

National Managed Clinical Networks

Annual Report for 2009-2010



Scottish HepatoPancreatoBiliary Network

Lead Clinician's Report	3
Introduction	6
Description of the Network	6
Purpose of the Network.....	7
Objectives of the Network	7
Organisation of the Network	7
Services Covered	9
Membership.....	10
Resources	10
Clinical Facilities.....	10
Clinical Quality Indicators	11
Activity Report.....	12
2009-2010 Work Plan	12
Accomplished Service Improvements	13
Number of Meetings held and brief summary of meetings	14
The 6th May 2009 meeting	14
The 8 th October 2009 meeting	15
The 9 th February 2010 meeting	15
Public and Patient Involvement.....	15
Audit Activity	16
Research and Teaching Activity	17
Work Plan for 2010-2011.....	19
Finance	19

Lead Clinician's Report

I am delighted to introduce the 4th Annual Report of the National Hepato-Pancreatico-Biliary (HPB) Managed Clinical Network. This has been another strong year for the network which is now very well established and has continued to progress a significant amount of work under the prioritised work plan for 2009-10. Lindsay Campbell has again contributed significantly as Network Manager and has provided a valuable link with the other National Networks and Regional Cancer Advisory Groups.

We continued our programme of protocol development and in 2009 signed off an agreed Scottish Protocol for the management of patients with cholangiocarcinoma and gallbladder cancer. This was finalised after wide consultation and was launched at the 2009 Annual Educational event. I am indebted to Mr Iain Tait for taking the lead in the writing of this document and it is now being widely circulated to appropriate bodies. The next phase of the protocol development work plan is to revisit the pancreatic cancer protocol and Dr Marianne Nicolson has taken on the responsibility for this.

Again this year we have spent significant time and effort in progressing the National Audit of current practice and management of patients with HPB malignancy. There has been a gradual increase in case ascertainment based on waiting time returns and this must be considered positively in that at least more patients with HPB cancer are being identified and their details logged. Following the initial attempt at a six month data capture between July 2007 and December 2007, it was agreed that we should attempt to collect one year's worth of data from 1 January 2008 to 31 December 2008 to review on a national basis. Again this has proven extremely challenging. Data capture has been extremely variable with some Health Boards managing a very high percentage of case ascertainment and returns, whereas existing methodologies and processes have resulted in 50% or less capture in other Health Boards. An initial analysis of the data by the HPB Executive Advisory Board revealed that there was so much variation in data capture that it would be unadvisable to present this in its original form. Therefore, we went back to the Health Boards and sought further information and additional data

capture. This process is continuing and it is hoped that within the next few months a more complete picture can be obtained with most of the large Health Boards contributing to the National HPB Cancer Clinical Audit with only some of the smaller Health Boards not contributing. This process has confirmed to the Executive Advisory Group that the current mechanism using Health Board of residence of the patients as the responsible Health Board for submitting data may not be the most appropriate model for National Networks where the patient journey often involves several Health Boards. It is our current feeling that the Health Board responsible for the principal complex management decision and/or treatment should ultimately have the responsibility of completing all the relevant data fields. As we move forward, this must be the major focus of activity as to how this whole process can be improved. Part of the challenge is the limited resources for clinical audit of HPB cancers, but another major factor is the whole process of who is responsible for data capture and how this can be streamlined.

I am very pleased that we will very shortly have the printed version of the HPB Cancer Patient Information sheets and a new HPB website which should help to promote the activity of the Network and in dissemination of information.

We had an excellent 4th Annual Educational event in November 2009 which focussed on cholangiocarcinoma. Professor John Primrose from Southampton was the principal guest and provided an excellent overview lecture. All the other speakers were highly stimulating and extremely well received. Support for the meeting was excellent with a very good turn-out, and the Royal Infirmary of Edinburgh proved an excellent venue.

