Creation of the first national linked colorectal cancer dataset in Scotland: prospects for future research and a reflection on lessons learned

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Dr Elizabeth Lemmon
Dr Peter Hall
Mr Steve Clark
Co-authors: Dr Holly Ennis, Professor Robert J Jones, Joy Hay, Professor Roger Halliday, Professor Eva Morris

Part of the UK Colorectal Cancer Intelligence Hub

Better health, better futures

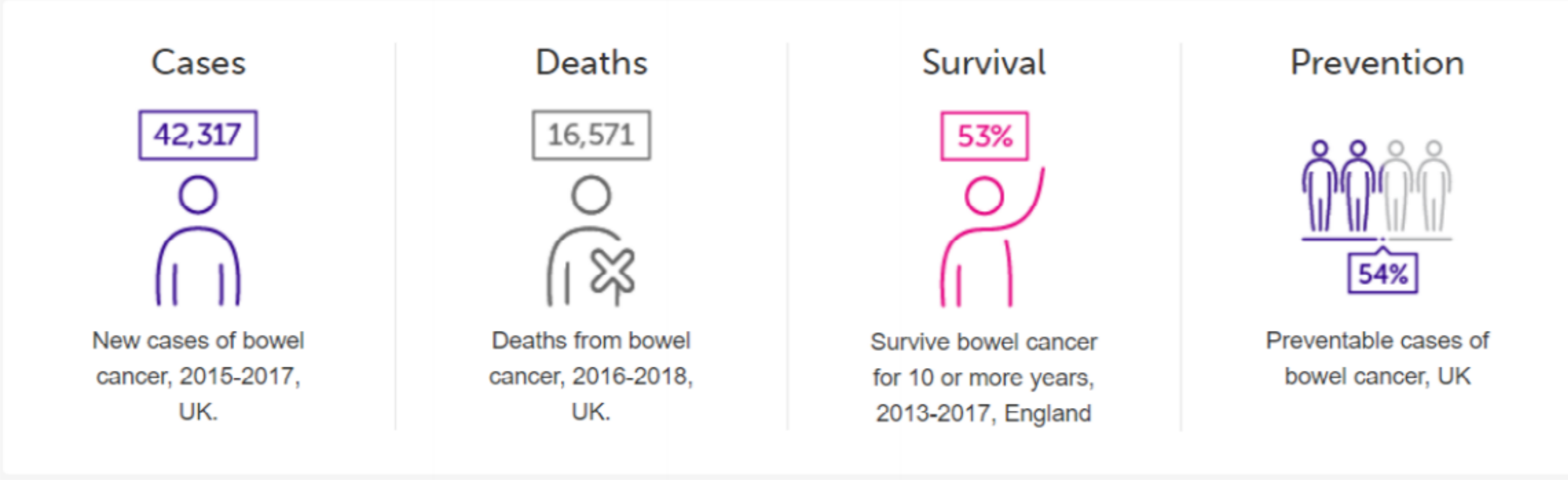
Outline

- **Part I:** Introduction to the project and administrative data landscape in Scotland
- **Part II:** Data acquisition and future recommendations
- **Part III**: Research projects
- **Part IIII**: The patient perspective

Part I

Introduction to the project and administrative data landscape in Scotland

Colorectal Cancer in the UK



Cases

42,317

New cases of bowel cancer, 2015-2017, UK.

Deaths

16,571

Deaths from bowel cancer, 2016-2018, UK.

Survival

53%

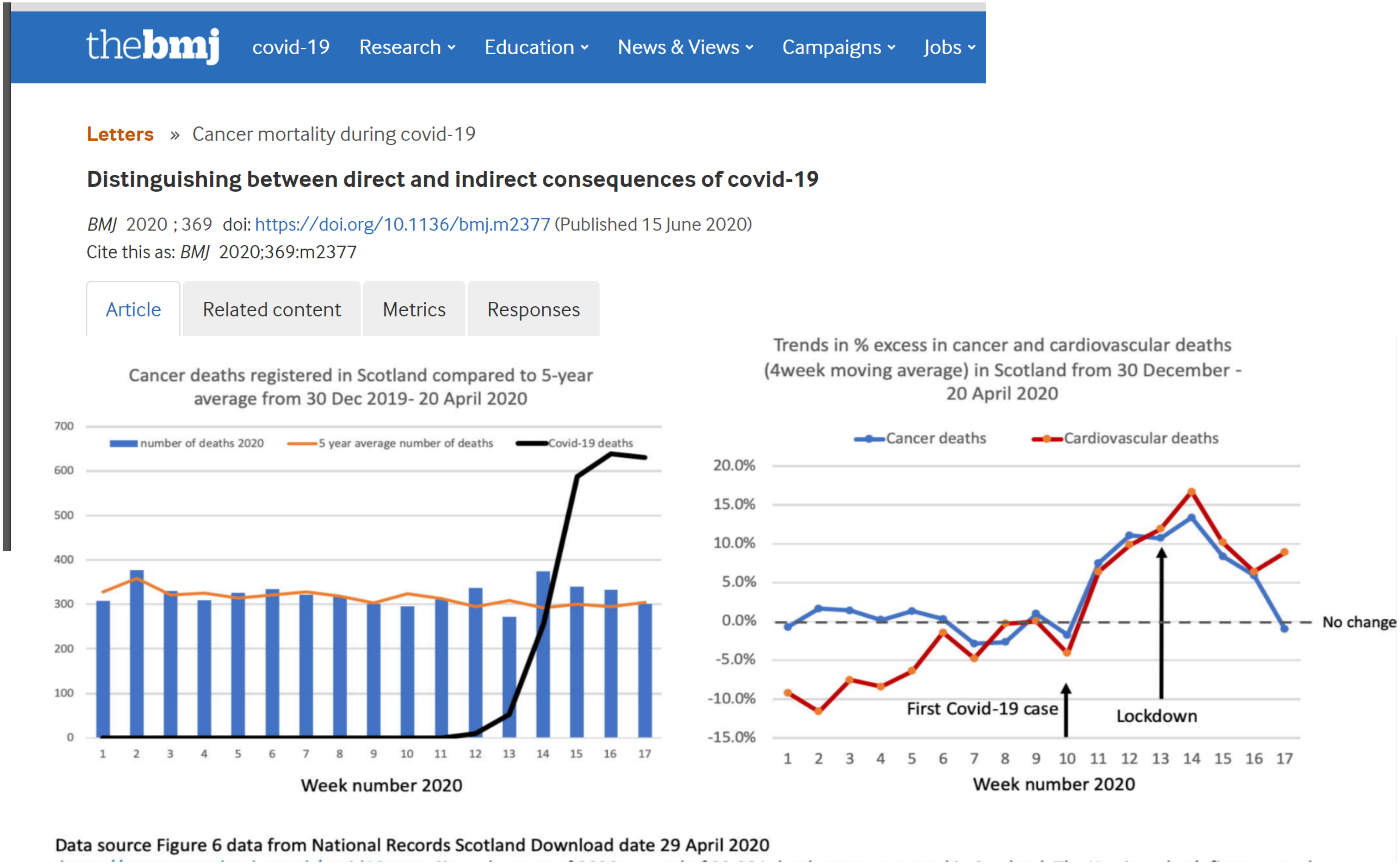
Survive bowel cancer for 10 or more years, 2013-2017, England

Prevention

54%

Preventable cases of bowel cancer, UK

Monitoring Cancer Services during the COVID-19 pandemic



Letters » Cancer mortality during covid-19

Distinguishing between direct and indirect consequences of covid-19

BMJ 2020 ; 369 doi: https://doi.org/10.1136/bmj.m2377 (Published 15 June 2020)
Cite this as: *BMJ* 2020;369:m2377

Cancer deaths registered in Scotland compared to 5-year average from 30 Dec 2019- 20 April 2020

Trends in % excess in cancer and cardiovascular deaths (4week moving average) in Scotland from 30 December - 20 April 2020

