment activity period used (see Table 1). This is because diagnosis data for part or all of the treatment activity period was not available from the National Cancer Registration Dataset at the time of analyses. For example the 1st breast release covered SACT treatment activity in 2019, and at the time of analysis the latest diagnosis data available from the National Cancer Registration Dataset was 2018. This means that those who have been diagnosed in 2019 may be missed from releases which have not used the Rapid Cancer Registration Dataset. However, it should be noted that the Rapid Cancer Registration Dataset has lower completeness than the National Cancer Registration Dataset so some patients diagnosed from 2019 onwards might not be included in the cohort.
- Only patients whose most recent cancer diagnosis was for the cancer site of interest were selected for inclusion in the analyses. If patients had more than one cancer diagnosed on the same day, the relevant cancer site was selected.
- For workbooks released up to May 2021 patients were only included if they received their latest treatment during the treatment period for the relevant cancer site.
- Patients who were only treated with an excluded regimen were excluded.
- Regimens were excluded if they were not SACT treatments (see Table 3 and Table 4), or if the regimen had been identified as not relating to the relevant cancer.

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http://www.ncin.org.uk/collecting_and_using_data/rcrd for example September 2021 data quality report: http://www.ncin.org.uk/view?rid=4333

- Patients who did not have a valid NHS number were excluded.

Q20. What is a case-mix adjusted rate and why is it useful?

Case-mix adjusted mortality post-SACT rates are reported in this workbook. Each trust will see and treat a wide variety of patients depending on the population they serve and the services they provide. The case-mix adjusted rates take into account these differences by producing rates that are based on an average group of patients rather than being solely based on the trust's own group of patients. The rates can then be compared between trusts and within a trust over time. This was done using statistical modelling (in this case, a mixed effects logistic regression model).

Q21. Why were those specific patient characteristics and clinical factors chosen to be adjusted for in the model?

The following variables were adjusted for in the analysis:

- age calculated as of the 1 January 2018, 1 January 2019 or 1 January 2020 (depending on treatment activity period)
- co-morbidity score[23]
- deprivation status[24]
- ethnicity[25]
- grade[26]
- hospital trusts (as a random effect[27])
- performance status[28]
- sex[29]
- stage at diagnosis[30]

[23] The co-morbidity score relates to the Charlson comorbidity score derived using inpatient Hospital Episode Statistics data with the same methodology as described by Maringe et al. but with a different time window: from 27 months to 3 months prior to the cancer diagnosis

[24] Using the income domain of the Index of Multiple Deprivation. IMD data from 2015 was used for tumours diagnosed between 2010 and 2013 and IMD data from 2019 was used for tumours diagnosed between 2014 and 2020.

[25] Grouped into White, non-White and Unknown categories for analysis as there were insufficient numbers in the other ethnic groups for robust analysis.

[26] Grade was only adjusted for within the follicular lymphoma CMAR analysis using C82 (follicular lymphoma) ICD-10 code. For further information please see the WHO ICD-10 C81-C96 page

[27] In a model, a random effect is usually a grouping factor (e.g. general practice, school, university), in this case the trust, for which we are trying to control and which we expect to be influencing the pattern of 30 day mortality.

[28] Performance status (PS) at start of cycle was used. PS at start of regimen was also included for cases where PS at start of cycle data was missing
This was adjusted for in the regression analysis by categorising as 0, 1, 2+ and Unknown
For further information please see the ECOG Performance Status page

[29] Sex was not adjusted for in the breast, ovarian and prostate releases as these analyses were restricted to female or male patients only

[30] Stage at diagnosis was not adjusted for in the cancer of unknown primary (CUP), acute lymphoblastic leukaemia (ALL), acute myeloid leukaemia (AML) and myeloma releases due to lack of

These variables were chosen because they are known to influence 30 day post-SACT mortality and have sufficient completeness. It is important to note that due to the absence of any information on factors such as patient choice and clinical factors such as liver function tests, the case-mix adjustment may not fully correct for the differences in caseload between trusts.

Q22. How is 30 day mortality after receiving Systemic Anti-Cancer Therapy (SACT) calculated?

