Cancer Medicines Outcomes Programme (CMOP)

Summary of Phase 1

Cancer Medicines Outcomes Programme (CMOP): Our Vision

The overall vision of CMOP is to better understand the real life impact of medicines used to treat cancer patients in Scotland.

Anti-cancer medicines (or systemic anti-cancer treatments (SACT)) are generally routinely available for prescribing after clinical trials have shown that they are safe and effective. However, the patients included in clinical trials may be different to the patients who receive these medicines in routine care (or 'real world patients'). Clinical trial patients may be younger or fitter, or have less pre-existing medical conditions, and are therefore better able to tolerate any unexpected side effects.

'Real world data' (such as information about hospital appointments/admissions, test results, prescribed medicines, side effects etc.) can provide useful information on the benefits and risks of medicines used in routine care. However, this information is often stored within lots of different healthcare record systems and is not always joined up. CMOP aims to better link these data together. This would allow healthcare professionals to have a better understanding of how treatment affects Scottish patients so they can provide a more personalised approach to care, for example through better management of side effects which might not have been identified during clinical trials.

Launched in 2016, CMOP is funded by the Scottish Government and is a collaboration between NHS Greater Glasgow & Clyde (NHS GGC) and the University of Strathclyde.

Phase 1 Overview

CMOP Phase 1 had two main areas of work:

Clinical Studies

- Test a way of electronically linking patient health data from different sources.
- Understand what happens to patients receiving anti-cancer medicines (SACT) (for example, how long they are on treatment, and survival rates).

Patient Reported Outcome Measures Studies

- Explore how information about the ways that medicines impact patient quality of life (sometimes known as Patient Reported Outcome Measures or PROMs) could be collected as part of routine care using digital solutions.
- Understand what type of PROMs should be collected as part of routine care and how these could be collected regularly.