Data source Figure 6 data from National Records Scotland Download date 29 April 2020

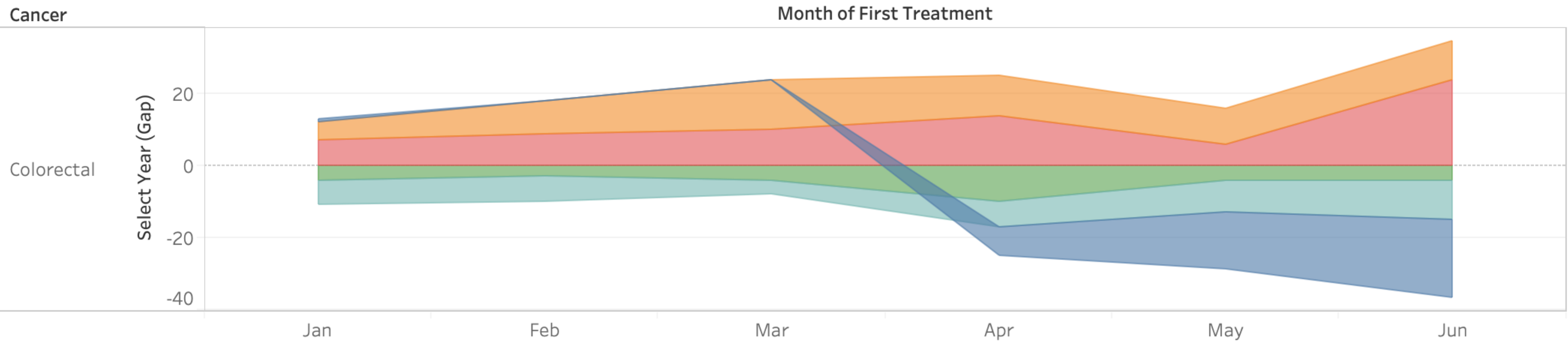
South-East Scotland COLORECTAL CANCER

Source of Referral - Gap

Source of Referral - Cumulative gap between 2020 actual and expected..

Cancer Colorectal
Board of Re.. All
Source of R.. All
Select Com.. 2019

Data shown are sourced from the PHS Cancer Waiting Times Datamart. Total counts of those recieving first treatment in each month may not match counts sourced from QPI Audit Data. As data in this sheet are based on waiting times data, they can be taken as complete. Please see summary sheet for more details.
..



	Month of First Treatment					
Source of Referral	**Jan**	**Feb**	**Mar**	**Apr**	**May**	**Jun**
Total Gap (sources selected only)	**2**	**8**	**16**	**0**	**-13**	**-2**
National Screening	1	0	0	-8	-16	-22
Primary Care (USoC)	5	9	14	11	10	11
Direct Referal	7	9	10	14	6	24
Primary Care (other)	-7	-7	-4	-7	-9	-11
Other	-4	-3	-4	-10	-4	-4

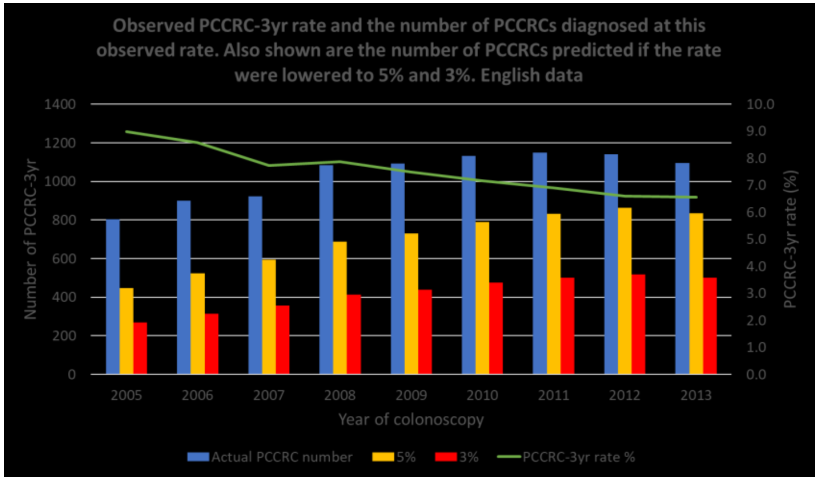
Source of Referral
- 🟦 National Screening
- 🟧 Primary Care (USoC)
- 🟥 Direct Referal
- ■ Primary Care (other)
- 🟩 Other

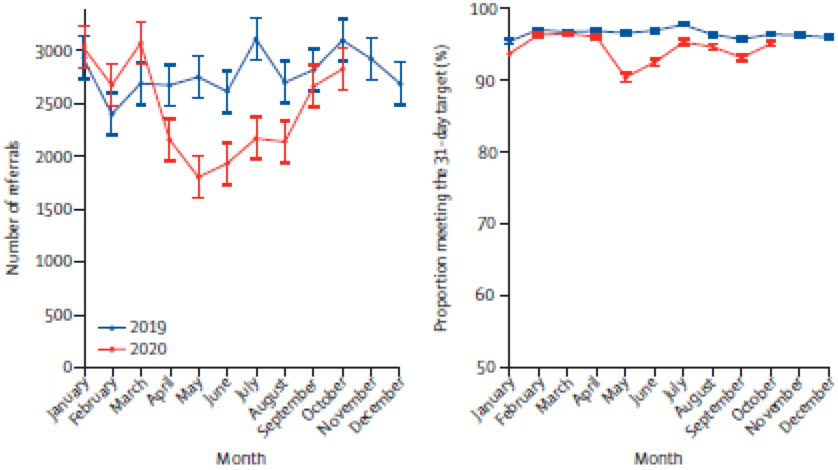
Mission

CANCER
RESEARCH
UK

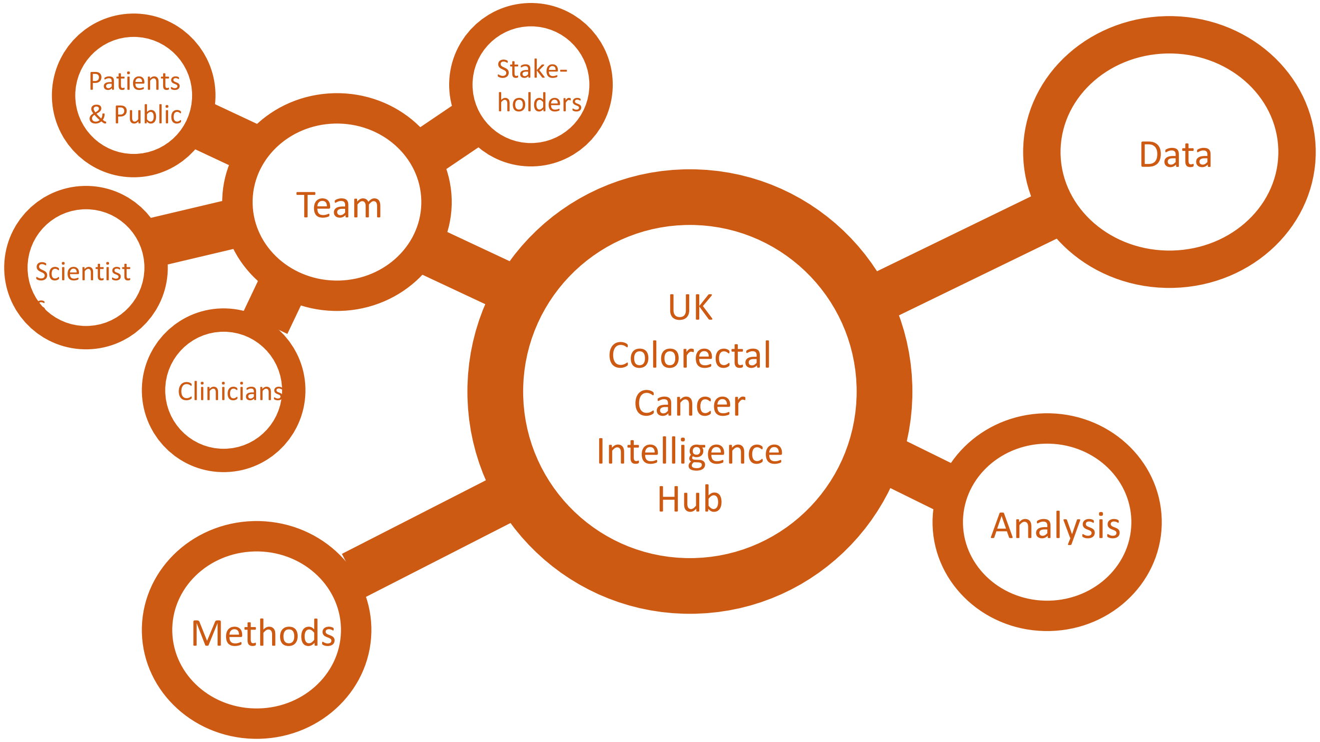
The UK Colorectal Cancer Intelligence Hub is:

- Supporting a rapidly growing and innovative portfolio of research
- Building capacity in population research
- Producing intelligence that is having a direct impact on patient care





UK Colorectal Cancer Intelligence Hub



UK Colorectal Cancer Intelligence Hub

Team

Patients & Public

Stake-holders

Scientists

Clinicians

Data

Analysis

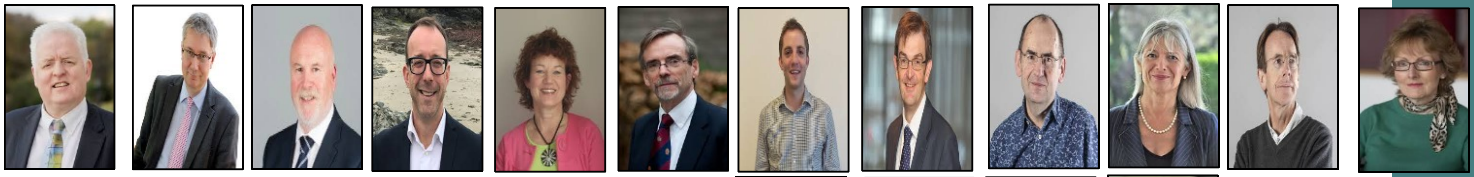
Methods

The Hub Team

Core Hub Team

BCI Bowel Cancer Intelligence

Hub Collaborators



CORECT-R
Trusted Research Environment

- The COloRECTal cancer Repository (CORECT-R)
- https://www.ndph.ox.ac.uk/corectr

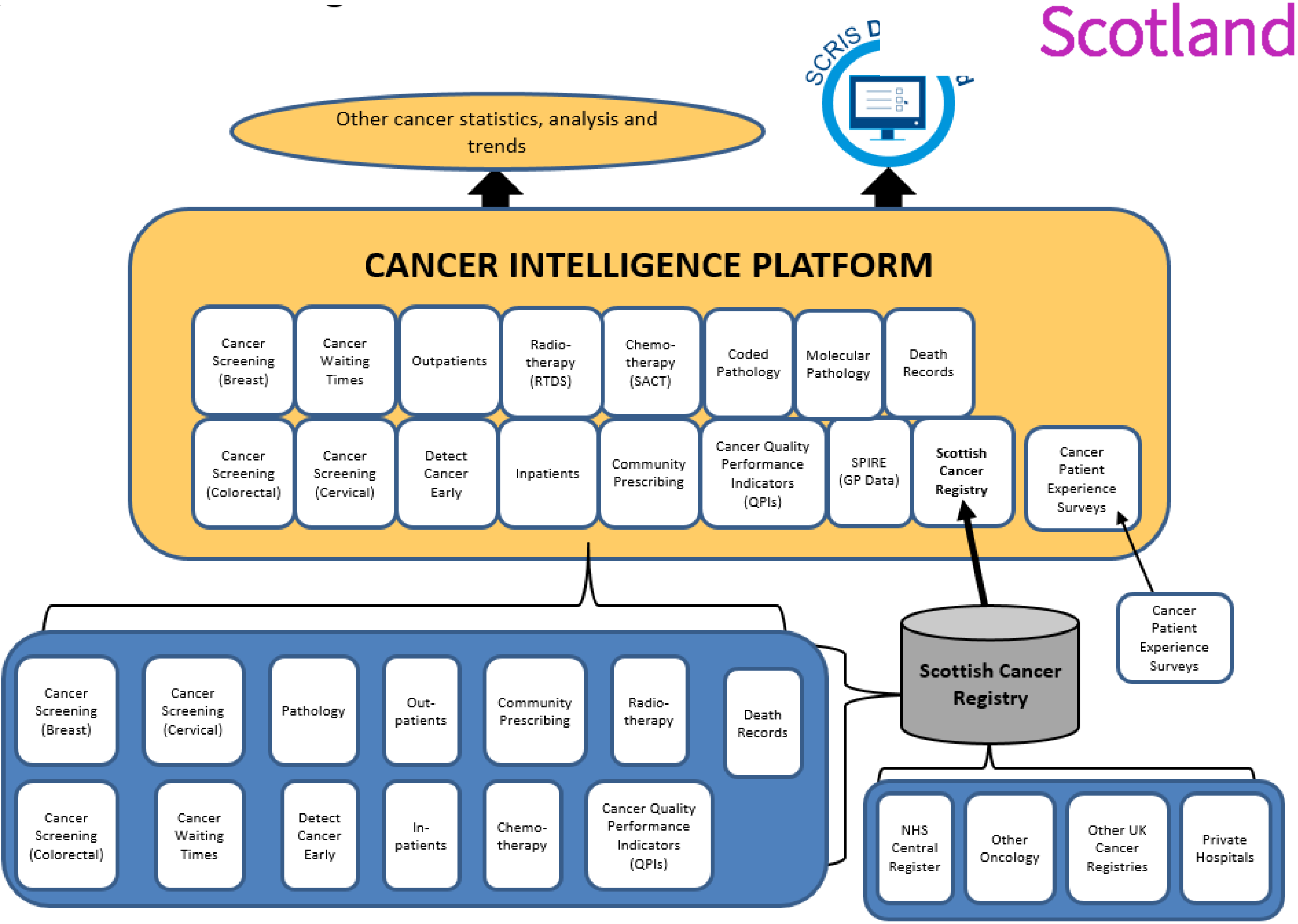
AIMES

Trusted Research Environment

eDRIS (PHS) and the Scottish National Safe Haven

Cancer Intelligence Platform

Public Health Scotland



SCRIS D

Other cancer statistics, analysis and trends

CANCER INTELLIGENCE PLATFORM

Cancer Screening (Breast)
Cancer Waiting Times
Outpatients
Radio-therapy (RTDS)
Chemo-therapy (SACT)
Coded Pathology
Molecular Pathology
Death Records
Cancer Screening (Colorectal)
Cancer Screening (Cervical)
Detect Cancer Early
Inpatients
Community Prescribing
Cancer Quality Performance Indicators (QPIs)
SPIRE (GP Data)
Scottish Cancer Registry
Cancer Patient Experience Surveys

Cancer Screening (Breast)
Cancer Screening (Cervical)
Pathology
Out-patients
Community Prescribing
Radio-therapy
Death Records
Cancer Screening (Colorectal)
Cancer Waiting Times
Detect Cancer Early
In-patients
Chemo-therapy
Cancer Quality Performance Indicators (QPIs)