Having seen the National HPB Cancer Network established in April 2005, I have been extremely privileged to have acted as Lead Clinician but now feel it is time to step down from this responsibility to focus on other commitments. I am extremely grateful for the support provided by Lindsay Campbell as Network Manager and the entire Executive Advisory Group who have worked so hard over the last few years. I truly believe we have progressed activity that has genuinely brought benefit to patients with HPB cancer in Scotland. Highlights

for me have been the development of nationally agreed management protocols for all the major HPB malignancies, support for the development of site-specific MDT's and appointment of clinical nurse specialists, improved referral pathways, four excellent and informative education events, development of an agreed audit database, significant improvements in HPB case ascertainment, establishment of ECASE as an appropriate audit tool nationally and an raised awareness of the challenges of management of these particular cancers. I am particularly delighted that Mr Colin McKay, who has been involved in the Network since its inception, has been appointed as the new Lead Clinician and I would like to wish him, and all those involved in the HPB Managed Clinical Network, every success as they promote the ongoing activities of the Network.

Rowan Parks, National Lead Clinician

31st May 2010

Introduction

The Scottish HepatoPancreatoBiliary Network (SHPBN) started in April 2005 and this is our fourth annual report covering the financial year from 1st April 2009 to 31st March 2010.

Approximately 1000 patients are diagnosed with HepatoPancreatoBiliary cancers each year with only 2-3% of these patients surviving long term. The network was established with the intention of better documenting care pathways and outcomes of patients for whom there were concerns that there might not be equity of access to appropriate management.

Description of the Network

The Scottish HepatoPancreatoBiliary Network is a National Managed Clinical Network as defined by the NHS MEL (1999) 10 and NHS HDL (2007) 21. The Network links groups of health professionals and organisations from primary, secondary and tertiary care, and promotes working in a coordinated manner with the aim of delivering high quality, clinically effective and equitable care to patients irrespective of their geographical location.

Mr Rowan Parks (Edinburgh) has been the National Clinical Lead since the inception of the Network which is now served by Lindsay Campbell as the Network Manager, Lynsey Connor provides administrative support and Keith Bryce provides web site support from the West of Scotland Cancer Network (WoSCAN). The Network web site is www.shpbn.scot.nhs.uk.

The Network is hosted by (WoSCAN) which in turn is hosted by NHS Greater Glasgow and Clyde. Funding for the National Clinical Lead, Network Manager and WoSCAN support is provided by National Services Division.

The Network comprises persons with an interest in the management and support of patients with cancer of the liver, pancreas, gall bladder and biliary tree across Scotland, and a desire to work together to improve existing services. The Network also includes links and support from patients, carers, charities and pharmaceutical companies.

The Network is integrated so as to involve all three Scottish cancer networks: West of Scotland Cancer Network, the North of Scotland Cancer Network (NoSCAN) and the South East Scotland Cancer Network (SCAN).

Purpose of the Network

The purpose of the Network is to optimise the management of people with primary cancer of the liver, pancreas, gall bladder and biliary tree in Scotland, to produce a single Scottish service with accessible regional teams in the network bringing together the existing HepatoPancreatoBiliary services in Scotland in a planned, co-ordinated single system for delivery of quality patient care through common protocols. The Scottish HepatoPancreatoBiliary Network is a prime mechanism for maintaining the collaboration and progressing improvements in service. It also fosters the development of and access to clinical research.

Objectives of the Network

Improve patient care and access to the best treatment.

Ensure equity of access through the production and implementation of national guidelines.

Establish and agree pathways of care for patients across Scotland so that they are seen in a timely manner and by the correct clinical teams.

Identify gaps in the evidence base to inform clinical trials portfolio.

Produce nationally comparative data on agreed clinical outcomes to identify variations, and where appropriate put in place plans to manage these variances.

Increase the number of patients in research studies irrespective of geography.

Improve education regarding HepatoPancreatoBiliary cancer on a Scottish wide basis, improve training at all levels, undergraduate and post graduate, in all areas pertinent to HepatoPancreatoBiliary cancer.

Generate better value for money.

Improve communication for patients on a Scotland wide basis.

Provide a group expertise from which stakeholder groups can draw advice.

Organisation of the Network

The network is led by an Advisory Group which meets quarterly.

Sub-specialty groups report to the Advisory Group along with any short working life groups tasked with specific work.