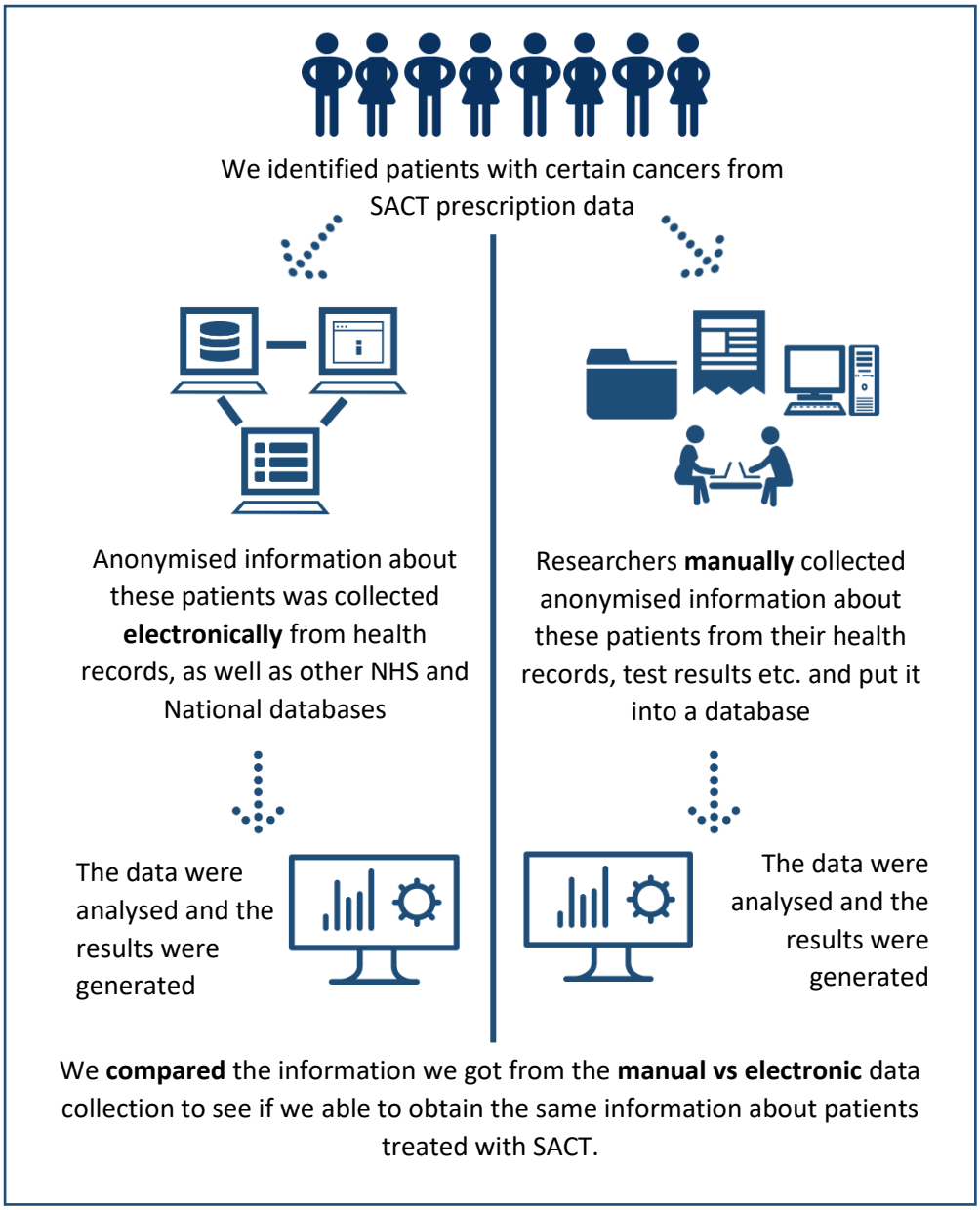
Clinical Studies: Background

What Were Our Aims?

A key aim of CMOP was to find out what happens to patients who are receiving SACT. We wanted to find out what kind of patients are receiving these treatments, what the benefits to patients are, and if there are many side effects. This type of work usually involves a researcher searching through each individual patient's case notes (paper or electronic) but this can be very time consuming. We wanted to find out if there was a more efficient way to do this by linking electronic health records.

What Did We Do?

Every patient has a unique Community Health Index (CHI) number that is used every time a patient encounters an NHS healthcare service from birth to death (e.g. your CHI number is in your prescription records, biopsies / blood samples sent to labs, information on hospital outpatient appointments or admissions etc.). We collected information on SACT prescribing and patient outcomes across a range of cancers (including prostate cancer and melanoma), and compared the information obtained through electronically linking records using patient CHI numbers, with the information that we could get from patient records to see if it would provide the same information. For this, we chose to focus on patients in the West of Scotland.



What Did We Learn?

We successfully linked up different electronic healthcare databases to get useful information on treatment outcomes for patients (see the Prostate Cancer and Melanoma Studies below to see what kind of information we obtained).

We did identify some gaps in the data and we hope to be able to improve these.

There are differences between the patients who receive SACT in routine care compared to those as part of a clinical trial, which we expected. This might explain why the results we see in the real world are not always the same as in the clinical trial results.

It is really important to continue to monitor the safety and benefits of cancer medicines once they become routinely available.

What Does This Mean for Me?

We have shared some of the results so far with the healthcare teams involved in the cancer areas included in these studies. There is a chance that they may discuss these results with you, but the results of this study should not negatively impact your treatment options.

STUDY 1: Prostate Cancer

What Did We Do?

What Did We Learn?

- Patients in the real world are different from those in the clinical trials. Of the 261 patients who received treatment in the real world, only about half of them were likely to have been eligible to be included in the clinical trials.
- Also, there were differences in survival rates between clinical trial patients and the patients receiving treatment in the real world.
- However, clinical trials tend to test medicines in fitter and younger patients first whilst in the real world patient group, some were older and less fit. These differences may explain why survival rates are shorter for some patients in the 'real world' compared to clinical trial patients.

STUDY 2: Melanoma

What Did We Do?

What Did We Learn?

- There are differences between those patients receiving each type of SACT compared to patients who participated in clinical trials but again, this is to be expected.
- Patients also experienced different side effects depending on what treatment they received, which is also to be expected. However, potential side effects are always discussed with patients to ensure that they can make the most informed decisions before starting a treatment.

Patient Reported Outcome Measures (PROMs) Studies

What Were Our Aims?

We aimed to understand how patients might provide information on how their medicines impact their quality of life, and how healthcare professionals could use PROMs as part of their routine care.

Medicines can have positive and negative impacts on a patient's quality of life. For example, patients may see improvements in their cancer symptoms but may also experience side effects from treatment. Patients often discuss how their medicines impact their quality of life with their healthcare professionals; however, this information is not always recorded in the patient's health record in a standardised way. This type of information is sometimes referred to as 'patient reported outcome measures' or 'PROMs'. Collecting PROMs can help patients and their healthcare professionals make more shared decisions about treatment; and on a larger scale, help understand the real-world impact of cancer medicines alongside clinical trial information.

STUDY 1: What matters to clinicians, patients and carers when discussing the impact of cancer medicines on quality of life?

What Did We Do?

We **recruited 71 prostate cancer patients and 2 carers** from NHS GGC as well as **21 healthcare professionals** from the West of Scotland to participate in a mixture of questionnaires or group discussions.

From a wide-ranging list of areas of quality of life, we asked them which mattered to them when discussing how their cancer medicines impact on their quality of life.

What Did We Learn?