The case-mix adjusted mortality rate (CMAR) for each trust is calculated as follows:

*CMAR = ((Observed Deaths in the trust / Predicted Deaths in the trust) * Population rate) * 100*

Observed deaths = the sum of the number of patients in each trust who died within 30 days of their latest treatment date.

Predicted deaths = the sum of the predicted probability of death for each patient within the trust.

The predicted probability is calculated from a case-mix adjusted logistic regression model. It takes into account (where these variables are appropriate or available) differences in the age, co-morbidity score, deprivation status, ethnicity, grade, performance status, sex, and stage at diagnosis of patients within each trust. These characteristics are known as the 'independent variables'. The regression model uses all the data to estimate the odds of a 30 day death for each patient. The trust is assigned as a random effect in the model which is a grouping factor for which we are trying to control and which we expect to be influencing the pattern of 30 day mortality. Because the logistic model gives the odds of a 30 day death, this is then converted to a probability. The equation for the odds ratio as derived from the logistic regression model (logodds) and predicted deaths are outlined below:

$$\textit{Predicted deaths} = \frac{e^{logodds}}{1+e^{logodds}}$$

Where the odds of death ('logodds') are obtained from the logistic regression model as follows:

$$logodds = \beta_0 + \sum_{i=1}^{j} \beta_{iX_i}$$

staging data for these sites. It was excluded from follicular lymphoma due to poor data completeness. For further information on stage at diagnosis please see the National Cancer Registration Dataset in England, Data Resource Profile

$\beta_{1,\ldots,}$ β_j = coefficient(s) on independent variables

$x_1,\ldots,x_j$ = independent variables

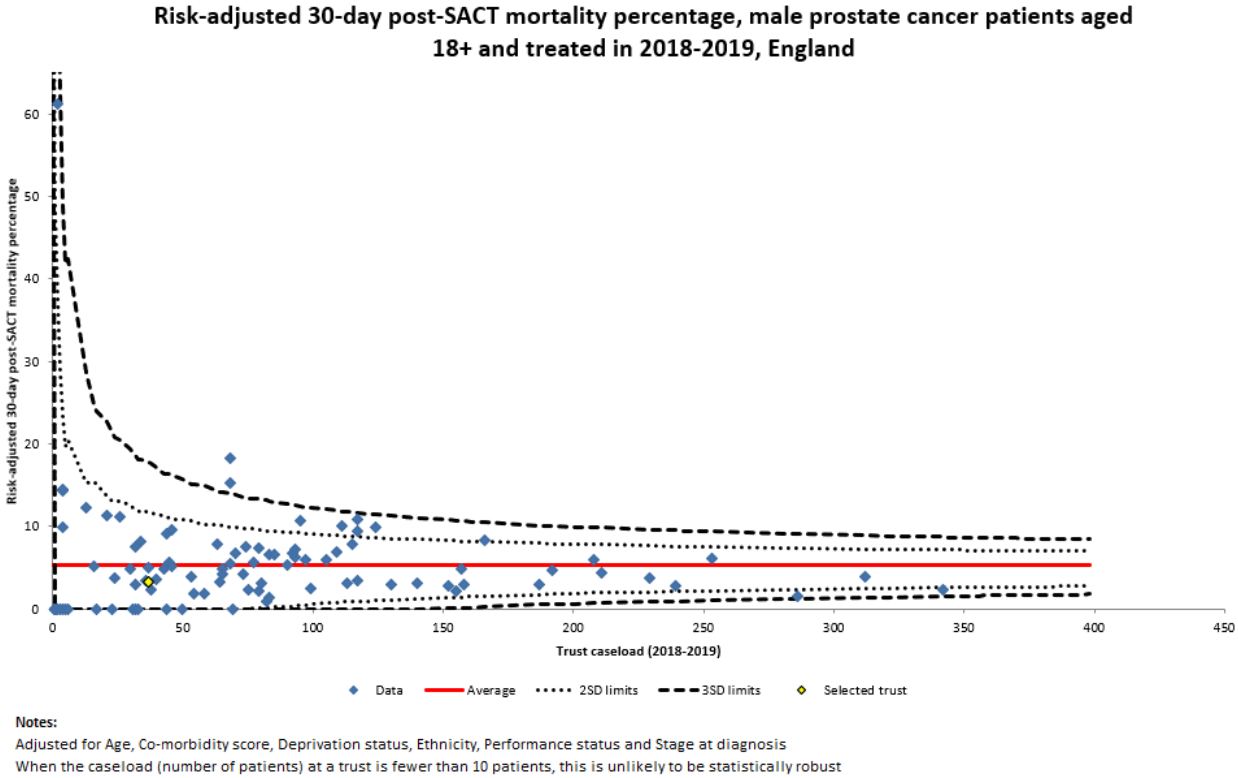
Population rate = this is the mortality rate for all the patients included in the analysis. It is calculated as follows:

Population rate =

Observed deaths within 30 days in the population / Number of patients in the population

Q23. How do I interpret the funnel plot?

A visual example of the funnel plot is provided below for prostate cancer:



The funnel plot[31] presented in the workbook is a means of visualising 30 day mortality post-SACT rates for the eligible[32] trusts in England.

- The volume of patients is on the horizontal axis. The more patients treated by your trust, the further to the right your trust will be.
- The 30 day mortality post-SACT is on the vertical axis. The higher the mortality post-SACT rate at your trust, the further up the graph it will appear.

[31] More information on funnel plot uses and interpretation can be found on the Public Health England Technical Guide and Tower Hamlets Clinical Commissioning Group Guide

[32] See data completeness restrictions section

- The solid red horizontal line shows the average mortality post-SACT rate of all trusts in England who were included in the analysis.
- Your trust is indicated by the yellow diamond, other trusts are represented by the blue diamonds.
- The dotted lines represent the ±2 standard deviations (SDs) (roughly equivalent to 95% confidence intervals); the dashed lines represent the ±3 standard deviations (SDs) (roughly equivalent to 99.8% confidence intervals). They are higher on the left because when a trust treats a smaller number of patients, chance will have a greater impact on the rate, and therefore the confidence intervals will be wider to reflect this.

Q24. What do the confidence intervals mean?

The confidence intervals presented in the workbook reflect the distribution of trust mortality post-SACT rates around the national average. The workbook highlights the mortality post-SACT rates for ±2 standard deviations (SDs) (roughly equivalent to 95% confidence intervals) and ±3 standard deviations (SDs) (roughly equivalent to 99.8% confidence intervals). Trusts with rates above the upper, +3SD will be identified as outliers.

- Trusts with rates above the upper, +3SD have a significantly higher than average 30 day post-SACT mortality rate.
- Trusts with rates below the lower, −3SD have a significantly lower than average 30 day post-SACT mortality rate.
- Trusts with rates within the confidence limits have an average 30 day post-SACT mortality rate.

It should be noted that outlier status can occur due to data quality issues, problems with linking the SACT data to the National Cancer Registration Dataset and Rapid Cancer Registration Dataset and other factors. All trusts are provided with the workbook prior to public release and invited to submit a statement. The statements provide valuable context, and in some cases, suggests that patients have been mistakenly included in the analysis or incorrectly identified as having died within 30 days of SACT treatment. The statements for each release are included in the companion brief which can be found on the SACT website[33].

Q25. Is the model re-run following the release to trusts?

The model is not re-run if new information comes to light after the workbook is shared with trusts, so the output should be interpreted with care, bearing in mind the

[33] SACT website: http://www.chemodataset.nhs.uk/

caveats and methods in this document and the companion brief for each release which can be found on the SACT website[34].

Q26. In our trust we treat many older patients with multiple co-morbidities – is the report adjusted to reflect this?

Yes – the report is case-mix adjusted, therefore the influence of these factors should be accounted for in the report. However, the absence of any information on critical factors such as frailty and patient choice as well as clinical factors such as liver function tests, mean that the case-mix adjustment may not fully correct for the differences in caseload between trusts.

Q27. Is adjusting for poor performance status and high levels of co-morbidities covering up the possibility of an overuse of SACT in patients with poor performance status and high levels of co-morbidity?

