



Scottish HepatoPancreatoBiliary Network (SHPBN)

Volume 1 Issue 4

Headlines



Inside this Issue:

Headlines	1
Best Supportive Care	2
Pancreatic Cancer Radiology Collaboration	2
Neo-adjuvant monthly meeting for Pancreatic Cancer	2
Scottish Cancer Network	3
Less Survivable Cancers	4
Education	4
National Clinical Trials	4
Charities Corner	5
Appendices: HCC and PC CNSs	9

Special point of interest:
SHPBN Education Event will be held in early 2022 – details to follow

Welcome to the SHPBN Winter 2021/22 Newsletter. It has been another difficult year across the country, and we hope everyone is keeping well.

Despite the ongoing challenges there has been exciting collaboration and progress within the Scottish HPB Network.

We were successful in securing funding from the Scottish Government cancer recovery plan to improve the pathways of Pancreatic and Hepatocellular Carcinoma and our project manager Jess Parish will provide an update in the near future.

A national neo-adjuvant pancreatic cancer educational meeting is now held monthly across the five units to discuss patients and learn from each other's experience. Thanks to Ms Sarah Thomasset for coordinating this meeting.

The Network has been invited to join the UK Liver Alliance, a group including all relevant health care and third sector parties aiming to improve the care of liver patients across the UK. We will keep you updated on developments from the alliance.

We continue our close collaboration with Charity organisations. Thanks to the Less Survivable Cancer Taskforce, British Liver Trust, Pancreatic Cancer Action Scotland and Pancreatic Cancer UK for providing their updates.

In each newsletter Dr Alan Christie has kindly provided an update on all possible clinical trials for our patients across the country. Thank you again Alan for ensuring this information is available for all our members.

We are planning our annual Educational Event in the first quarter of 2022. Due to the current climate, we may have to repeat a virtual, Microsoft Teams meeting but we will ensure the content and discussion is as thought provoking as on previous years.

Can I take this opportunity to thank everyone within this HPB community for your support and contribution to this network. Wishing you all a happy Christmas and looking forward to continuing to strive for the best possible care for all our patients across Scotland in 2022.

*Ms Anya Adair
Consultant Surgeon at Edinburgh Royal
Infirmary and SHPBN's Clinical Lead*

Best Supportive Care Collaborative (Dr Jo Bowden)

Despite several setbacks due to the Covid-19 pandemic, we remain committed to improving the reliability and quality of best supportive care (BSC) for people with hepatopancreatobiliary cancer in Scotland, and those they are close to. We are on the cusp of piloting a patient and family information leaflet detailing what best supportive care is, what kind of care and support is available and how it can be accessed. This important resource has been co-developed by the BSC Collaborative, with invaluable input from HPB charities and service users.

The pilot will take place in Fife, with learning shared with the national group. Ultimately, we envisage a generic information resource, overseen and quality assured by the SHPBN, with bespoke regional adaptations reflecting local support services.

We have wider ambitions including the development of national quality standards of BSC and a national programme of online communication training for clinicians working in HPB cancer care, supporting them to have sensitive and honest conversations and to undertake anticipatory care planning. Watch this space in 2022!

Anyone wishing to join the BSC Collaborative can email Jo at: joanna.bowden@nhs.scot

Pancreatic Cancer Radiology Collaboration (Mr Nigel Jamieson)

Our thanks to Mr Nigel Jamieson for leading on this collaboration with the rest of the UK and will hopefully provide an update in the next issue of the newsletter. Anyone wishing to know more about the collaboration can email Nigel at: nigel.jamieson@ggc.scot.nhs.uk

Neo-adjuvant monthly meeting for Pancreatic Cancer (Ms Sarah Thomasset)

Our pancreatic cancer neo-adjuvant meeting has successfully continued on a monthly basis, involving all centres across the network. We have now discussed many interesting cases and although practice varies between units, we have all benefited from hearing different perspectives on oncological and surgical management strategies. The cases we bring to the meeting are invariably very challenging and our detailed discussions certainly benefit us and our patients. Revisiting cases previously discussed has also provided further opportunities for learning. The other definite benefit of this meeting has been to maintain communication between units on a monthly basis.

We are very grateful for your continued support of this meeting and in particular thank Abdullah Al-Adhami for his input from a radiology perspective and Euan Dickson for his efficient chairing.

Scottish Cancer Network (SCN)

What is the Scottish Cancer Network?

NHS National Services Scotland is hosting the Scottish Cancer Network. This is a dedicated national resource to support and facilitate a 'Once for Scotland' approach to cancer services which will assist in enabling equitable access to care and treatment across Scotland.