The Advisory Group are;

Mr Rowan Parks	National (until 31/3/2010) and SCAN Clinical Lead, Consultant Surgeon, Edinburgh
Mr Colin McKay	National Clinical Lead (from 1/4/2010), Consultant Surgeon, Glasgow
Prof James Garden	Regius Professor of Clinical Surgery, Edinburgh
Mr Colin MacKay	WoSCAN Clinical Lead, Consultant Surgeon, Glasgow
Mr Irfan Ahmed	Consultant Surgeon, Aberdeen
Mr Iain Tait	NoSCAN Clinical Lead, Consultant Surgeon, Dundee
Dr Andy Fraser	Consultant Gastroenterologist, Aberdeen
Dr Marianne Nicolson	Consultant Oncologist, Aberdeen
Dr Nick Church	Consultant Gastroenterologist, Edinburgh
Mr Ron Coggins	Consultant Surgeon, Inverness
Elsbeth Cowan	Clinical Nurse Specialist, Glasgow
Sandra Thornton	Patient Participant, Edinburgh
Gordon Smith	Patient Participant, Glasgow
Evelyn Thomson	WoSCAN Coordinator
Julia Holmes/Graeme Morrice*	Clinical Service Manager, Edinburgh
Lindsay Campbell	MCN National Manager
Dr Des Alcorn	Consultant Radiologist, Glasgow
Prof Steve Wigmore	Professor of Transplantation Surgery, Edinburgh

* = previous name/current name of post holder

The Advisory Group has a geographical spread and spread of services and includes patient involvement. The role of the Advisory Group is to agree and monitor the implementation of the work plan and inform strategy for the SHPBN. The Advisory Group will contribute to the Annual Report, which is drawn together by the Lead Clinician and the Network Manager.

In the last year, Dr Des Alcorn, Consultant Radiologist and Prof Steve Wigmore, Consultant Surgeon joined to maintain a geographic and specialty balance. Gordon Smith joined as a Patient Participant and Graeme Morrice replaced Julia Holmes as Edinburgh Service Manager.

Services Covered

The clinical services involved are funded through their local Health Boards and where supra-regional services are provided financial arrangements have been made with the providing Health Boards for these. There is a nationally funded service in liver transplant which is centred in Edinburgh. The medical staff who provide services to patients with hepato-pancreato-biliary cancer do not only provide this subspecialty service, but are involved with management of patients with other diseases within their specialty (e.g. other medical or surgical conditions or other cancer types).

The services covered include the following:

Radiology

Pathology

Clinical Specialist Nurses

Gastroenterology

Surgery

Clinical Oncology

Palliative Care

Clinical Psychology

Nursing and Allied Health Professionals

Membership

All healthcare professionals, allied health professionals, research, clinical audit and administration staff delivering the service along with patients, their representatives, charities and pharmaceutical companies form the network. All were invited to the annual education event held on 30th November 2009 in Edinburgh Royal Infirmary, and are kept up to date with regular e-mailings from the Network Manager.

The membership was 179 as at 31/3/2010.

Resources

National Clinical Lead (1 session per week)

National Network Manager (0.33 WTE)

Administration support (as required)

Web site support (as required)

Clinical Facilities

There are five cancer centres offering open access referral to weekly Multi-Disciplinary Team (MDT) meetings and fast track investigation, diagnosis and treatment appropriate to individual need from NHS Boards. They are;

Inverness	Highland and Western Isles
Aberdeen	Grampian, Shetland and Orkney
Dundee	Tayside
Edinburgh	Lothian, Fife, Borders and Dumfries and Galloway
Glasgow	Greater Glasgow and Clyde, Lanarkshire, Forth Valley and Ayrshire and Arran

Clinical Quality Indicators

All patients are to be treated within 62 days of referral.

All patients are to be included in a national prospective audit.

All patients should be discussed at a regional or multi-regional MDT meeting.

All patients should have access to a nurse specialist with an interest in HPB cancer.

All patients should have access to other disciplines, as required (e.g. dietetics, palliative care).

All patients should have access to approved clinical trials.

The Network is to be accredited by NHS Quality Improvement Scotland (NHS QIS).

The Network is to complete an Equality Impact Assessment (EQIA).

