

## Scottish HepatoPancreatoBiliary Network (SHPBN)

#### Volume 1 Issue 2

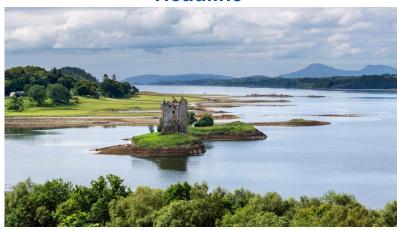
#### Inside this issue:

Headline	1
Forthcoming Scottish HPB Event	1
Vacancy / Best Supportive Care	2
Collaboratives—update	3
Charity Corner	4/5
National Clinical Trials	6/7
Forthcoming Events	8
Membership lists	9-13
Trends in Incidence	14

#### Special points of interest:

- National SHPBN Education Event 2020
- Collaborative Working
- Clinical Trials Update
- New Clinical Director for HPB Cancer in North Cancer Alliance

#### Headline



Welcome to the second issue of the SHPBN Newsletter.

The newsletter will be published biannually and if you have any news that you feel would be of interest to the network members please let us know and we will include in subsequent editions.

I would like to take this opportunity to thank everyone for their enthusiasm in moving the network forward and to all those who are supporting the collaborative working groups and the formal review of the HPB Cancer Quality Performance Indicators (QPIs)

Ms Anya Adair

Consultant Surgeon at Edinburgh Royal Infirmary and SHPBN's Clinical Lead

### **Forthcoming Event**

The Scottish HPB educational meeting will be held in Glasgow on *Friday 17th January 2020*.

The event will focus on the National questionnaires reviewing of current services across Scotland for the management the Colorectal Liver Metastases, Hepatocellular and Pancreatic Cancer that were carried out this year. These will formally be presented with an opportunity to discuss.

#### **Vacancy**

Scottish HepatoPancreatoBiliary Network (SHPBN) is looking for an enthusiastic motivated Clinical Nurse Specialist to improve support for Hepatocellular Cancer (HCC) patients across Scotland.

A five month secondment for an experienced Clinical Nurse Specialist (CNS) to undertake a structured review of current CNS and key worker provision for HCC patients in hospitals across Scotland along with setting up an nationwide HCC network for CNS specialists in all fields of health-care.

We are looking for a CNS from a range of specialities e.g. Liver, Upper GI, Surgery ID, Oncology or Palliative Care who would be interested in taking up this role potentially from January to May 2020. Past experience in working with HCC patients would be preferable but not essential.

If you would like further information or are interested in this post please contact: Anya Adair, Clinical Lead for SHPBH—anyaadair@nhs.net / Tel: M: 07968 711417

### **Development of the SHPBN Best Supportive Care Collaborative**

A high proportion of people with hepatobiliary cancer are unable, or choose not to, receive cancer treatment (including surgery and chemotherapy). This is often because their cancer is very advanced at diagnosis, and/or because they are too weak and frail to cope with cancer treatment. Care for people in this category is often termed 'best supportive care'. Best supportive care encompasses several aspects of care, such as honest and sensitive conversations about the diagnosis and what it means, symptom management, planning for the future and support for families and carers.

People with hepatobiliary cancers who are for best supportive care often have troublesome symptoms, such as pain, low energy, poor appetite and nausea. They are also at risk of complications arising from the cancer such as jaundice and infections. These factors mean that they can often require hospital admission, even though many people are keen to avoid this if at all possible. For most people, maintaining quality of life and independence, even as their illness gets more advanced, is the priority. Best supportive care aims to support these important aims.

Best supportive care is provided by a range of professionals including specialist cancer nurses, surgeons, oncologists, palliative care teams and people's own GPs and district nurses. Many people with hepatobiliary cancer receive good care and support from their usual care teams. However, there are currently no minimum standards of best supportive care. What this means is that some patients and those close to them can miss out on the honest conversations, symptom control, planning ahead and family/carer support that they need and deserve because it is not considered a mandatory or essential part of a person's care.

We are working with a multidisciplinary group of clinicians across Scotland to develop minimum standards of care for people with hepatobiliary cancers who are for best supportive care. Alongside this, we plan to test a working model of best supportive care, to check that it is possible to deliver. We aim to ensure that all people with hepatobiliary cancers who are for best supportive care have access to the best possible care.

