NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NHS England

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

A companion brief to support the interpretation of this data

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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Overview

This document provides specific details for the follicular lymphoma workbook release. For detailed information on the Case-Mix Adjusted Rates (CMAR) workbooks, including background information, the methodology used, data restrictions, and guidance on how to interpret the data, please refer to the **CMAR Toolkit**.

The data for CMAR workbooks are also 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.

Please see the UK Chemotherapy Board (UKCB) morbidity and mortality within 30 days of SACT recommended proforma[1] for information on reviewing current practice.

Summary

In February 2022, the National Disease Registration Service (NDRS) team, as part of the NHS Digital (NHSD) / NHS England-Improvement (NHSE-I) SACT data partnership, produced a revision to the September 2021 case-mix adjusted 30 day mortality post Systemic Anti-Cancer Therapy (SACT) rates (CMAR) for follicular lymphoma. The February 2022 workbook replaces the September 2021 version. These CMAR were calculated for NHS trusts.

The data is case-mix adjusted to allow for comparisons to be made between trusts and within a trust over time. Trusts are able to request NHS numbers of patients who have died within 30 days of receiving SACT at their trust. We developed this information to support clinical governance at trusts and potentially identify areas where clinical care could be improved. We provided all trusts with the opportunity to comment on their data and their statements are included in this Companion Brief, published February 2022.

[1] 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

Key messages

- For the 105 NHS trusts included in the analyses, the average case-mix adjusted 30 day mortality post-SACT rate was 4.6%.
- No trusts were identified as outliers on the basis of their case-mix adjusted 30 day mortality post-SACT.
- 27 trusts had no deaths within 30 days of SACT treatment among patients receiving treatment between January 2017 and the end of November 2020.
- The number of patients receiving SACT treatment for follicular lymphoma in the study period and meeting the study inclusion criteria varied by NHS trust, ranging from 7 to 116 and with an average caseload of 43.
- 19 trusts were excluded from the analyses as they did not meet the 70% data completeness threshold for the data-fields used to adjust for case-mix.
- 2 trusts had no patients meeting the study inclusion criteria, so were excluded from the analyses.
- 3 trusts treated fewer than 10 patients during the study period, so their case-mix adjusted mortality rates are not considered statistically robust.

Workbook

The workbook is produced as part of the NHSD / NHSE-I SACT data partnership and is based on routine data submitted by NHS trusts to the SACT Dataset[2]. It includes patients diagnosed with follicular lymphoma cancer in England between 2010 and 2018 and treated with SACT in an NHS trust in England between January 2017 and November 2020. Each patient was allocated to the trust where they received their final treatment, regardless of any prior treatment received at other trusts.

Table 1: ICD-10 code and treatment activity covered

Cancer site	ICD-10 code	Period of treatment activity
Follicular lymphoma	C82.0, C82.1, C82.2, C82.3, C82.5, C82.6, C82.7, C82.9	Jan 2017–Nov 2020

For the purposes of the analysis, patients were selected from the National Cancer Registration Dataset (NCRD)[3]. 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 specific restrictions applied to the data are outlined below. A full overview of all CMAR restrictions is available in the **CMAR Toolkit**.

Cancer restrictions

- The cohort was restricted to diagnoses between 2010 and 2018.
- Patients whose most recent cancer diagnosis was follicular lymphoma were selected. If patients had more than one cancer site diagnosed on the same day, the follicular lymphoma cancer site was selected.

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

[2] 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

[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

Data completeness restrictions

Trusts with less than 70% completeness for the key variables of co-morbidity score[4], grade[5] and performance status[6] were excluded from the analysis. Please note that these variables were sourced from the SACT Dataset, National Cancer Registration Dataset and Hospital Episode Statistics[7]. For 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. Initial project design stages showed a higher percentage of trusts (~30%) being excluded for follicular lymphoma. This was set as a 'one-off' release on this basis. For the current analysis, 15% of trusts were excluded for follicular lymphoma.

Please refer to the **CMAR Toolkit** for more information.

Data consistency restrictions

- The trust at which the latest SACT treatment was completed in the treatment activity period is important for calculating the CMAR. Any patients whose latest SACT treatment 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.

These were not common events in the data.

30 day SACT mortality restrictions

We count deaths (for any reason) within 30 days of the date that the last SACT treatment was prescribed. For oral treatments the 30 day window starts 28 days after the last administration date recorded in SACT, as most oral treatments have a prescription length of 28 days. Please see the Cancer Drugs Fund (CDF) methodology document[8] for further details. The method of setting all oral treatments to 28 days is being reviewed for future SACT outputs.