Activity Report

2009-2010 Work Plan

Objective	Please include reference to specific actions within National Policies e.g. Better Cancer Care (BCC); Living & Dying Well (L&DW)	Key Milestones & Specific Actions	Named Lead	Due date	Status at 1/4/2009
Early Detection					
Project bid to Chief Scientist Office to secure funding	“to identify the groups of high-risk individuals” P45	Study to examine Risk Factors to developing HPB Cancer and establish tissue bank, and linking to ECASE	Mr Rowan Parks/Mr Colin MacKay/Mr Iain Tait/Prof James Garden/Mr Irfan Ahmed/Mr Ron Coggins	31/3/2010	Building on 2008/9 work
Referral					
Referral guidelines for Pancreas already in place so creating Liver and Gallbladder	“Expertise in identifying patients who require prompt referral” P47	Liver and Gallbladder guidelines created and implemented	Mr Rowan Parks	31/12/2009 and 31/3/2010	
Aiming for 100% electronic referral and vetting	Efficiency Target of 90% by 12/2010	SCI GATEWAY configured for SHPBN	Lindsay Campbell	31/3/2010	SSN first, then SANON and finally SHPBN
Treatment					
Ensure access to clinical trials for patients	“ensure recruitment continues to exceed 13.9%” P67	Ensure SHPBN patients can participate in available trials	Mr Rowan Parks	31/3/2010	

Service Provision & Access					
Cholangiocarcinoma Protocol		Finalised and implemented	Mr Iain Tait	30/9/2009 and 31/3/2010	Drafted and in review
Living with Cancer					
SHPBN patient information booklet	“improving quality and access to information” P72	Implement this booklet via the CNS’s	Elspeth Cowan	31/3/2010	Booklet created and working with Printer on 2009/10 delivery to CNS’s
SHPBN web site operational	“speed up communication” P79	Populate and launch web site	Lindsay Campbell	30/6/2009 and 30/9/2009	Web site registered and being designed with SHOW and Keith Bryce
Improving Quality of Cancer Care for Patients					
National audit via ECASE continually improved	“how the results of these audits are acted upon locally” P90	In collaboration with Boards and ISD ensure all data is captured via ECASE and interpreted consistently	Lindsay Campbell	31/3/2010	1/7-31/12/2007 data captured via ECASE and local databases. NHS Fife last Board to use ECASE. Quarterly reviews to achieve consistent interpretation

Accomplished Service Improvements

The Advisory Group is able to meet in person or by video conference in any of the 5 Centres, with Aberdeen now able to participate from Mr Irfan Ahmed’s office, and is continuing to work with the Scottish Centre for Telehealth to provide video conferencing even closer to the Centre staff.

A project bid to the Chief Scientist Office was successful and tissue banking has now been extended from Dundee and Glasgow to include Edinburgh, with Aberdeen and Inverness to follow.

Referral guidelines were reviewed and no update was required as liver and gall bladder cancer are covered in the HCC and Cholangiocarcinoma guidelines respectively.

Electronic referrals will be mainly from Hospital Consultant to Hospital Consultant and this functionality is being tested between NHS Grampian and NHS Orkney or NHS Shetland by the NoSCAN team.

Scottish patients did participate in NCRI trials including ESPAC-3, BILCAP and Photostent and new trials are anticipated to start in due course. The Scottish Cancer Research Network will be providing updates on trials going forward.

The Cholangiocarcinoma guideline was completed and circulated to the Network, the Scottish Society of Gastroenterologists, each Board Lead Cancer GP and the regional Cancer network websites (NoSCAN, SCAN and WoSCAN). The Primary Care Network is supporting the circulation via the SCI GATEWAY Upper GI Referral Template.

The Patient Information Booklet has been finalised and is awaiting the Printer to print and deliver to the Board CNS's, who will then provide it to each patient or their carer. 2 years worth of booklets have been purchased.

The website (www.shpbn.scot.nhs.uk) is based on the new technology implemented on the Scottish Adult Neuro Oncology Network (www.neurooncology.scot.nhs.uk).

1st January to 31st December 2008 is being audited and progress was presented at the annual education meeting.