Its main aims are to:

- Develop and operate a system for the production, review, and hosting of National Clinical Management Guidelines.
- Oversee and drive improvement of existing National Managed Clinical Networks and adopt similar national network approaches for other areas, for example areas with low volume activity that may benefit.

The Scottish Cancer Network is working collaboratively with already established regional and national Cancer Networks to understand the processes and progress made around Clinical Management Guidelines and National Managed Clinical Networks. It will also work to assist the networks in continuing to make the best use of clinical time, ensuring best care for patients wherever they are in Scotland.

The Scottish Cancer Network will develop Clinical Management Guidelines and improvement in patient pathways, including surgery, for less common cancers. Clinical consensus, ongoing improvement and equitable access will be key founding principles.

What will this new resource mean for cancer services in NHS Scotland?

- Improved pathways leading to better patient experience and outcomes
- A consistent approach to the production of high-quality clinical management guidelines, backed up a universally accessible digital space
- Increase in public and professional confidence
- Cohesion between healthcare and patient networks

How does this fit with the existing Scottish HPB Network?

Existing National Managed Clinical Networks do a fantastic job and this work will look to build on that by bringing national cancer networks together under the Scottish Cancer Network umbrella. The blueprint for this will be informed and developed by those involved in the existing national networks; to utilise existing approaches where appropriate, to ensure equity, transparency and good governance, and to add value by working together as a collective.

We welcome your views and invite you to join the conversation by participating in a [short survey](#). There will be many more opportunities to contribute as this collaboration evolves and you can contact the team any time.

The SCN team, in the meantime, is working in partnership with the Scottish HPB Network to progress their service improvement project. This project bid successfully achieved Scottish Government funding to improve the current pathways for patient with hepatocellular or pancreatic cancer across Scotland.

Clinical leadership is provided by the National Clinical Lead, Noelle O'Rourke: noelle.orourke@nhs.scot

Programme leadership is provided by the National Programme Director, Nicky Waters: nicola.waters@nhs.scot

You can contact the team anytime via nss.scottishcancernetwork@nhs.scot

Less Survivable Cancers Taskforce

The Less Survivable Cancers Taskforce is an alliance of charities representing people diagnosed with one of the six less survivable common cancers: cancers of the lung, pancreas, liver, brain, oesophagus and stomach.

There are some cancers which have seen remarkable progress in survivability but others that are just as deadly as they were 40 years ago. People diagnosed with these six cancers have a shockingly low life expectancy. Today, on average, the chance of someone surviving for five years after being diagnosed with one of these cancers is only 16%.

Over 80,000 people are diagnosed with one of these cancers every year in the UK, including nearly 9,000 people in Scotland. They account for a quarter of all cancer cases but half of all cancer deaths.

Our charities joined together to improve outcomes and experiences for all people diagnosed with a less survivable cancer across the UK. We know that diagnosing people earlier and faster, and ensuring optimal pathways into treatment, will improve outcomes and experiences for thousands of people in Scotland.

We welcome the Scottish Government's commitments in making improvements for people with a less survivable cancer in the Scottish Recovery and Redesign Action Plan, and we look forward to continuing our work in Scotland to help make these commitments a reality. We strongly support SHPBN's aim to ensure equality of care for patients cancer of the liver, pancreas, gallbladder or biliary tree, and particularly their commitments to measuring and improving quality of care and clinical outcomes for Scottish patients.

You can find out more here: [Less Survivable Cancers Taskforce](#) and follow our work on Twitter @LessSurvivable.

Education

The annual mortality and morbidity review was virtual for the second time on Monday 8th November 2021 and compared 2020 with the previous three years. Our thanks to Prof Damian Mole, Mr Stephen McNally and Mr Euan Dickson for chairing the sessions.

The 2022 SHPBN education event is being planned and given the COVID-19 pandemic may be virtual again. The day, time and programme will be advised as soon as possible.

National Clinical Trials

Our thanks to Dr Alan Christie, Consultant Medical Oncologist, who is leading on a list of National Clinical Trials available in Scotland, and these can be found on the Clinical Trials page on the website at: <https://www.shpbn.scot.nhs.uk/clinical-trials/>

Charities Corner



Putting patient support at the heart of our work

The British Liver Trust is the only charity providing direct patient for support for liver patients in Scotland, whatever the type and cause of their liver condition. We want every person affected by a liver condition to have access to accurate, up-to-date information about their condition, to feel supported and empowered to get the best possible care.