Scottish Cancer Registry

Cancer Patient Experience Surveys

NHS Central Register
Other Oncology
Other UK Cancer Registries
Private Hospitals

Sources of data accessed by the Cancer Intelligence Platform

Regional data assets

Enhanced granularity

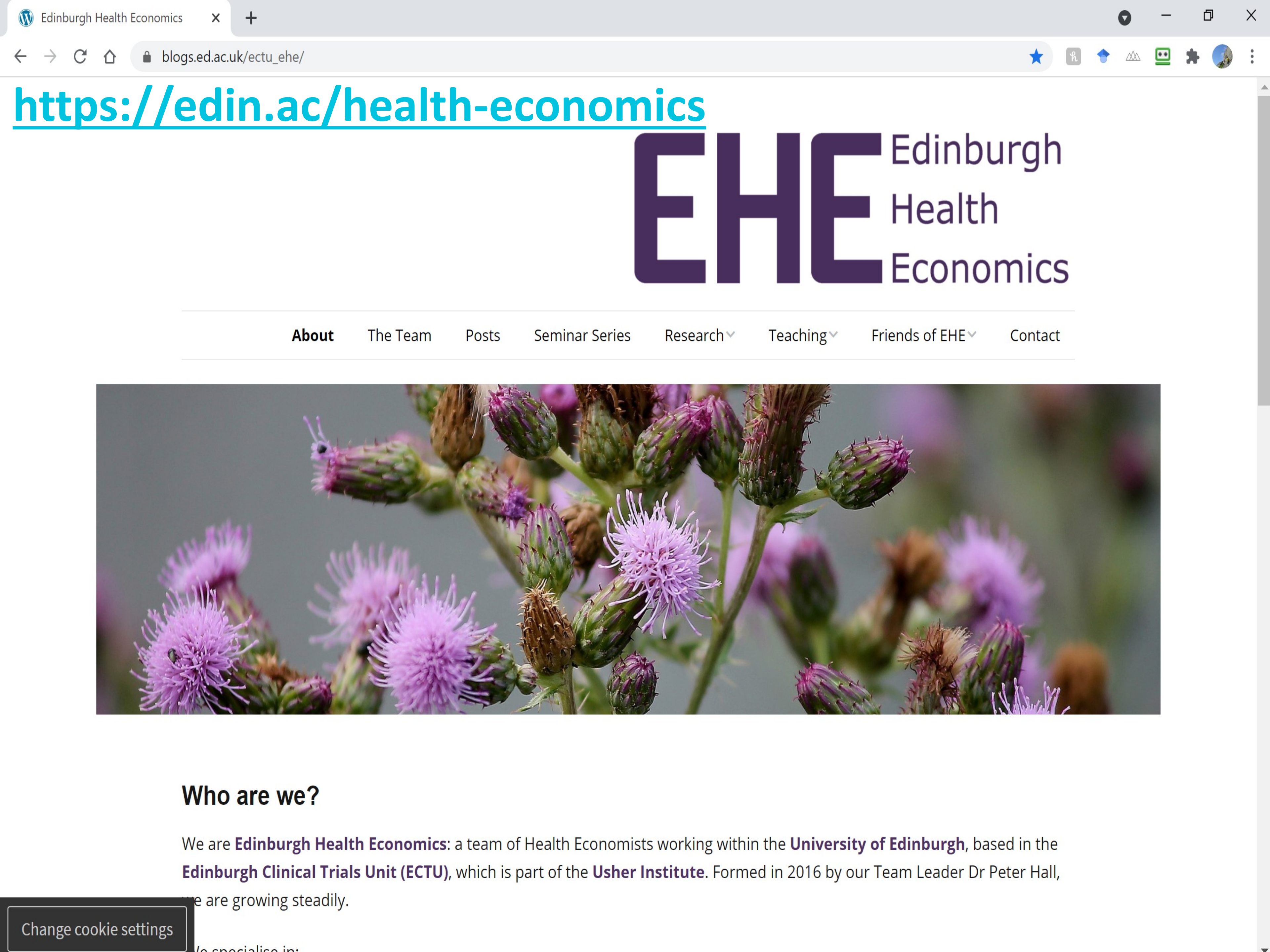
- Chemotherapy prescribing (ChemoCare)
- Radiotherapy (RTDS)
- Surgical administration (ORSOS)
- Clinical genetics
- Labs (SciStore - Heam, biochem, micro)
- Reports (Path, Radiology free text)
- Clinical annotations free text
- Quality performance indicators

CORECT-R in Scotland

- Aim create a population level dataset in Scotland of patients with a diagnosis of CRC.

- Applied analysis

- Toolkit of methods for economic analysis https://edin.ac/health-economics

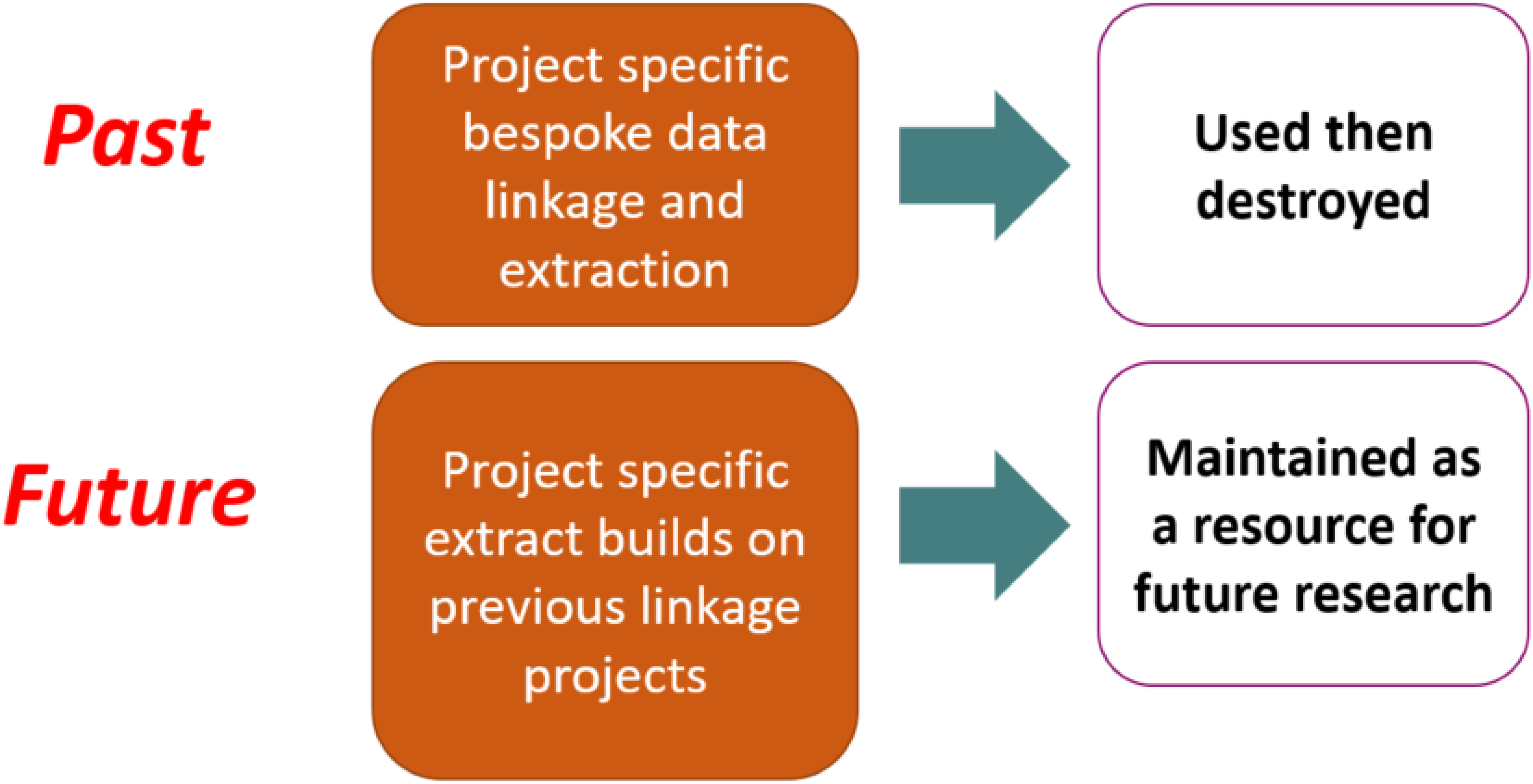


Who are we?