[4] 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

[5] Grade was adjusted for within 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

[6] 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

[7] Hospital Episode Statistics (HES) is a data warehouse containing details of all admissions, outpatient appointments and A and E attendances at NHS hospitals in England: https://digital.nhs.uk/data-and-information/data-tools-and-services/data-services/hospital-episode-statistics

[8] Appendix links for the CDF methodology document: Appendix A (oral treatment duration calculations) and Appendix B (caveats associated with oral treatment duration calculations)

Treatment restrictions

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:

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 (January 2017 to November 2020).
    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.
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 within the relevant timeframe and fell within 31 days before and 456 days after the diagnosis of interest. The decision to restrict based on the time between treatment and diagnosis is in accordance with Version 4.6 of the 'Linking treatment tables – chemotherapy, tumour resections and radiotherapy' standard operating procedure[9]. 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 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.
4. Patients latest treatment records (from January 2017 to November 2020) for non-haematological ICD-10 codes in the SACT primary diagnosis field were also excluded where the SACT primary diagnosis was a non-haematological ICD-10 code and the SACT regimen included treatments that were not treatment options for haematological malignancies.
5. Regimens that clinicians had advised us were not treatments for these cancers were also excluded.

Excluded treatment regimen values

Regimens that were non-harmful, supportive treatments, hormones and non-chemo treatments were excluded from the analysis. 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.

[9] Version 4.6 of the 'Linking treatment tables – chemotherapy, tumour resections and radiotherapy' standard operating procedure: http://www.ncin.org.uk/view?rid=4299

The set of values from the treatment regimen data fields which have been excluded are listed below. These were selected for exclusion in consultation with clinicians and pharmacists and are reviewed on a site-specific basis for every release. Please note some terms in this list, e.g. retinoblastoma, are not regimens, but reflect data incorrectly entered in the regimen fields within the SACT Dataset.

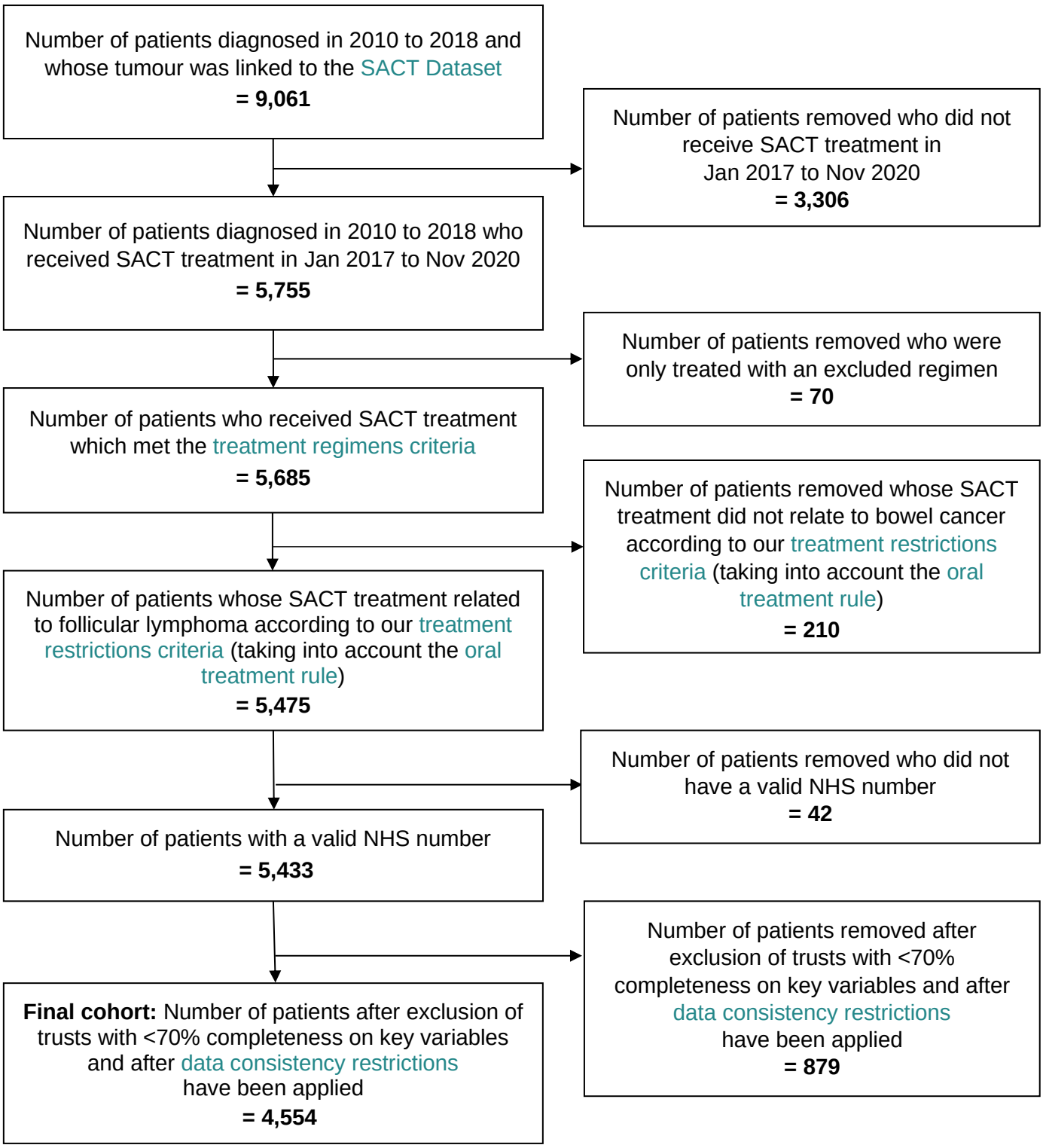
Table 2: Excluded treatment regimen values