Membership of this group is detailed on page 11 and if anyone else is interested in joining this group please contact Lindsay Campbell at: lindsay.campbell@nhs.net

#### Colorectal Cancer Liver Metastases (CRCLM) Cancer

Baseline audit with Colorectal MDTs completed data capture and analysis to be presented at the 17th January 2020 education event by Professor Ewen Harrison, Edinburgh Centre.

Referral form to Glasgow HCC MDT being developed in partnership with Edinburgh Centre

#### **Pancreatic Cancer Collaborative**

Survey of hospitals across Scotland nearing completion and analysis to be presented at the 17th January 2020 education event by Mr Ross Carter, Glasgow Centre.

The referral form to the Glasgow PB MDT has been developed and is being utilised by eHealth to design the new MDT application for the West of Scotland.

### **Hepatocellular Carcinoma Collaborative**

At the British Society of Gastroenterology (BSG) UK annual national meeting NHS Greater Glasgow and Clyde presented our Surveillance data for HCC (increasing year on year and associated with improved outcomes). Data has been combined with NHS Lothian and are in the process of preparing a paper for publication on this topic.

(Please see appendix at end of newsletter for full poster presentation)

#### **Charity Corner**

#### **British Liver Trust**

The British Liver Trust, is the largest UK liver charity for adults and we lead the fight against liver disease and liver cancer.

#### **Support Groups**

British Liver Trust currently manages and facilitates 12 liver support groups across Scotland. There are a variety of different groups from general liver groups, genetic/autoimmune, Hepatitis C to pre & post liver transplant groups.

These groups run in Edinburgh, Forth Valley, Dundee, Glasgow, Aberdeen and more recently Inverness and Ayr. Meeting face to face is valuable because it allows patients and family members to speak to others and share experiences. Patients find these support groups a real lifeline.



#### **National Lottery Community Fund**

The National Lottery Community Fund recently awarded British Liver Trust a 2-year grant to extend our work in Scotland. This funding will enable us to:

- Expand the number and frequency of groups on the east coast across the Central, Lothian and Borders regions;
- Expand the number and frequency of groups on the west coast across Strathclyde and Dumfries and Galloway regions; and
- Create a new network of liver patient support groups across the Highlands and Islands and Grampian regions.

Two new part time support group facilitators have joined the team in Scotland to help carry out this work. Gillian McLeod has taken the role of support group facilitator for Glasgow and the West Coast and Eden Reid has taken the role of support group facilitator for Highlands and Grampian.

If you would like any information on any of British Liver Trust's Scotland work please get in touch with **Amy Caffrey** at the **British Liver Trust** (amy.caffrey@britishlivertrust.org.uk).

### **Charity Corner**

#### Pancreatic Cancer UK

#### Dawn Crosby, Head of Scotland

Dawn has over 13 years experience in the third sector in Scotland, coming from Teenage Cancer Trust where she built the presence and activity of the charity, working closely with the NHS, Scottish Government, funders and other partners to ensure that young people's voices were heard, their age appropriate needs were met - ultimately reaching every young person with cancer wherever they were diagnosed in Scotland.

In her role as **Head of Scotland** for Pancreatic Cancer UK, Dawn will ensure that the charity's work is appropriately tailored to meet the needs of people affected by pancreatic cancer in Scotland. Her key focus will be to establish the charity's presence and profile in Scotland working to engage with key stakeholders to increase service presence, influence to improve treatment and care, increase research collaboration and work closely with existing and future supporters. Dawn can be contacted on M: 07967 300875.

#### New Easy Read booklets about pancreatic cancer now available

Pancreatic Cancer UK have produced a series of new easy read booklets about pancreatic cancer, explaining how the cancer is diagnosed, the possible treatments, and how symptoms managed.

Easy read uses pictures and simple words, and are useful for anyone who struggles with written information. It is a format that can be helpful for people with lower health literacy, people with learning disabilities, or people who don't speak English as a first language.

These new booklets have been produced in conjunction with a specialist accessible information agency. People with learning disabilities were involved in producing the booklets, and testing them.



#### The series includes:

- Pancreatic cancer What is it? How is it diagnosed?
- Pancreatic cancer Surgery to remove pancreatic cancer
- Pancreatic cancer Treatment if you can't have surgery
- Pancreatic cancer Treating symptoms and getting support

If these booklets would be suitable for any of your patients, you can download and order them for free from our website: pancreaticcancer.org.uk/publications

#### **National Clinical Trials**

Our thanks to Alan Christie, Consultant Medical Oncologist who is leading on a list of National Clinical Trials available in Scotland.

