

**National cancer data collection and analysis in the COVID-19 pandemic
A discussion paper for the NHS-E cancer centres teleconference 27 April 2020,
since updated with new information**

This paper is intended to summarise the current known plans for data collection and analysis and to prompt discussion in the UK cancer community so that we can collaborate as effectively as possible.

A. Background

1. The Coronavirus pandemic has led to many changes in the management of patients with cancer. These changes reflect the need to prioritise treatments within a rapidly changing and resource constrained environment, to protect patients who are vulnerable or shielding from possible virus exposure and to reduce footfall in hospitals as part of social distancing.
2. Many organisations have developed guidelines to support clinicians and the services they lead to make these challenging decisions. Modifications to systemic anti-cancer treatment (SACT) include treatment breaks, regimen changes and new therapies approved by the Cancer Drugs Fund (CDF). Radiotherapy changes include increasing hypo-fractionation and in some cases the use of radiotherapy in place of surgery. Where it is considered safe, complete omission of treatments has also been suggested. While aimed at minimising risk to patients and ensuring services are able to deliver priority treatments these changes are often based on uncertain evidence.
3. Four main questions relevant both to current and future patients remain.
 - Q1) How is cancer management being modified in response to the pandemic?
 - Q2) What are the reasons for changes in the management of individual patients?
 - Q3) What effect will these changes have on patient outcomes? e.g. Are the hypofractionated radiotherapy regimens effective as more fractionated treatments? Can radiotherapy be used to spare some patients surgical intervention? What are the consequences of implementing treatment breaks in systemic anti-cancer therapy?
 - Q4) What are the risks of COVID-19 infection and death for patients having cancer treatment during the coronavirus pandemic? Despite this being critical information to decision-making it remains unknown.
4. The routine healthcare data collected, curated and held by the National Cancer Registration and Analysis Service in Public Health England (NCRAS, PHE) places the NHS in a unique position to begin to answer these questions. This resource incorporates national cancer registration data, linked to the national radiotherapy dataset (RTDS), systemic anti-cancer therapy (SACT) dataset and hospital episodes statistics (HES) datasets. It provides an unparalleled opportunity to understand the consequences of the pandemic for patients with cancer and help to inform decision-making both during and beyond the pandemic.

B. Current projects and people

5. The Clinical Oncology Faculty of The Royal College of Radiologists (RCR) has been supporting departments as they change their pathways and protocols in response to COVID-19. Many departments have been collecting prospective data on changed pathways/possible harms via Harm Review Templates e.g. Taunton (Emma Cattrell/Julie) Walther and Cambridge (Pippa Corrie/Emma Beddowes/Sian Pugh). Other centres mentioned similar plans for data collection at the NHS-E oncology centre weekly conference (Peter Johnson, Wendy Makin) on 17 April.
6. The RCR has a longstanding partnership with the RTDS team from PHE/NCRAS (Kat Roe, Sabrina Sandhu). Data on dose/fractionation regimens by tumour site can be compared to national guidance. The RCR (Tom Roques, Matt Williams, Katie Spencer) and NHS-E radiotherapy CRG (Kim Fell) have both asked RTDS team to provide comparative data from March 2019 and 2020 to assess the impact of COVID-19 on radiotherapy dose/fractionation schedules.
7. PHE (Rebecca Smittenaar) is working on generating a set of SACT metrics using the SACT dataset. This might link with UKCCMP. Pippa Corrie has also been discussing with Rebecca the potential to interrogate the SACT dataset to evaluate change in survival rates over time associated with treatment modifications.
8. The National Cancer Research Institute Clinical and Translational Radiotherapy Research Working Group (CTRad) have developed a proposal – COVID-19 RT through the CTRad Executive, a webinar engaging the CTRad membership and consultation with key partner organisations. They aim to determine the impact of the pandemic on:
 - i) patient outcomes by collecting information on decisions regarding decision -making for radiotherapy (omit, delay) and changes to standard radiotherapy prospectively using a standard template. They plan to combine prospective data with retrospective linkage with RTDS and NHS Digital and have liaised with Kat Roe and Kim Fell.
 - ii) radiotherapy treatment policy and prioritisation by analysing treatment policy and prioritisation protocols for each radiotherapy centre.
 - iii) the UK radiotherapy service and workforce in partnership with the RCR, SCoR and IPEM.This is likely to launch in early May and has the support of the RCR and SCoR.
9. The NIHR LCRN Cancer Cluster (led by Matt Seymour) are discussing whether it is feasible to harmonise collection of treatment modification data in relation to SACT (Pippa Corrie), radiotherapy (Jon Wadsley) and surgery (Nigel Bundred). This group were previously unaware of the CovidSurgCancer group and a new initiative would lead to duplication. CTRad has liaised with this group and will address radiotherapy as above.
10. The [UK coronavirus cancer monitoring project](#) (UKCCMP; Gary Middleton/Rachel Midgeley/Lennard Lee/Anna Olsson-Brown) is collecting data on patients with cancer who have proven COVID-19 infections. They are meeting weekly with PHE.
11. Tumour-specific groups are proposing projects to look at changes to the whole patient pathway in individual tumour sites. e.g. UK Covid and Gynaecological Cancer Study, similar studies for lung and genito-urinary tumours.
12. KSS and Guys (Catherine Harper-Wynne) are working up a point prevalence study for asymptomatic patients attending RT departments for one week in June.