- A wide range of things matter to patients, carers and healthcare professionals when discussing the impact that cancer treatment has on quality of life, and they mostly agree with each other.
- The broad areas of quality of life important to the healthcare professionals, patients and carers who took part in our study can be seen below:

SYMPTOMS & SIDE EFFECTS

MOOD & EMOTIONS

FUNCTIONALITY & DAY-TO-DAY LIVING

RELATIONSHIPS & SOCIAL LIFE

PATIENT'S INFORMATION NEEDS
(Access to Test Results / Medical Records etc.)

PATIENT-CLINICIAN COMMUNICATION
(Support from Healthcare Professionals etc.)

OVERALL QUALITY OF LIFE

STUDY 2: What would a digital tool look and work like to collect and use PROMs as part of routine cancer care?

Mobile phone apps are becoming increasingly popular for collecting and using PROMs from patients. If patients used an app to record PROMs on how their medicines are impacting their quality of life, those PROMs may be linked directly to the patient's electronic health record. Their healthcare professional could use this standardised PROMs information to make informed decisions by having immediate access through the patient's electronic health record. They could address any concerns a patient may have during their usual clinic appointment.

What Did We Do?

We designed examples of a patient mobile phone app (to collect PROMs), and a healthcare professional "dashboard" (to view the patient's PROMs). In the examples of the patient app, we included the questions that we felt best represented what patients, carers and healthcare professionals felt was important to them in Study 1.

We recruited **35 patients, 1 carer and 15 healthcare professionals** from mostly prostate cancer, gynaecological cancers and melanoma to take part in a mix of interviews, group discussions and online questionnaires. We got their feedback on how the example app and dashboard looked, how useful and easy to use they thought they might be, and if they would be likely to use them.

What Did We Learn?

Patients and carers found it **"quite likely"** that an app would be **easy to use**, **improve their quality of life** and help them **communicate better with their healthcare professional during clinic appointments.**

80%

Patients reported there was **an 80% chance** they would use an app like this for collecting PROMs and would **recommend it to other patients**.

Healthcare professionals also felt viewing patient's PROMs information would **help support the decisions made with patients and carers regarding their treatment**.

70%

Healthcare professionals reported there was a **70% chance of them using the dashboard to view the patients' PROMs information in the clinic** on a regular basis.

Discussing the patient's PROMs (collected through the patient app and viewed on the healthcare professional dashboard) would help **empower patients, improve communication and help patients make shared decisions** with their healthcare professional about their treatment.

End of CMOP Phase 1 Reflections

Successes

- We know we can electronically link health databases to understand very complex patient data. We also developed a good understanding of the types of analyses we used to do this, and their advantages and disadvantages.
- We know more about what matters to patients, carers and healthcare professionals when they are discussing the impact that cancer medicines have on quality of life, and their views on digital solutions for collecting and using PROMs information.

- Key findings have been shared with healthcare professionals, and are already being used to inform some discussions clinicians have with some patients about their treatment. The findings have also helped improve some of the electronic systems clinicians use every day.

Challenges

- The process to access electronic patient data can be both complicated and time consuming.
- Some of the studies had very small patient numbers which affects how the data is analysed. More advanced methods will be needed.
- We would have liked to have spoken to a broader range of patients with different cancers, and more carers too.
- We need to better understand how PROMs information collected through digital solutions (like apps) can be linked with the patient's health record.

What Next for CMOP?

We will continue to share our Phase 1 study findings through presentations, publications and reports. CMOP received funding for Phase 2 which will continue until 2023. We want to build upon the work we have done in Phase 1 by scaling up our studies to include the whole of Scotland or other parts of the UK. We are also trying to overcome the challenges we have mentioned.

Finally…

We wish to thank our sponsor, Scottish Government, all clinicians and staff who have supported this programme, the Scottish Government Digital Health & Care Division Decision Support Programme and Tactuum ©, the NHS GGC safe haven team and the team at eData Research and Innovation Service (eDRIS). The patient health data analysed in CMOP's work is provided by patients and collected by the NHS as part of their routine care and support. We wish to also thank all patients, carers and healthcare professionals who took part or recruited participants for the PROMs studies.

We are looking for previous or current cancer patients, their friends or family carers, and other members of the public to get more involved in the CMOP Programme and share their valuable experience to help shape the work that we do. **If you are interested in how you can help us, please email ggc.cmop@ggc.scot.nhs.uk**

Want to keep up-to-date with what's happening with the CMOP Programme? For all the latest news, follow us on Twitter at **@CMOProgramme** or visit **www.ggcmedicines.org.uk/cmop/** If you have any questions about any of the Phase 1 CMOP studies, please email **ggc.cmop@ggc.scot.nhs.uk**