#### **PANCREATIC CANCER**

Peri-Operative / Adjuvant Locally Advanced

SCALOP-2 (Click HERE for info) 1st Line Metastatic 2nd Line Metastatic Supportive Care

**ABERDEEN** 

DUNDEE

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PRIMUS 001 (Click <u>HERE</u>

**EDINBURGH** 

PRIMUS 002 (Click HERE for info) Pending

MENAC (Click <u>HERE</u> for info) PRIMUS 001 (Click HERE for info) Pending

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#### **National Clinical Trials**

#### **HEPATOCELLULAR CARCINOMA**

Advanced

1st Line Metastatic

CHECKMATE-

(Click HERE for info) **Pending** 

9DW

2nd Line

Supportive

**EDINBURGH** 

**GLASGOW** 

TACE-3

for info)

(Click HERE **Pending** 

TACE-3 (Click HERE for info) **Pending** 

**LEAP-002** 

(Click HERE for info)

**MEDIVIR** MIV-818-101/201 (Click HERE

**OUTREACH** (Click HERE for info) **Pending** 

AFPc332T **Cell Therapy** (Click HERE for info)

#### **SMALL BOWEL CARCINOMA**

**GLASGOW** 

**BALLAD** (Click HERE for info)

**BILIARY TRACT CANCER** 

ABERDEEN

**KEYNOTE-966** 

(Click HERE for info)

**Pending** 

FIGHT-302 (Click HERE

for info) **Pending** 

**EDINBURGH** 

**ACTICCA-1** (Click HERE for info)

**GLASGOW** 

**ACTICCA-1** 

(Click HERE for info)

ABC-07 (Click HERE

for info)

TOFFEE (Click HERE

for info)

**MEDIVIR MIV** -818-101/201

(Click HERE for info)

#### **Future Events**

British Transplant Society, Wednesday 4th March - Friday 6th March 2020, Belfast

https://bts.org.uk/events-meetings/bts-annual-congress-2020/

HCC-UK Friday 13th and Saturday 14th March, 2020, London



We would like to offer our congratulations to Mr Stephen McNally who has been appointed as HPB Clinical Lead for North Cancer Alliance (NCA).

"I'm delighted to have recently taken up the post as Clinical Director for HPB Cancer for the North Cancer Alliance. The NCA has been established to take the lead for collaboration and planning for HPB cancer provision across the North of Scotland. This covers 6 different health boards (Western Isles, Shetland, Orkney, Grampian, Tayside and Highland). Our focus is on establishing a model of care which is sustainable across the whole of the North. My first challenge in the post is to work out how we can work more collaboratively to provide the best possible care for our patients".

Mr Stephen McNally



Our new website will be going live in the next couple of weeks

If you have any further information you would like to include can you please email to

Lindsay Campbell

Managed Clinical Network National Manager for HepatoPancreatoBiliary

Lindsay.campbell@nhs.net

## **SHPBN Steering Group**

Name	Specialty	Unit	Region	Role
Anya Adair	Surgery	Edinburgh	Scotland	SHPBN Clinical Lead
Irfan Ahmed (Professor)	Surgery	Aberdeen	NCA	Aberdeen Centre Lead
Umesh Basavaraju	GI/EUS	Aberdeen	NCA	PC Collaborative Representative
Lindsay Campbell	MCN Management		Scotland	SHPBN National MCN Manager
Ross Carter	Surgery	Glasgow	WoSCAN	PC Collaborative Representative
Lorraine Cowie	Management	North of Scot-	NCA	Regional Manager (Cancer)
Euan Dickson	Surgery	Glasgow	WoSCAN	Glasgow Centre Lead
Jim Gordon-Smith	Interventional Radiology	Edinburgh	SCAN	HCC Collaborative Representative
Tim Gordon-Walker	Hepatology	Edinburgh	SCAN	HCC Collaborative Representative
Janet Graham	Oncology	Glasgow	WoSCAN	CRCLM and HCC Collaboratives Representative
Ewen Harrison	Surgery	Edinburgh	SCAN	CRCLM Collaborative Representative
Andrew Healey	Surgery	Edinburgh	SCAN	Edinburgh Centre Lead
James Mander	Surgery / SCAN Clinical Lead	Edinburgh	SCAN	CRCLM Collaborative Representative
Andrew McMahon	Surgery	Glasgow	WoSCAN	CRCLM Collaborative Representative
Stephen McNally	Surgery	Inverness	NCA	Inverness Centre Lead
Les Samuel	Oncology	Aberdeen	NCA	CRCLM Collaborative Representative
Adrian Stanley	Hepatology	Glasgow	WoSCAN	HCC Collaborative Representative
lain Tait	Surgery	Dundee	NCA	Dundee Centre Lead
Evelyn Thomson	Management	West of Scot- land	WoSCAN	Regional Manager (Cancer)
Lucy Wall	Oncology	Edinburgh	SCAN	PC Collaborative Representative