We are **Edinburgh Health Economics**: a team of Health Economists working within the **University of Edinburgh**, based in the **Edinburgh Clinical Trials Unit (ECTU)**, which is part of the **Usher Institute**. Formed in 2016 by our Team Leader Dr Peter Hall, we are growing steadily.

We specialise in:

New culture for data and research



Past

Project specific bespoke data linkage and extraction

Used then destroyed

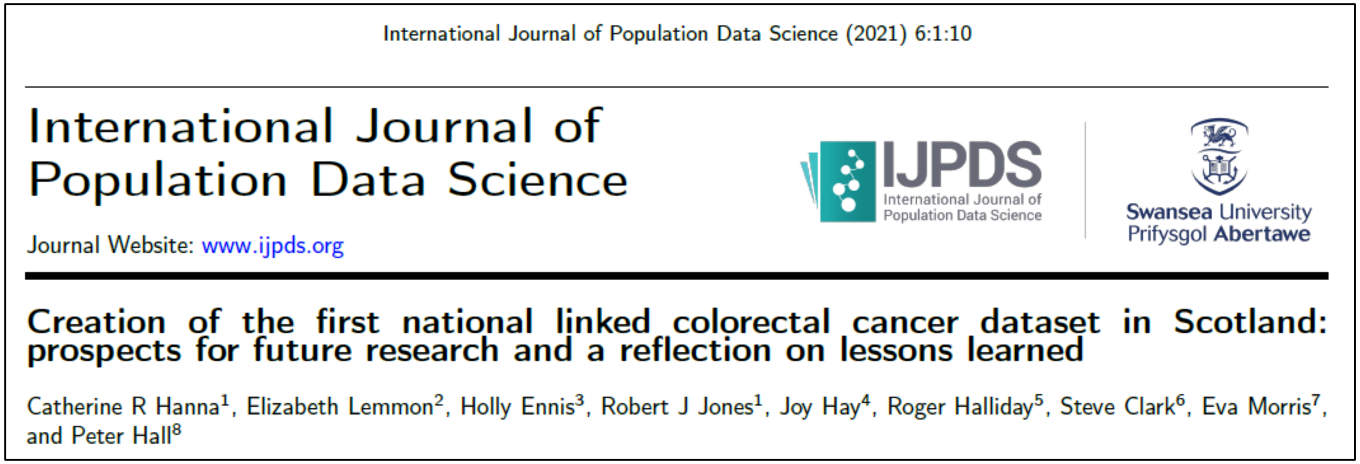
Future

Project specific extract builds on previous linkage projects

Maintained as a resource for future research

Part II

Data curation and recommendations for the future



International Journal of Population Data Science (2021) 6:1:10

International Journal of
Population Data Science

Journal Website: www.ijpds.org

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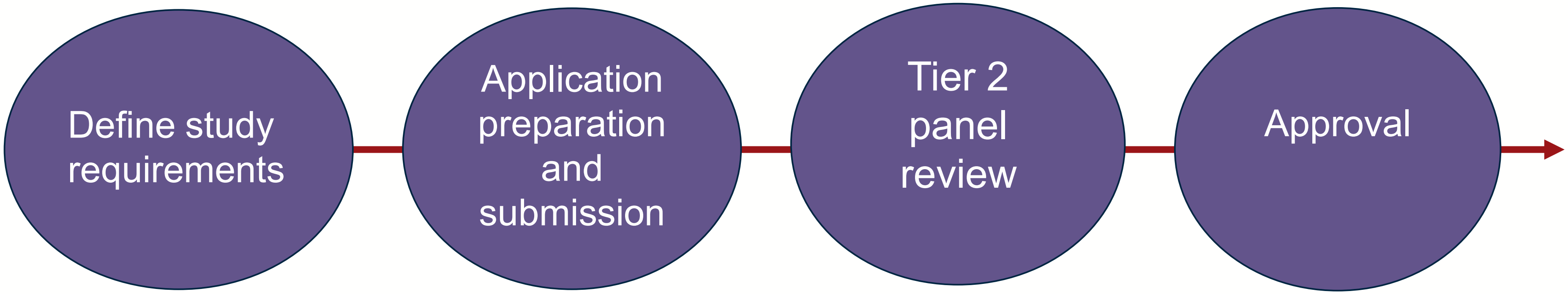
Catherine R Hanna[1], Elizabeth Lemmon[2], Holly Ennis[3], Robert J Jones[1], Joy Hay[4], Roger Halliday[5], Steve Clark[6], Eva Morris[7], and Peter Hall[8]

Applications

- PBPP: Public Benefit and Privacy Panel
- eDRIS: Electronic Data Research and Innovation Service

https://www.informationgovernance.scot.nhs.uk/pbpphsc/


Define study requirements

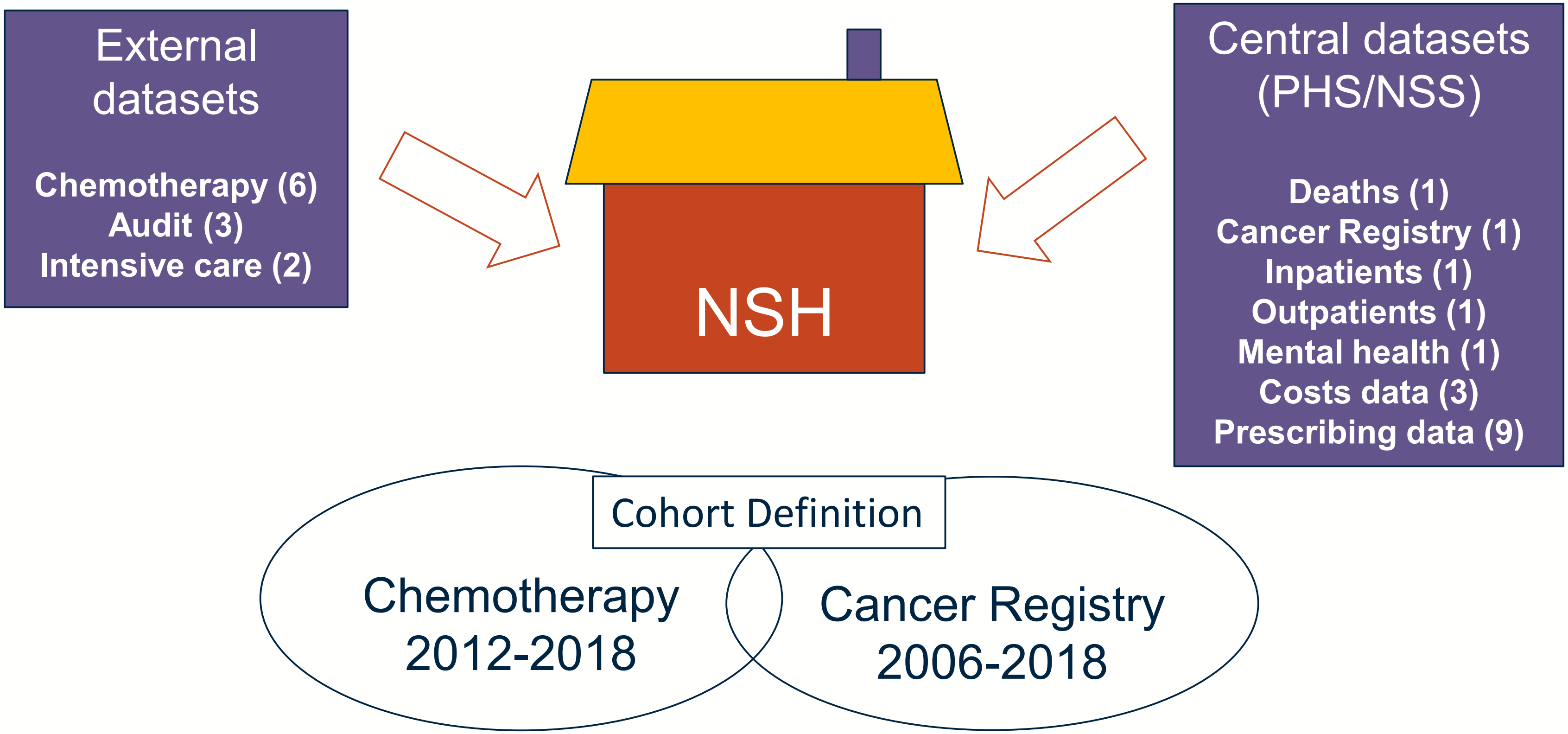
Application preparation and submission

Tier 2 panel review

Approval

- Intensive care data (SICSAG)