Number of Meetings held and brief summary of meetings

3 Advisory Group meetings were held; on 6th May 2009, 8th October 2009 and 9th February 2010.

The 6th May 2009 meeting

The annual education meeting was arranged and guest speaker selected. The criteria for the 2008 audit were agreed and AUGIS requirements were progressed. The Cholangiocarcinoma guideline was progressed. The Pancreatic Cancer guideline was agreed to be updated from three regional to one Scottish guideline and to be led by Dr Marianne Nicolson. The production of the patient information booklets had been held up by the publishing printers who were being pressed to produce these. The logo for the Network was selected to be used in future mailings and advertising of activities. The development of the website was being progressed in tandem with the upgrading of the SANON website. MDT Coordinators in each the 5 Centres were to be confirmed. The SCAN timed pathway was to be expanded Scotland-wide.

The 8th October 2009 meeting

Prof Steve Wigmore participated for the first time. 2010 education event was agreed as a joint event with the Scottish Society of Gastroenterologists (SSG). Programme for the 2009 education event was progressed. First pass of 2008 audit was reviewed but case ascertainment was lower than expected and Centres agreed to improve case ascertainment before re-analysing. AUGIS audit was discussed. The Cholangiocarcinoma guideline was progressed. The Pancreatic Cancer guideline update was progressed. The patient information booklet was delayed and an alternative Printer was considered. The website development was behind schedule. MDT Coordinator in each of the 5 Centres was confirmed. Trials were reviewed. The Scottish timed pathway was approved. Mr Rowan Parks advised he was stepping down as National Clinical Lead by 31/3/2010. Scottish Medicines Consortium (SMC) has requested an Advisor on HPB cancers. Pancreatic Cancer awareness week will be led by Elspeth Cowan.

The 9th February 2010 meeting

Gordon Smith participated in his first meeting. Dr Marianne Nicolson agreed to be the Advisor to SMC. 2009 Pancreatic Cancer awareness week was successful. 2009 education event was successful and improvements for 2010 identified. 2010 education event with SSG progressing and will take place in Edinburgh. 2008 audit in progress. Future audit will be led by Mr Colin McKay and proposal to separate HPB from Upper GI dataset brought forward. The Cholangiocarcinoma guideline was progressed further. The Pancreatic Cancer guideline update was progressed. The patient information booklet is progressing with the original Printer. The website is making progress. AUGIS audit will await result of 2008 audit and Prof Steve Wigmore is leading on service mapping. 2010-11 work plan was drafted. TNM7 is being implemented in 2010 by all 5 Centres and is being led by Dr Alan Foulis. 2010 Pancreatic Cancer awareness week is being planned.