Recently, the British Liver Trust has created a new free downloadable [fact sheet](#) for people with primary liver cancer (HCC) which outlines the care people should receive and has questions for patients to ask at each stage of their treatment.

Patient support group

The British Liver Trust run a bi-monthly liver cancer virtual support group in Scotland. This group is to support patients and family members at any point of their liver cancer journey. It is a peer support group and patients and family members offer one another support through their cancer journey. The groups have been well attended and were supported by liver nurse specialist Aisling Bradley.

If any patient wants to attend the liver cancer group, they can sign up here: [Register interest in attending a virtual liver support group](#)

Liver nurse helpline and online community

The British Liver Trust offers a freephone helpline, with calls answered by a team of Liver Nurse Specialists, including two nurses based in Dundee and Edinburgh, who have many years' clinical experience in NHS hepatology.

The charity's liver nurses respond to over 3,000 helpline enquiries - as well as managing a growing [online community](#) of over 26,000 people. For many, the stigma associated with liver disease prevents them for asking for the help they are entitled to, and some are embarrassed even to seek support from friends and family, which is why our confidential helpline is so important.

The helpline number is **0800 652 7330** and is open between 10am and 3pm Monday to Friday (not bank holidays). Patients can also email helpline@britishlivertrust.org.uk (emails can be sent at any time and are answered during helpline hours).

Liver cancer campaign work: Less Survivable Cancer Taskforce

As part of the Less Survivable Cancer Taskforce, the British Liver Trust has been working alongside the Scottish Government to improve care and support for all HCC patients in the country, as well as part of the new action plan for cancer services: [Hepatocellular carcinoma in Scotland: a new action plan for better care](#)

Supporting new treatments for liver cancer patients in Scotland

The British Liver Trust works with the Scottish Medicines Consortium to provide a patient perspective on new medicines to treat liver disease and liver cancer. This helps widen the treatment options available to patients in Scotland.

Pancreatic Cancer Action Scotland



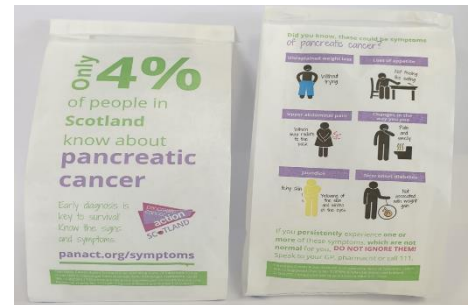
Our mission is to improve survival rates of pancreatic cancer by ensuring more people are diagnosed early and that everyone has access to effective treatments, support, information and care.

We raise public **awareness** of pancreatic cancer and its symptoms, **campaign** for change, provide pioneering educational **training resources for healthcare professionals**, support and fund **innovative research**, ensure patients and families are **offered information and support** and fund a specialist pancreatic cancer **nursing** post within NHSScotland.

Our website <https://pancreaticcanceraction.org/> provides helpful information & advice, including guidance during the pandemic, sources of support & [free patient information booklets](#) (online and/or printed).

WE HAVE BEEN RAISING AWARENESS WITH:

- Symptoms information on 100,000 pharmacy bags across community pharmacies in Glasgow & Lanarkshire; Ayrshire and Arran; Dumfries & Galloway and Fife.
- Digital & social media engagement
- Pharmacies & GP's including our online training modules
- Building relationships with trusted community partners
- ["Islets of Silence" Play by Tram Direct Theatre Company](#)
- TV Advertising on STV, ITV2 and ITV3



Kenny Smith talks in our [TV advert](#) about losing his mum 41 days after diagnosis and is followed by a survivor talking about early diagnosis being key to survival.

We direct the public to know the signs & symptoms, learn more via our website and contact their GP with new or unusual persistent symptoms.

Our purple "Pan Can Van" was outside Scottish Parliament on World Pancreatic Cancer Day.

Our team and supporters spoke with over 30 MSP's, highlighting the need for continued commitment and increased investment to ensure pancreatic cancer remains a priority. We shared information about The SHPBN Improving Pathways Project and how the 2020's should be "The Decade of Change" for the world's toughest cancer.



BREAKING DOWN THE LANGUAGE BARRIERS:

We have translated several of our key pancreatic cancer information & resources for the top six languages spoken in the UK after English: Polish, Punjabi, Urdu, Bengali, Gujarati & Arabic.

Further information is available at: <https://pancreaticcanceraction.org/resources-in-other-languages/>

READ AN INSPIRING SURVIVOR STORY at <https://pancreaticcanceraction.org/news/debra-grindall-story/> which was also covered by [STV News](#) for November's Pancreatic Cancer Awareness Month.