Data extraction and transfer



External datasets

Chemotherapy (6)
Audit (3)
Intensive care (2)

NSH

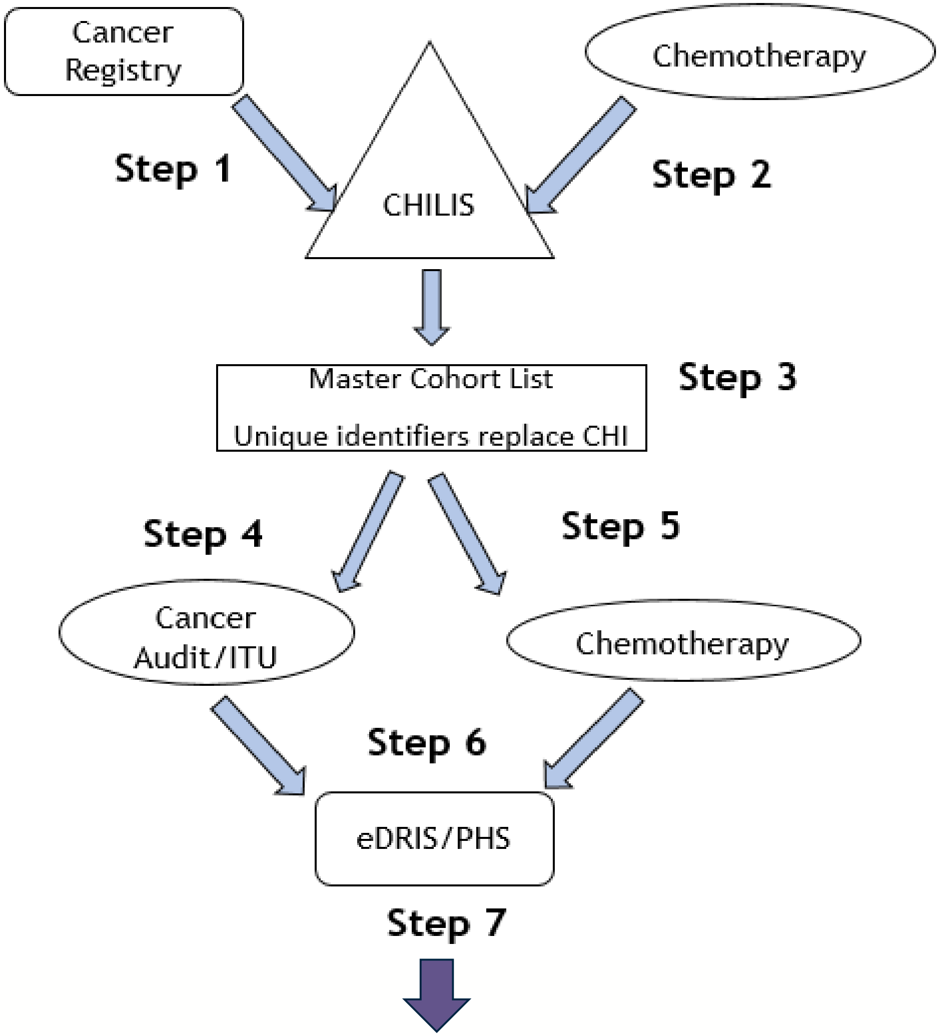
Central datasets (PHS/NSS)

Deaths (1)
Cancer Registry (1)
Inpatients (1)
Outpatients (1)
Mental health (1)
Costs data (3)
Prescribing data (9)

Cohort Definition

Chemotherapy
2012-2018

Cancer Registry
2006-2018



Cancer Registry

Chemotherapy

Step 1

CHILIS

Step 2

Master Cohort List

Unique identifiers replace CHI

Step 3

Step 4

Step 5

Cancer Audit/ITU

Chemotherapy

Step 6

eDRIS/PHS

Step 7

Data linkage and release

N=28 transfers

N=32 datasets

ICU/HDU data

ChemoCare WoS

ChemoCare SCAN

ChemoCare Highlands

ChemoCare Tayside

ChemoCare Grampian

CORECT-R Scotland

QPI SCAN

QPI NoS

QPI WoS

Outpatients

Inpatients

Cancer Registry

NRS Deaths

Unscheduled care

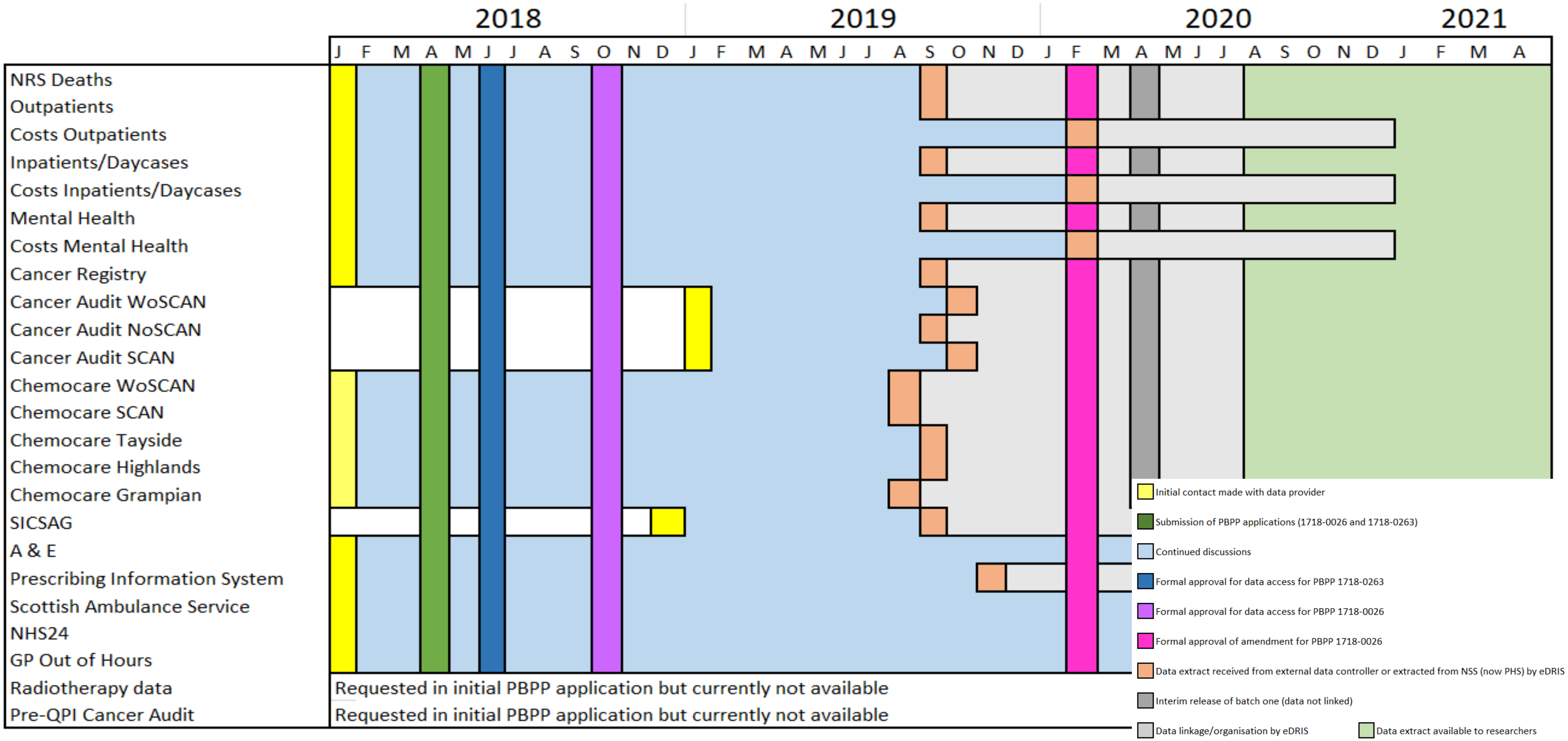
Prescribing Information System

Mental Health

Costing data (PLICS)