Updated November 2019

## **SHPBN Pancreatic Cancer Collaborative**

Name	Specialty	Unit	Region
Hugh Brown	General	Co-Chairs - Scottish Primary	Scotland
Lorna Porteous	Practitioners	Care Cancer Group	
Christoph Kulli	Surgery	Dundee	NCA
Stephen McNally	Surgery	Inverness	NCA
James Milburn	Surgery	Aberdeen	NCA
lain Tait	Surgery	Dundee	NCA
Andrew Healey	Surgery	Edinburgh	SCAN
Rajan Ravindran	Surgery	Edinburgh	SCAN
Ross Carter	Surgery	Glasgow	WoSCAN
Euan Dickson	Surgery	Glasgow	WoSCAN
Asa Dahle-Smith	Oncology	Dundee	NCA
Walter Mmeka	Oncology	Inverness	NCA
Adnan Shaukat	Oncology	Aberdeen	NCA
Lucy Wall	Oncology	Edinburgh	SCAN
Derek Grose	Oncology	Glasgow	WoSCAN
Mark White	Oncology	Glasgow	WoSCAN
Umesh Basavaraju	GI/EUS	Aberdeen	NCA
Elaine Henry	GI/EUS	Dundee	NCA
Neil Jamieson	GI/EUS	Inverness	NCA
Sandeep Siddhi	GI/EUS	Aberdeen	NCA
Ian Penman	GI/EUS	Edinburgh	SCAN
Jack Straiton	Radiology	Aberdeen	NCA
Abdullah Al-Adhami	Radiology	Glasgow	WoSCAN
Vicki Save	Pathology	Edinburgh	SCAN
Fraser Duthie	Pathology	Glasgow	WoSCAN
Jo Bowden	Palliative care	Fife	SCAN
Angela Rollo	CNS	Aberdeen	NCA
Jake McGhie	CNS	Fife	SCAN
Kimberley Booth	CNS	Glasgow	WoSCAN
Elspeth Cowan	CNS	Glasgow	WoSCAN
Jen Milne	CNS	Glasgow	WoSCAN
Sarah-Jane Thomson	CNS	Glasgow	WoSCAN
	1	1	Continued on next page

# SHPBN Pancreatic Cancer Collaborative Continued

Name	Specialty	Unit	Region
Karen Henderson	Dietetics	Edinburgh	SCAN
Beverley Wallace	Dietetics	Edinburgh	SCAN
Min Bhatta	MDT coordination	Aberdeen	NCA
Georgia Papacleovoulou	Policy and Intelligence Manager	Pancreatic Cancer UK	UK
Rachel Richardson	CNS	Pancreatic Cancer UK	UK
Sarah Bell	PCUK Head of Services	Pancreatic Cancer UK	UK
Fiona Brown	Development Manager	Pancreatic Cancer Scotland	Scotland
Debbie Provan	Clinical Lead for Living with and Beyond Cancer	WoSCAN	WoSCAN

## **SHPBN Best Supportive Care Collaborative**

Name	Role	Region
Amy Caffrey	Scotland Projects Manager	British Liver Trust
Angela Southam	Specialty Palliative Care Dietitian	NHS Fife
Anya Adair	Consultant Surgeon and SHPBN Clinical Lead	NHS Lothian
Dawn Crosbie	Scotland Manager	Pancreatic Cancer UK
Debbie Provan	Clinical Lead for Living with and Beyond Cancer	WoSCAN
Elspeth Cowan	Clinical Nurse Specialist	NHSGGC
Fiona Brown	Development Manager	Pancreatic Cancer
		Scotland
Fiona Finlay	Palliative Care Consultant	NHSGGC
Helen MacDonald	Specialist Palliative Care Nurse	Ayrshire Hospice
Jake McGhie	Clinical Nurse Specialist	NHS Fife
Joanna Bowden	Palliative Care Consultant	NHS Fife
Lindsay Campbell	National MCN Manager	SHPBN
Lorraine Kirkpatrick	Clinical Nurse Specialist	NHS Lothian
Ross Carter	Consultant Surgeon	NHSGGC