We have been asking people to reflect and recall on their experience and association with pancreatic cancer and share their story to help inform The Decade of Change for pancreatic cancer. Further stories can be read at: <https://pancreaticcanceraction.org/news/category/patient-stories/>

Pancreatic Cancer UK is here so people don't have to face pancreatic cancer alone. A diagnosis can be a terrible shock, but we are here to help them make sense of it and guide and support them and their family at every step that follows. **For Health Professionals**, we have a range of **free events, training and resources** so you can learn, develop and collaborate with the pancreatic cancer community. You can also access our **expert information and services** to support your patients at every stage of their journey.

Health professional training and events

We have held a range of events so far this year, with a highlight being our two-part event for support workers and patient navigators: **Supporting patients with pancreatic cancer**, which explored the key areas of a pancreatic cancer patient's pathway. [View the recordings and slides](#)

"Will feel more comfortable to talk to patients after this study day."

Attendee at supporting patients with pancreatic cancer, March 2021

Upcoming events

Our [National Study Sessions](#) were held back in October, and explored Enhanced Supportive Care (ESC). We ran a selection of free, virtual sessions including: symptom assessment and management; effective communications; emotional support; end of life care; and models of best practice in ESC. We also delivered some diet sessions. On 21st October 2021, Specialist HPB Dietitian Mary Phillips joined us to deliver [a PERT educational session](#). All of these sessions were recorded and can be accessed on our [website](#). On 2nd December 2021, we are holding [dietetic management training](#).

Partnership opportunities

We love partnering with teams across the UK to deliver useful and relevant events for the health professional community. Recently we held an [All Wales Webinar on Pancreatic Cancer](#) with the Macmillan Primary Care Cancer Framework and a [South West Study Session](#) with the HPB team at Derriford Hospital both events were well attended with 97% of attendees rating them as good or excellent and 100% saying they would recommend to their peers. If you're interested in teaming up with us to deliver an event, please get in touch with our events manager at: harriet.smith@pancreaticcancer.org.uk.

"An excellent webinar. I found this incredibly useful - thank you all for taking the time to share your expertise"

Attendee at All Wales Webinar on Pancreatic Cancer. June 2021

Support for your patients

Online Support Sessions

Our specialist nurses run regular sessions over Zoom to help support your patients with managing nutrition, coping with treatment and more. We also run monthly sessions for family and friends. We've supported 145 individuals since we started these sessions last July, with attendees rating the sessions 4.45/5, and 100% saying they'd recommend a session to someone else. [Check out our upcoming support sessions and share with your patients.](#)

"It's easy to feel very alone with our problems especially during the current climate. It was so nice to be able to hear from others at different stages of the journey" Attendee at an online support session

Publications

We have recently updated [our end of life care booklet](#). It is one of our most popular information resources providing key information for people at this difficult time, explaining the symptoms people may get and how to manage these, and how to access the care and support they need. We also launched patient [information on type 3c diabetes](#) on our website and a [free diabetes fact sheet](#) for patients to download. We have [more free information](#) covering all aspects of pancreatic cancer which is easy to understand and reviewed by clinical experts so you can share it with your patients with full confidence.

Support line

Our specialist nurses are experts in pancreatic cancer and are only a phone call away. Our confidential support line is open Mon, Tue, Thu and Fri, 9am – 4pm, and Wed 10am – 6pm. Please tell your patients to call 0808 801 0707 or [contact a nurse via email](#).

Transform lives: Prescribe campaign and our PERT Hub

In May we launched our [Transform Lives: Prescribe campaign](#) calling for all pancreatic cancer patients to have access to pancreatic enzyme replacement therapy (PERT). As part of this campaign, we launched a [new health professional hub of resources on pancreatic cancer and PERT](#), including our [short online course](#) endorsed by the BDA and PSGB&I, and guides for health professionals and your patients. So far, over 2,300 healthcare professionals have downloaded our PERT guide or completed our online course.