Radiotherapy

Data acquisition timeline



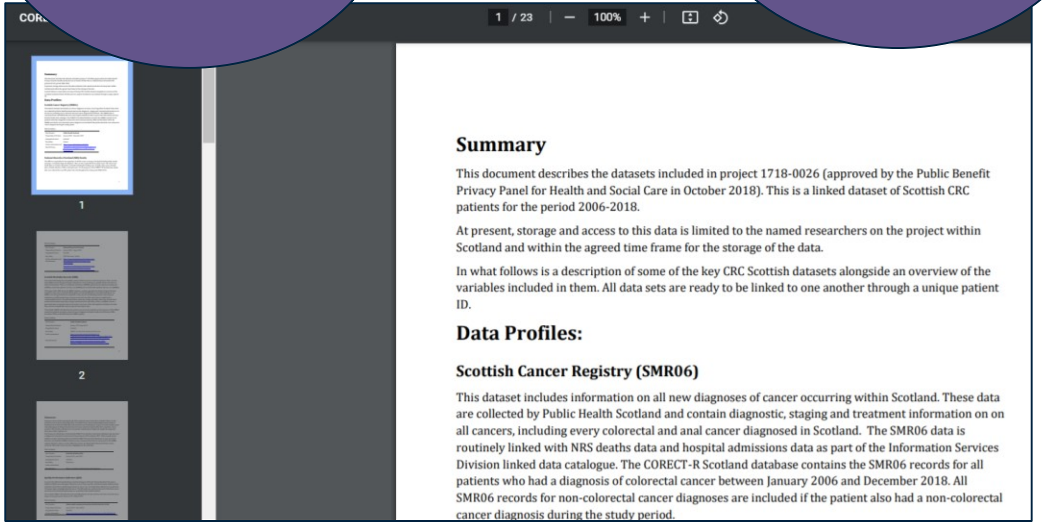
- 🟨 Initial contact made with data provider
- 🟩 Submission of PBPP applications (1718-0026 and 1718-0263)
- 🟦 Continued discussions
- 🟦 Formal approval for data access for PBPP 1718-0263
- 🟪 Formal approval for data access for PBPP 1718-0026
- 🟪 Formal approval of amendment for PBPP 1718-0026
- 🟧 Data extract received from external data controller or extracted from NSS (now PHS) by eDRIS
- ⬛ Interim release of batch one (data not linked)
- ⬜ Data linkage/organisation by eDRIS
- 🟩 Data extract available to researchers

Recommendations

Data dictionaries

Staff capacity

Data transfer platform



Summary

This document describes the datasets included in project 1718-0026 (approved by the Public Benefit Privacy Panel for Health and Social Care in October 2018). This is a linked dataset of Scottish CRC patients for the period 2006-2018.

At present, storage and access to this data is limited to the named researchers on the project within Scotland and within the agreed time frame for the storage of the data.

In what follows is a description of some of the key CRC Scottish datasets alongside an overview of the variables included in them. All data sets are ready to be linked to one another through a unique patient ID.

Data Profiles:

Scottish Cancer Registry (SMR06)

This dataset includes information on all new diagnoses of cancer occurring within Scotland. These data are collected by Public Health Scotland and contain diagnostic, staging and treatment information on on all cancers, including every colorectal and anal cancer diagnosed in Scotland. The SMR06 data is routinely linked with NRS deaths data and hospital admissions data as part of the Information Services Division linked data catalogue. The CORECT-R Scotland database contains the SMR06 records for all patients who had a diagnosis of colorectal cancer between January 2006 and December 2018. All SMR06 records for non-colorectal cancer diagnoses are included if the patient also had a non-colorectal cancer diagnosis during the study period.

https://blogs.ed.ac.uk/ectu_ehe/wp-content/uploads/sites/769/2020/12/Data_Dictionary.pdf

Recommendations

Trusted
Safe Haven

AIMES

Intelligent Data Solutions

Improving the efficiency, reliability and security of data

Public Health Scotland

Data and intelligence

Previously ISD Scotland

Use of the National Safe Haven

eDRIS

Recommendations

Trusted Safe Haven

Location of datasets

Resources

AIMES

Intelligent Data Solutions

Improving the efficiency, reliability and security of data

Public Health Scotland

Data and intelligence

Previously ISD Scotland

Use of the National Safe Haven

eDRIS

Resources

Funders for data	Research Personnel	Data access Personnel
£47,924 (charity funds) to eDRIS for data linkage and access	Principal investigator Postdoctoral fellow Project manager PhD Fellow	eDRIS co-ordinator PBPP panel/panel manager eDRIS data analyst 3 x ChemoCare data controllers 3 x QPI data controllers SICSAG data controller CHILIS staff PHS analyst from PLICS team Unscheduled care team

Major recommendation = data repository

Summary

- Data acquisition
- Challenges
- Recommendations for the future
- Part III

Part III

Research Projects

Patterns in early colorectal cancer treatment and outcomes

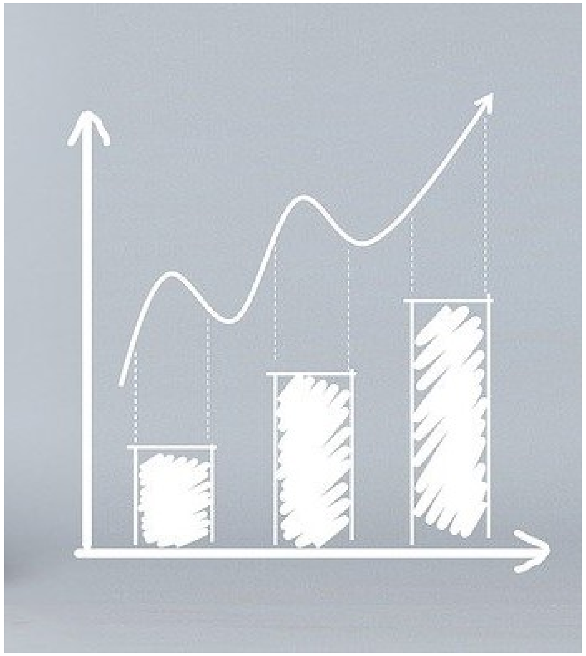
- **Aim**: to provide up to date, population level evidence on patterns in colorectal cancer treatment and survival outcomes in Scotland

- **Motivation and contribution:** Scotland lags behind some of its UK and European counterparts on survival. There are few studies using linked administrative data to study colorectal cancer in Scotland

Methods: Retrospective cohort study, descriptive, Cox proportional hazard regressions

Practice change following a clinical trial on chemotherapy prescribing

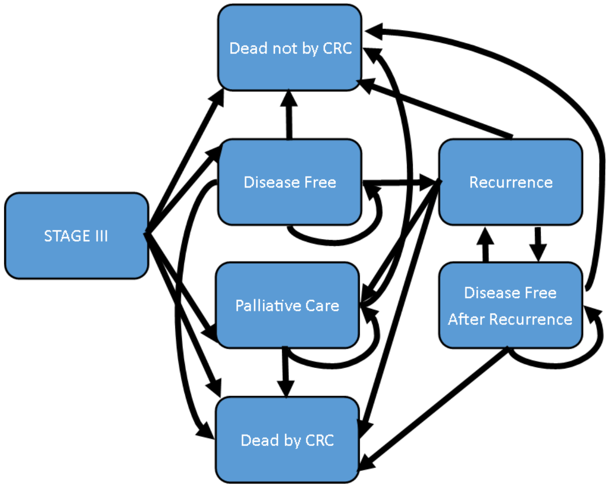
- **Aim**: Examine the impact of the Short Course Oncology Treatment (SCOT) trial results on real world practice
- **Motivation and contribution:** First time linking chemotherapy data to registry on a national scale. Only national study to look at practice change following the trial



Methods: Population retrospective cohort study, regression

An economic model of colorectal cancer

- **Aim**: to create and populate a simple economic model of colorectal cancer. To identify where administrative data can contribute and update the existing evidence.