Updated November 2019

## **SHPBN Hepatocellular Carcinoma (HCC) Collaborative**

Name	Specialty	Unit	Region
Hugh Brown	General	Co-Chairs - Scottish Primary	Scotland
Lorna Porteous	Practitioners	Care Cancer Group	
Irfan Ahmed	Surgery	Aberdeen	NCA
Mohammad Habib	Surgery	Aberdeen	NCA
Stephen Wigmore	Surgery	Edinburgh	SCAN
James Powell	Transplant	Edinburgh	SCAN
Andrea Broad	Hepatology	Inverness	NCA
Mike Miller	Hepatology	Dundee	NCA
Balasubramaniam Vijayan	Hepatology	Aberdeen	NCA
Tim Gordon-Walker	Hepatology	Edinburgh	SCAN
Tom Bird	Hepatology	Edinburgh	SCAN
Adrian Stanley	Hepatology	Glasgow	WoSCAN
Matthew Priest	Gastroenterologist	Glasgow	WoSCAN
Ishtiaq Zubairi	Oncology	Aberdeen	NCA
Alan Christie	Oncology	Edinburgh	SCAN
Jeff Evans	Oncology	Glasgow	WoSCAN
Shilpi Pal	Interventional Radiology	Dundee	NCA
Jim Gordon-Smith	Interventional Radiology	Edinburgh	SCAN
Hamish Ireland	Interventional Radiology	Edinburgh	SCAN
Ram Kasthuri	Interventional Radiology (TACE)	Glasgow	WoSCAN
David Kay	Interventional Radiology (RFA)	Glasgow	WoSCAN
Mary Galloway	Pathology	Aberdeen	NCA
Tim Kendall	Pathology	Edinburgh	SCAN
Lorraine Kirkpatrick	CNS (HPB)	Edinburgh	SCAN
Rachel Thomson	CNS (HPB)	Aberdeen	NCA
Lorna Bailey	CNS (Liver)	Aberdeen	NCA
Lorna Porteous	General Practitioner	Co-chair Scottish Primary Care Cancer Group	Scotland
Hugh Brown	General Practitioner	Co-Chair Scottish Primary Care Cancer Group	Scotland
Sigrid Hendry	MDT coordination	Glasgow	WoSCAN
Fiona Finlay	Palliative Care	Glasgow	WoSCAN
Amy Caffrey	British Liver Trust		

## **SHPBN** Colorectal Cancer Liver Metastases Collaborative

Name	Specialty	Unit	Region
Appou Tamijmarane	Surgery (HPB)	Inverness	NCA
Ewen Harrison	Surgery (HPB)	Edinburgh	SCAN
Rowan Parks	Surgery/ RCS (Ed)	Edinburgh	SCAN
Francesco Polignano	Surgery (HPB)	Dundee	NCA
Bassam Alkari	Surgery (HPB)	Aberdeen	NCA
Nigel Jamieson	Surgery (HPB)	Glasgow	WoSCAN
James Mander	Surgery (CRC)/SCAN lead	Edinburgh	SCAN
Susan Moug	Surgery (CRC)	Paisley	WoSCAN
David Chong	Surgery (CRC)	Glasgow	WoSCAN
Michael Walker	Surgery (CRC)/MCN lead	Inverness	NCA
Andrew McMahon	Surgery (CRC)/MCN lead	Glasgow	WoSCAN
Satheesh Yalamarthi	Surgery (CRC/MCN lead	Fife	SCAN
Les Samuel	Oncology	Aberdeen	NCA
Janet Graham	Oncology	Glasgow	WoSCAN
Ewan Brown	Oncology	Edinburgh	SCAN
Walter Mmeka	Oncology	Inverness	NCA
Stephen Glancy	Radiology	Edinburgh	SCAN
Lokesh Saraswat	Radiology	Aberdeen	NCA
David Kay	Interventional Radiology	Glasgow	WoSCAN
Graeme Murray	Pathology	Aberdeen	NCA
Linda Sherwood	CNS (CRC)	Edinburgh	SCAN
Jackie Rodger	CNS (CRC)	Dundee	NCA
Laura Copeland	CNS (CRC)	Aberdeen	NCA
Erin McNally	MDT coordination	Edinburgh	SCAN
Lorna Porteous	General Practitioner	Co-chair Scottish Primary Care Cancer Group	Scotland
Hugh Brown	General Practitioner	Co-Chair Scottish Primary Care Cancer Group	Scotland
Kirsty Martin	Audit	SCAN	SCAN
Judith Crawford	Macmillan	Tayside	NCA
Claire Donaghy	Bowel Cancer UK		
Kevin Campbell	MCN Management (CRC)	WoSCAN	WoSCAN