"Think this is one of the best courses by far" PERT course participant

Pancreatic Cancer UK Fellowships

We are pleased to announce two new Fellowships to support post-doctoral researchers to realise their research aims and career ambitions. Following discussions with the community we have developed two fellowships that will support post-doctoral researchers, no matter what their experience or career stage. This is the first time Pancreatic Cancer UK has delivered fellowships. We will pilot their structure and processes in 2021/22, testing the fellowships in the community, evaluating with feedback from the applicants and wider field and, if necessary, redeveloping for future rounds. To find out more about the Pancreatic Cancer UK Fellowships go to our [website](#)

Scottish Hepatocellular Carcinoma (HCC) Clinical Nurse Specialists (CNSs)

Northern Cancer Alliance (NCA)	
Orkney	Aberdeen Royal Infirmary (Grampian)
Roddy Harper	Rachel Thomson
Linzi Mowatt	Susan Marnoch (for General Surgical patients only)
Ann Gregg	
	Dundee Ninewells Hospital (Tayside)
Shetland	Mairi Macpherson
Dawn Umphray	Pam Steedman
Western Isles	Inverness Raigmore Hospital (Highland)
Mairi Smith and Donna Young (Lewis & Harris)	Angela Macgregor
Fiona Creighton and Mary Buchanan (Uist & Barra)	Louise Glendinning
South East Scotland Cancer Network (SCAN)	
Borders	Edinburgh Royal Infirmary (Lothian)
Rachel Johnson	Lorraine Kirkpatrick and Jade Tierney (for General Surgical patients only)
Christine Henderson	
	Edinburgh Western General Hospital (Lothian)
Dumfries & Galloway	Jackie Brown
Helen Johnstone	Rachel Haigh
Fife	
Tanya Sullivan	
West of Scotland Cancer Network (WoSCAN)	
Ayrshire & Arran	Inverclyde Royal Hospital (GGC)
Oighrig Park	Linzi Binnie
Lynn Kennedy	
	Royal Alexandra Hospital (GGC)
Forth Valley	Aisling Bradley
Helen Upfold	Maxine Brown
Hairmyres Hospital (Lanarkshire)	Beatson West of Scotland Cancer Centre (GGC)
Jacqueline Bonnar	Jen Milne
Kathleen Coyle	
Lorna Mitchell	
Monklands Hospital (Lanarkshire)	
Josephine Arthur	
Lorraine Allan	
Wishaw General Hospital (Lanarkshire)	
Louise Desport	
Audrey Duffy	

Scottish Pancreatic Cancer (PC) Clinical Nurse Specialists (CNSs)

Name / Title	NHS Board
Lynne Kennedy (Upper GI CNS)	A&A
Oighrig Park (Upper GI CNS)	A&A
Helen Upfold (Upper GI CNS)	Forth Valley
Lorna Mitchell (Upper GI CNS) (Hairmyres)	Lanarkshire
Louise Desport (Upper GI CNS) (Wishaw)	Lanarkshire
Caitlin Mulligan (Upper GI CNS) (QEUH)	GGC
Claire Foster (Upper GI CNS) (GRI)	GGC
Eileen Murray (Upper GI CNS) (QEUH)	GGC
Elsbeth Cowan (Upper GI CNS) (GRI)	GGC
Fiona Clark (Upper GI CNS) (RAH)	GGC
Jen Milne (Upper GI CNS) (BWoSCC)	GGC
Kimberley Booth (Pancreatic CNS) (GRI)	GGC
Lee Nicholson (Upper GI CNS) (QEUH)	GGC
Linda Dewar (Upper GI CNS) (GRI)	GGC
Linzi Binnie (Upper GI CNS) (IRH)	GGC
Christine Henderson (CNS) (CNS)	Borders
Rachel Johnson (CNS)	Borders
Helen Johnstone (CNS)	D&G
Kerys Russell (Upper GI CNS)	Fife
Tanya Sullivan (HPB CNS)	Fife
Jackie Brown (CNS) (ECC)	Lothian
Jade Tierney (HPB CNS) (ERI)	Lothian
Lorraine Kirkpatrick (HPB CNS) (ERI)	Lothian
Rachel Haigh (CNS) (ECC)	Lothian
Susan Marnoch (HPB CNS) (ARI)	Grampian
Rachel Thomson (HPB CNS) (ARI)	Grampian
Angela Macgregor (Upper GI/HPB CNS) (Raigmore)	Highland
Louise Glendinning (Upper GI/HPB CNS)	Highland
Mairi MacPherson (Upper GI CNS) (Ninewells)	Tayside
Pam Steedman (Upper GI CNS) (Ninewells)	Tayside
Ann Gregg (CNS)	Orkney
Linzi Mowatt (CNS)	Orkney
Roddy Harper (CNS)	Orkney
Dawn Umphray (CNS)	Shetland
Mairi Smith (CNS) (Lewis & Harris)	Western Isles
Donna Young (CNS) (Lewis & Harris)	Western Isles
Fiona Creighton (CNS) (Uist & Barra)	Western Isles
Mary Buchanan (CNS) (Uist & Barra)	Western Isles

Updated: 6th December 2021