- **Motivation and contribution:** The data landscape in Scotland

- **Methods**: Simple Markov model

Costing methodologies in health economics

- **Aim:** to implement and compare costing methodologies applied to a colorectal cancer cohort. To provide a framework for future health economic studies.

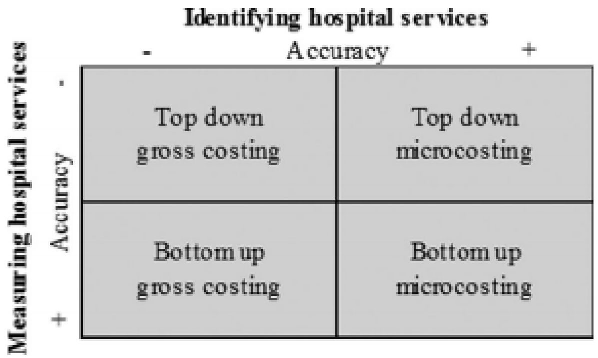


Figure 1. Methods for the cost estimation of healthcare services.
Source: Tan SS, Rutten FF, van Ineveld BM, Redekop WK & Hakkaart-van Roijen L. Comparing methodologies for the cost estimation of hospital services. *Eur J Health Econ.* 2009;10: 39-45 (24)

- **Motivation and contribution**: Lack of consistency and confusion over terminology in current research. No existing colorectal cancer costing in Scotland.
- **Methods:** Scottish costs and national tariff, health care resource groups, patient level information costs (including chemotherapy prescribing)

Post colonoscopy colorectal cancer (PCCRC) rates

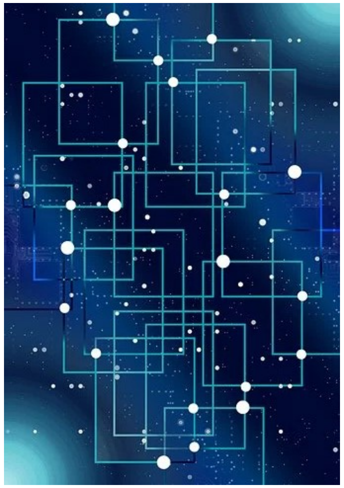
- **Aim**: calculate the PCCRC rate in Scotland, using the methods as proposed in Burr et al. (2019)

- **Motivation and contribution:** No national PCCRC rates available for Scotland. PCCRC is a key indicator of colonoscopy quality.

- **Methods:** Population based retrospective cohort study. Descriptive, logistic regression.

And much more…

- Variation in prescribing
- Inequity in treatment and outcomes
- Social care utilisation
- Data harmonization between Scottish and English data
- Cross country comparisons



Part IIII

The patient perspective

Accessing health data for research – the patient perspective

Steve Clark

Bowel Cancer Intelligence UK
Using information to improve bowel cancer care nationwide

UNIVERSITY OF OXFORD
UNIVERSITY OF LEEDS
THE UNIVERSITY *of* EDINBURGH

Content

- My background
- The Patient Public Group of BCI UK
- Current data accessibility – the patient perspective
- Future implications & questions for the data

My background

- Diagnosed May 2013 with stage 4 colorectal cancer
  - Large primary plus 3 secondaries in liver and 8 in lungs
  - Resection, intense chemo, ablation and maintenance chemo have worked for me
  - NED for past 2 years
- Volunteering with **Bowel Cancer UK** since 2014 and **Cancer Research UK** since 2020
- Set up **Strive for Five** in 2017 to help others with stage 4 bowel cancer
- Became involved in **BCI UK** in 2019 as the concept of using information to improve care is something I believe in

Bowel Cancer Intelligence UK
- the umbrella name for 2 programmes

Bowel Cancer Intelligence UK

Using information to improve bowel cancer care nationwide

UNIVERSITY OF OXFORD · UNIVERSITY OF LEEDS · THE UNIVERSITY *of* EDINBURGH

The UK Colorectal Cancer Intelligence Hub (the Hub)

- Funded by *CRUK*, the Hub is creating a single colorectal research data system: the COloRECTal cancer Repository (CORECT-R).
- Our ambition is for CORECT-R to become the richest population based data resource for colorectal cancer in the world.

The Bowel Cancer Improvement Programme (BCIP)

Funded by *Yorkshire Cancer Research*, BCIP aims to understand the variation in management of bowel cancer for patients across Yorkshire and the Humber.

- The goal is to then improve outcomes by addressing these variations.

www.bci.leeds.ac.uk

Bowel Cancer Intelligence UK - the Patient and Public Group

PPG roles

- Critically appraising research proposals
- Reviewing proposed programme outputs
- Producing, reviewing, approving and communicating reports & summaries

Bowel Cancer Intelligence UK
Using information to improve bowel cancer care nationwide

Accessing data for research – the patient perspective

"WHY IS DATA BEING COLLECTED IF IT ISN'T GOING TO BE FULLY UTILISED?"

- Essential that data is 'joined up', accessible and can be easily interrogated
    - Allows more meaningful studies
    - Trends and patterns in care can be identified
    - Ensures that the same mistakes don't get replicated

- Should be without barriers – devolved nations and local authorities should be connected & integrated in this

- Ultimately, data analysis must inform clinical practitioners on management of their patients – new findings need to be rolled out into clinical practice in a structured way

Questions these data could answer

1. Identifying **hotspots** across the country – good and bad – and addressing the gaps;
2. **Maintenance chemo** for long term care of stage 4 – what regimens get best balance of effect and lifestyle;
3. Impact of different **support programmes** on treatment success and tolerability;
4. Clear evidence to help drive significant investment to ensure **early diagnosis** of cancer

As patients, we don't have the luxury of time - data needs to be accessed quickly or it might be too late for us.

It's not always about new treatments, we need better use of existing therapies through recognising and sharing best practice.

Future implications

Ultimately need a **united "cancer network"** for whole of UK

- Foundation for research
- Informs clinical decision making
- Ensures best practice – patients getting access to the right treatment for them regardless of their location
- Increased efficiency through reduced bureaucracy caused by fractured datasets

Establishing, maintaining and increasing awareness of **CORECT-R**, a single, coordinated linked database, is essential and urgent

- Not just for research, but for clinical decision making too

Involve **informed patients** / PPG at design stage for studies

A final thought for designing studies – please remember

We are patients … **but we are people first and foremost**

Bowel Cancer Intelligence UK
Using information to improve bowel cancer care nationwide

Bowel Cancer Intelligence UK
Using information to improve bowel cancer care nationwide

STRIVE FOR FIVE
TO BEAT BOWEL CANCER

www.bci.leeds.ac.uk
@BCI_UK

www.striveforfive.org
@striveforfiveBC

Summary

- The wider project and data landscape in Scotland
- Lots of challenges in getting the dataset set up
- But also lots of learning to take forward
- Things are changing for the better
- There is a huge potential for carrying out research that benefits patients

Thank you! Questions?

- Peter Hall: p.s.hall@ed.ac.uk
- Catherine Hanna: catherine.hanna@glasgow.ac.uk
- Elizabeth Lemmon: elizabeth.lemmon@ed.ac.uk
- Steve Clark: steve@striveforfive.org