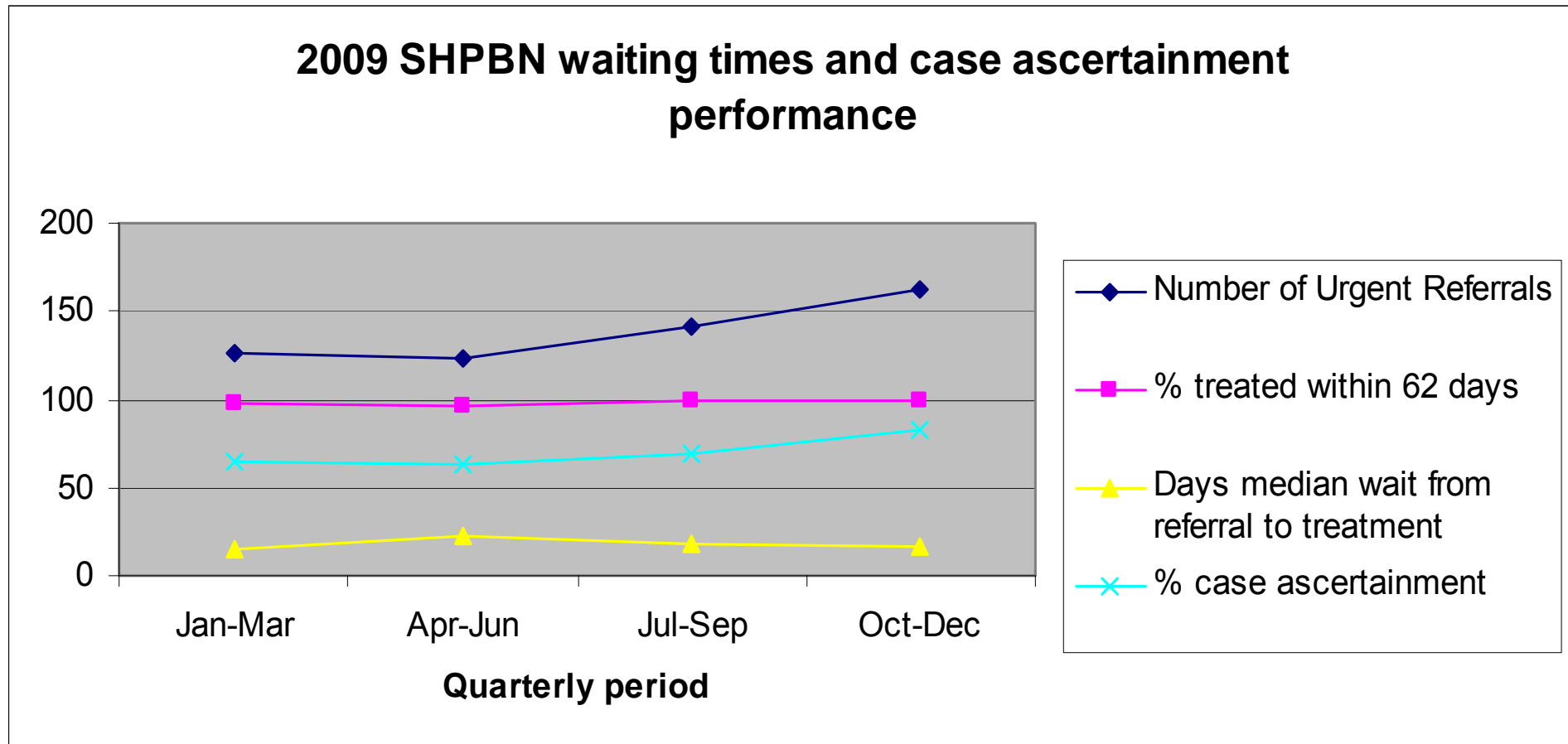
Public and Patient Involvement

The Patient Information Booklet is in progress but has been delayed. The 2009 Education Event included Sandra and Gordon's experience facilitated by Prof James Garden and included Diane Smith's experience as Gordon's carer. Pancreatic Cancer awareness week was successfully supported.

Audit Activity

1st January to 31st December 2008 patient data were audited and analysed but case ascertainment was lower than expected and is being increased by the Centres before re-analysis. Five Boards submitted waiting times data only and nine Boards submitted waiting times and clinical data.

ISD Waiting Times Quarterly Reports showed the 95% target had been met and case ascertainment improved (rose to 80%).



Research and Teaching Activity

The annual education event was held on the 30th November 2009 in Edinburgh Royal Infirmary. There were 46 attendees, 7 posters displayed and sponsorship from 4 pharmaceutical companies. The theme was Cholangiocarcinoma and the programme was;

12-2	Lunch, networking and posters	All
2-2.20	Scottish Cholangiocarcinoma Guidelines	Mr Iain Tait
2.20-3	Update on Management of Cholangiocarcinoma	Prof John Primrose
3-3.10	The Tumour Microenvironment in Cholangiocarcinoma	Mr Andrew Robson
3.10-3.20	Best clinical study poster Does analgesic method influence post-operative course following liver resection?	Miss Erica Revie
3.20-3.30	Chemotherapy followed by chemoradiotherapy for locally advanced non-metastatic pancreatic cancer- A new paradigm? A Single centre experience	Dr David McIntosh
3.30-3.50	Break	All
3.50-4.30	Patient perspectives on cancer treatment	Sandra Thornton and Gordon Smith facilitated by Prof James Garden
4.30-5	2008 Audit	Mr Rowan Parks

The winner of the poster prizes were;

Mr Andrew Robson

Miss Erica Revie

Dr David McIntosh

Emma Scott

The posters displayed were;

Authors	Department and Location	Title
A Robson, K Samuel, OJ Garden, JP Iredale, SJ Forbes	W2.29 Centre for Inflammation University of Edinburgh	The Tumour Microenvironment in Cholangiocarcinoma