In most instances there is NICE guidance which is relevant, such as only treating patients with PS 0-1 and without other significant medical complications. However, decision-making is complex and there are more factors considered than we are able to adjust for in these analyses. The quarterly Rapid Data Review (RDR) data feed produced by the SACT team provides trusts with details of patients who died within 30 days of SACT, with the aim of supporting routine clinical audit to review the safety and quality of care and address decision making in outlier trusts or services.

Q28. What is the expected mortality post-SACT rate for these cancer diagnoses?

There is no ‘target’ mortality post-SACT rate for these treatments. It is acknowledged that many of these drugs have a narrow therapeutic index, and that a certain level of risk needs to be accepted when prescribing these drugs.

Generally, lower rates are better as they reflect that in curative settings, complications are being identified and managed rapidly. In palliative settings they reflect that the clinician is aware when the patient is in the final stages of their disease and discusses with the patient whether other non-SACT treatment options are more appropriate.

However, persistently very low mortality post-SACT or zero mortality post-SACT rates may be indicative of a risk aversive approach to prescribing, whereby patients who may potentially have benefitted from SACT are not receiving this treatment. Trusts who have persistently very low mortality post-SACT or zero mortality post-SACT rates may want to consider auditing their clinical practice for this reason.

[34] SACT website: http://www.chemodataset.nhs.uk/

Q29. We treat very small numbers of patients for certain disease groups. Will this make a difference?

If you only treat small numbers of patients and one dies within 30 days, your mortality post-SACT rate will be high. However, the funnel plot structure may account for this as the confidence limits will be wider for trusts treating a smaller number of patients.

Trust Status

Q30. My trust has been listed as 'no data' in the workbook, what does this mean?

Some trusts had 'no data' in the workbook. This could occur for the following reasons:

- patients were still receiving treatment after the period of interest. Please see Table 1 for the period of interest at each cancer site. For follicular lymphoma and the 2nd bowel, breast and lung report we consider any patient having treatment in the relevant years irrespective of whether they had completed treatment or not
- patients were treated with regimens that were excluded from the analysis (see list of excluded regimens for details of the core exclusions. We also exclude regimens that are identified as being treatments for cancer sites other than the cancer site of interest)
- patients received their last treatment at a different trust
- we were not able to match the patient's diagnosis in the National Cancer Registration Dataset or Rapid Cancer Registration Dataset (where relevant) to that of the diagnosis captured in the SACT Dataset and the patient's treatment fell outside of the diagnosis-to-treatment time window

Each companion brief presents a table of those trusts with no data in the analysis.

Q31. My trust has been listed as 'excluded' in the workbook, what does this mean?

Excluded based on the 70% data completeness threshold. Please see the data restrictions section for further information.

Q32. My trust has been listed as 'outlier' in the workbook, what does this mean?

- Outliers for the 30 day post-SACT mortality rates, which have been included in analysis.
- Outlier trusts included in analysis are referred to as 'Outlier (>3SD)' in the table. Please see funnel plot section for further information on the 3SD (standard deviation) calculations.
- If the trust caseload (number of patients) is fewer than 10 patients, this is unlikely to be statistically robust. Therefore, where a trust is >3SD but has fewer than 10 patients they are not noted as an outlier.
- For a small number of the CMAR releases, when running the original mixed-effects logistic regression model, trusts with ≤1 patient generated a highly inflated case-mix adjusted rate (>100%). These outliers were excluded from the model and not presented in the data[35].

Trusts that are found to be outliers by having 30 day mortality post-SACT rates that are above the upper, +3SD limit will be informed of this. All trusts are given the opportunity to respond to the SACT team prior to this information being made available to the public, and we particularly encourage responses from outlying trusts.

Q33. Which trust mergers are covered in the workbook?

Trusts presented in the analysis have been grouped to reflect any mergers that had taken place up to the date the analysis was run. The aim of this work is to highlight areas for improved data submission and clinical governance procedures, for which we have chosen to present the most up to date trust codes at the time the analysis was undertaken. This means that, if two trusts merged following the CMAR treatment window, the two trusts will appear under their single merged trust name in the workbook, even though treatment activity for the relevant period was received for the two trusts individually.