## Trends in the incidence of Hepatocellular Carcinoma in Scotland 2001-2015

Thomas Drake<sup>1,2</sup>, Lindsay Campbell<sup>3</sup>, Peter C Hayes<sup>4</sup>, Ewen M Harrison<sup>1</sup>, Stephen J Wigmore<sup>4</sup>, Anya Adair<sup>5</sup>, Adrian J Stanley<sup>6</sup>, Thomas G Bird<sup>2,4</sup>

1. Surgical Informatics Group, Usher Institute, University of Edinburgh, 2. Cancer Research UK Beatson Institute, 3. Scottish HepatoPancreatoBiliary Managed Clinical Network, 4. School of Clinical Sciences, University of Edinburgh, 5. Royal Infirmary of Edinburgh, NHS Lothian, 6. Glasgow Royal Infirmary, NHS Greater Glasgow and Clyde



Global Health Problem 4th highest cause cancer mortality



274% increase in incidence across Scotland 2001-2015, across all regions



No change in proportion of HCC patients accessing

#### Introduction

Hepatocellular carcinoma (HCC) is the 4th highest cause of cancer mortality worldwide. Rates are increasing in both high and low-middle income countries. If detected early, HCC can be cured by resection or transplant. However, most patients present with advanced disease where treatment with curative intent is not possible.

#### Objective

To examine trends in the incidence and regional disparities in HCC

#### Methods

- We included all patients in Scotland with a diagnosis of Hepatocellular Carcinoma with a C22.0 ICD10 code between the years of 2001 and 2015. We chose this code over all C22 codes due as it is more specific for HCC. A two-step validation process was undertaken to check these diagnoses were accurate; first by checking cases identified against clinical records of those which were likely to be missed and second by checking the ICDO2/3 codes for appropriate diagnosis.
- We extracted population level statistics for the number of adults at the level of each health board region to calculate the standardised incidence rate per 100,000 population. Finally, we used autoregressive integrated moving average modelling (ARIMA) to predict trends in HCC in the next 30 years.

#### Results 3

We found a large 274% increase in HCC incidence across Scotland from 2001 to 2015. This was not confined to specific geographic regions, rather was seen as a uniform rise across all regions. The areas of highest disease burden were Glasgow, Lothian and Lanarkshire. NHS Ayrshire and Arran had the greatest increase at 644%. Rates of surgery were static over this

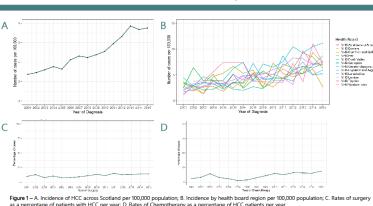
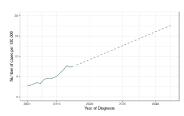


Figure 1 – A. Incidence of HCC across Scotland per 100,000 population; B. Incidence by health board region per 100,000 population; C. Rates of surgery as a percentage of patients with HCC per year; D. Rates of Chemotherapy as a percentage of HCC patients per year.

#### The future

If rates continue to increase at modelling rates, our estimates suggest the incidence of HCC will reach 17.7 (95% confidence interval 13.1 to 22.4) cases per 100,000 by 2045.



#### Scan Me!

To view interactive data explorer



Argoshare.is.ed.ac.uk/ HCC\_incidence

#### Conclusion

HCC incidence has markedly across Scotland over the past 20 years. The rate of increase across each region were comparable when population density was taken into account, however urban areas had the greatest caseload.

Rates of curative surgical treatment have remained relatively static across this period, whereas use of chemotherapy has increased. Future randomised trials should focus on how to detect HCC earlier at a population level.

We have requested detailed data on patients with liver disease and HCC in order to identify what is driving this trend.