13. Carlo Pamieri (Clatterbridge) is working with the [UK Clinical Characterisation Protocol \(ISARIC\)](#) team to analyse data on patients recruited into prospective ISARIC/WHO Clinical Characterisation Protocol for Severe Emerging Infections in the UK (CCP-UK). He has also registered a formal request to access the UK ITU dataset via [ICNARC](#) given approx. 2% of all COVID ITU admissions are patients with haem malignancy and metastatic cancer. He is collating a table of international COVID-19 and cancer studies.
14. In Scotland, the Cancer Treatment Response Group (CTRG, John Murphy) are co-ordinating their response to COVID-19 from the cancer point of view. They are collating parallel data to England and have a weekly update of SACT activity. The National Services Division and the Innovative Healthcare Delivery Programme (a joint venture with NHS-S and University of Edinburgh with David Cameron directly involved) may be useful resources.

C. Possible next steps

15. Q1 *How is cancer management being modified in response to the pandemic?*
This can probably be answered for radiotherapy and chemotherapy by routinely collected NCRAS data. There is a two- to three-month lag from data collection to publication. Analysis ideally needs to be performed as quickly as possible and made available to all cancer centres.
16. Q2 *What are the reasons for changes in the management of individual patients?*
This needs to be answered by collecting data from individual trusts and MDTs about why treatment plans are modified in the light of COVID-19 and what modifications are being made. Currently this is being addressed in a variety of ways across the country – examples exist of trust-wide approaches, disease-specific initiatives or specific treatment modalities (e.g. COVID-RT CTRad project). A more comprehensive, joined up approach with data collected systematically into a central portal might be more efficient and would facilitate linkage to NCRAS/PHE data in due course.
17. Q3 *What effect will these changes have on patient outcomes?*
This can be answered by linking information from Q1 and Q2 with clinical outcomes data. A major challenge will be identifying and collecting the relevant clinical outcomes. Smaller project teams may prospectively collect data not available within NCRAS, such as local recurrence data and health-related quality of life.
18. Q4 *What are the risks of COVID-19 infection and death for patients having cancer treatment during the coronavirus pandemic?*
This is potentially the most valuable information to inform current risk/benefit discussions with patients. It is hoped that data held by NCRAS can be linked with data informing COVID-19 status, providing key information about the risk of infection and risk of adverse outcomes for patients with cancer. Information on co-morbidities, ethnicity and other risk factors for severity of COVID-19 infection would also need to be evaluated and accounted for in the analysis.
19. The organisations mentioned above need to work together to develop simple, robust data collection tools to collect and analyse relevant information from cancer teams. Support from larger stakeholders can help to ensure efficient data collection and enable access to routine healthcare data. This will supplement and enhance the work of smaller teams who wish to address specific questions.

D. Suggested questions for discussion

- Should we be encouraging a national collaborative approach to collecting treatment on cancer patients during COVID-19?
- Who do we need to involve to discuss a national approach, if this is the way forward? - NHS-E and devolved nations, PHE, CRUK, NCRI, NIHR, RCR, CTRad
- What can NCRAS/PHE realistically provide in terms of treatment information and outcomes?
- Can we link NCRAS and COVID-19 data in a robust, useful way?
- What resources are needed to deliver this? Who will provide them?
- What data is being collected elsewhere in the world? Whilst NCRAS data is probably unique, other countries may have better COVID data (Germany?). Other initiatives are already underway e.g. [COVIDSurg](#) and [CCC-19](#)

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Any omissions or errors are entirely unintentional. We have listed individual names to try to avoid forgetting people who need to be contacted.