Regimen A-E	Regimens F-O	Regimens P-Z
Abiraterone	Finasteride	Pamidronate
Anagrelide	Flutamide	Pasireotide
Anastrozole	Folinic Acid	Progesterone
Anti-Emetics	Fulvestrant	Retinoblastoma
Anti-Histamines	GCSF	Sandostatin
Apalutamide	Goserelin	Signifor
APML	Hepatoblastoma	Somatostatin
B12	Hormone	Somatuline
Bicalutamide	Hydrocortisone Intrathecal (Any Age)	Steroid
Bisphosphonates	Hydroxycarbamide	Stilbestrol
Clodronic Acid	Ibandronic Acid	Stilboestrol
Cyproterone	Lanreotide	Tamoxifen
Cyproterone + Goserelin	Letrozole	Trial
Darolutamide	Leuprorelin	Triptorelin
Degarelix	Medroxyprogesterone	Vitamin
Denosumab	Megestrol	Zoledronic Acid
Enzalutamide	Not Chemo	
Exemestane	Octreotide	

Presentation of results

As all trust caseload counts were greater than 5, no counts have been suppressed in the output.

CMAR follicular lymphoma flowchart



Please refer to the **CMAR Toolkit** for detailed information on the methodology and risk-adjustments applied.

Trusts with no data

Some trusts had ‘no data’ in the workbook. This means that they had no activity data for patients who were treated in the treatment period (January 2017 to November 2020), who fit the inclusion criteria. Strict criteria were applied to the data for this work and so there are a few reasons why a trust may have no data in the workbook. Examples of this include:

- Patients were treated with regimens that were excluded from the analysis (see list of excluded regimens)
- 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 to that of the SACT Dataset and the patient’s treatment fell outside of the diagnosis-to-treatment time window

The table below presents those trusts with no data in the analysis.

Table 4: Trusts with no data

Trust name	Follicular lymphoma
Homerton University Hospital NHS Foundation Trust	No data
Tameside and Glossop Integrated Care NHS Foundation Trust	No data

Excluded trusts and outlier trusts

The table below presents those trusts that were found to be excluded based on the 70% data completeness threshold[10]

Table 5: Trusts that were excluded based on the 70% completeness threshold

Trust name
Croydon Health Services NHS Trust
Isle of Wight NHS Trust
London North West University Healthcare NHS Trust
Maidstone and Tunbridge Wells NHS Trust
Medway NHS Foundation Trust
Norfolk and Norwich University Hospitals NHS Foundation Trust
North West Anglia NHS Foundation Trust
Oxford University Hospitals NHS Foundation Trust
Pennine Acute Hospitals NHS Trust
Portsmouth Hospitals University NHS Trust
Royal Berkshire NHS Foundation Trust
St Helens and Knowsley Teaching Hospitals NHS Trust
Surrey and Sussex Healthcare NHS Trust
The Clatterbridge Cancer Centre NHS Foundation Trust
The Dudley Group NHS Foundation Trust
The Princess Alexandra Hospital NHS Trust
The Shrewsbury and Telford Hospital NHS Trust
University Hospitals Plymouth NHS Trust
West Suffolk NHS Foundation Trust

[10] Trusts with less than 70% completeness for the key variables of co-morbidity score, grade and performance status were excluded from the analysis. Please note that these variables were sourced from the SACT Dataset, National Cancer Registration Dataset and Hospital Episode Statistics
Trusts excluded based on the 70% completeness threshold are referred to as 'Excluded' in the table

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