A concrete example of this would be as follows:

The CMAR follicular lymphoma release covered treatment dates from Jan 2017 to Nov 2020 with analysis undertaken in June 2021. Brighton and Sussex University Hospitals NHS Trust (RXH) and Western Sussex Hospitals NHS Foundation Trust (RYR) merged in April 2021 to become University Hospitals Sussex NHS Foundation Trust (RYR). Because this merger was in place by April 2021 and analysis took place in June 2021, figures in the workbook for University Hospitals Sussex NHS Foundation Trust (RYR) will represent activity for both Brighton and Sussex University Hospitals NHS Trust (RXH) and Western Sussex Hospitals NHS Foundation Trust (RYR) over the treatment period.

[35] Outlier trusts excluded from analysis are referred to as 'Excluded Outlier' in the companion brief tables

Further information on NHS trust mergers can be found on the NHS Digital Organisation changes webpage[36].

Communication of the Workbooks

Q34. Who is this data sent to within the trust? Can we nominate members of staff to receive it?

The SACT Dataset helpdesk at NHS Digital (ndrs.datasets@nhs.net) compiled a list of named contacts at each NHS trust including the SACT uploader, lead cancer clinician, the regimen mapper, CEO and medical director, unless we were otherwise notified. Please contact the helpdesk if you would like to make changes to your distribution list.

The workbooks are sent to these named contacts. There is no patient identifiable data included in the workbooks. Trusts are invited to request the NHS numbers of patients in their data who have died within 30 days of receiving SACT. NHS numbers will only be provided via secure means following a request from a trust. This aims to restrict the circulation of this sensitive information to individuals who intend to use it for clinical audit and local governance processes.

Q35. When will trusts be able to access the latest workbooks?

The workbooks are made publicly available on the SACT website[37] within two months following release to the NHS trusts.

Trusts were invited to provide a statement for inclusion in the companion brief, across all published CMAR reports.

Each release will be publicised through a range of channels, including the SACT and the National Disease Registration Service (NDRS) newsletters.

Q36. How often will we receive this data? Will we receive information for other cancer sites?

Future releases are planned for this work, with some releases planned annually and every two years depending on the cancer site. More information and the links to previous releases can be found in Q4 on which cancer sites are covered in the workbooks or on the SACT website[37].

[36] NHS Digital Organisation changes webpage: https://digital.nhs.uk/services/organisation-data-service/organisation-changes
[37] SACT website: http://www.chemodataset.nhs.uk/

Data Queries

Q37. Can my trust access the underlying patient data for this report?

You can request the NHS numbers for patients who died at your trust within 30 days of receiving SACT. To request this information please contact the SACT Dataset Helpdesk (ndrs.datasets@nhs.net).

Q38. I have the extract of patient data for those patients who died within 30 days post-SACT, but can I request the patient data for the denominator group?

No, only the details of those patients who died within 30 days are available so that it can be used for audit. This is also in accordance with regulations surrounding data minimisation. Any requests for additional patient data should go through the Office for Data Release[38].

Q39. Please can we have the GMC code for each responsible consultant, so each consultant can review their own data?

No, only the NHS numbers of those patients who died within 30 days are available for this output. GMC code for 30 day mortality is provided as part of a separate data feed called the Rapid Data Review (RDR). Please contact the SACT Dataset Helpdesk (ndrs.datasets@nhs.net) for further information about this.

Q40. We think the data which has been submitted for our trust is incorrect – can we correct this?

Unfortunately, we cannot accept data re-submissions, corrections or re-run the report. The report is a snapshot of the data at the present time. However, if you have identified errors in the data submitted to SACT we recommend that you make changes in your current practice to reduce such errors going forward. Please contact the SACT Dataset Helpdesk (ndrs.datsets@nhs.net) for support with this.

If you have any questions regarding this work, please contact the SACT Dataset Helpdesk (ndrs.datasets@nhs.net)

[38] Office for Data Release, Accessing PHE data through the Office for Data Release webpage: https://www.gov.uk/government/publications/accessing-public-health-england-data/about-the-phe-odr-and-accessing-data