	Research	
Dr Jan Bappu, Mr Azhar Shabhir, Mr Irfan Ahmed, Mr Bassam Alkari	Ward 31/ Hepatobiliary Unit, Aberdeen Royal Infirmary	Streamlining a dedicated Hepatobiliary Service: Impact on the number of operations and outcome
Damian J Mole ^{1,2} , Ciaran O'Neill ³ , Peter Hamilton ³ , Bayanne Olabi ¹ , Victoria Robinson ¹ , O James Garden ¹ , Thomas Diamond ⁴ , Mohammed El-Tanani ^{5*} and F Charles Campbell ^{5*}	<ol style="list-style-type: none"> 1. Clinical and Surgical Sciences (Surgery), The University of Edinburgh 2. MRC Centre for Inflammation Research, Queen's Medical Research Institute, The University of Edinburgh 3. Department of Pathology, Royal Group of Hospitals NHS Trust 4. Mater Hospital, Crumlin Road, Belfast, Northern Ireland. 5. Centre for Cancer Research and Cell Biology, Queen's University of Belfast 	Differential expression of osteopontin and its transcription activation complex components β -catenin/Tcf4, Ets1 and PEA3 in primary tumours and matched liver metastases is associated with extended survival in colorectal cancer.
Miss Natasha P Ross, Dr J McPhee, Mr R Coggins, Mr A Tamijmarane	HpB/Upper GI Unit, Raigmore Hospital	Analysis of 5 cases who underwent Whipple's resection demonstrated benign Adenomyomatous Hyperplasia
Dr David McIntosh and Dr Adnan Shaukat	Beatson West of Scotland Cancer Centre	Chemotherapy followed by chemoradiotherapy for locally advanced non-metastatic pancreatic cancer- A new paradigm? A Single centre experience
Emma Scott, Mark Duxbury, Angie Miller, Ernest Hidalgo	Hepatobiliary and Pancreatic Surgery Unit, Edinburgh Royal Infirmary	Should preoperative endoscopic biliary drainage in patients undergoing pancreaticoduodenectomy for pancreatic adenocarcinoma be restricted to specialist centres?
Revie E, Massie L, McNally SJ, McKeown DW, Garden OJ, Wigmore SJ	Clinical and Surgical Sciences (Surgery) University of Edinburgh	Does analgesic method influence post-operative course following liver resection?

19 questionnaires were returned (54%) and 100% would attend a future annual education event. More details are available from the Network Manager.

Work Plan for 2010-2011

Ref.	Objective (What is the Goal?)	Priority Ranking High (H) Medium (M) Low (L)	Deliverables / Outcomes (Tangible / Measurable benefits)	Planned Timescales		Alignment with National/ Regional Strategies (Reference to Cancer Strategies /LDW etc)
				Start Date	End Date	
1	Audit 2009 and undertake preparatory work to identify top 10 QPI's and develop initial list of QPI's to report against <i>(adopt methodology currently being developed by National Cancer Quality Steering group)</i>	H	2009 audit demonstrates continual improvement and 10 measurable outcomes for patients with cancer of the liver, pancreas, gallbladder or biliary duct	1/4/2010	31/3/2011	"all tumour networks take part in national audit" P90 and as required by the NCQSG
2	Project through Chief Scientist Office to bank tissue	H	Establishing tissue banks for future research	1/4/2010	31/3/2011	"Work with the Chief Scientist Office to examine opportunities" P39
3	In collaboration with the Scottish Cancer Research Network ensure access to trials	H	"to ensure recruitment continues to exceed 13.9%" P67	1/4/2010	31/3/2011	Support SCRN as required
4	Pancreas and Liver guidelines revised	H	Existing guidelines reviewed and updated if necessary	1/4/2010	31/3/2011	To conform with SIGN guideline review schedule
5	Undertake an in-depth critical review of MDT practices across the region to optimise efficiency and effectiveness.	H	Clear action plans developed to address issues raised within the specified timescale	1/4/2010	31/3/2011	"Seek ways to improve and speed up communication to patients and between professional disciplines and service" P79

Finance

The Network operated within budget.