



CHOLANGIOCARCINOMA UK CONFERENCE: 7th DECEMBER 2018, FRIENDS HOUSE, LONDON

SUMMARY REPORT OF THE MEETING

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BACKGROUND

The idea of a pan-specialty national group dedicated to cholangiocarcinoma has been brewing amongst specialists in the field for several years due to the increasing burden of this highly fatal disease, which has several areas of unmet need. In September 2017, the then President of the British Association for the Study of the Liver (BASL), Prof Graeme Alexander instigated the creation of several Special Interest Groups (SIGs) for various liver diseases, including a specific SIG for Cholangiocarcinoma. In parallel, Prof Nigel Heaton organised a national Cholangiocarcinoma Conference at Kings College Hospital, held in January 2018 and attended by many specialists from across the UK. This successful meeting reinforced the need for a sustainable professional body dedicated to cholangiocarcinoma in the longer term. Prof Shahid Khan was asked by BASL to be the working chair for Cholangiocarcinoma UK, a multi-disciplinary SIG under BASL and to help organise an inaugural conference via a working committee.

The **Working Committee** for Cholangiocarcinoma UK was set up in December 2017, as follows:

Chair Shahid Khan, Imperial College London

Secretary Derek Manas, Freeman Hospital, Newcastle upon Tyne

Basic Science David Bates, University of Nottingham

Clinical Oncology Maria Hawkins, University of Oxford

Endoscopy Steve Pereira, University College London (UCL)

Hepatology Simon Rushbrook, Norfolk & Norwich Hospital

Medical Oncology John Bridgewater, UCL; Juan Valle, University of Manchester

Patients Advocate Helen Morement, AMMF

Surgery Nigel Heaton, Kings (KCL); Hassan Malik, Aintree University Hospital

Trainee Representative Geri Keane, Derriford Hospital, Plymouth

The Core/Executive Committee, to ensure actions arising from the broader committee are carried out, currently consists of Shahid Khan, John Bridgewater, Derek Manas and Helen Morement.

The Working Committee agreed the following **Mission Statement** for Cholangiocarcinoma UK:

“Cholangiocarcinoma UK, an affiliate of the British Association for Study of Liver Disease (BASL), is a multi-disciplinary Special Interest Group (SIG) of clinicians, scientists and patient advocates whose purpose is to facilitate collaborative research, enhance service development and raise awareness of Cholangiocarcinoma.”

and the following **Aims**, to:

- *Be the recognised leading professional authority on cholangiocarcinoma in the UK*
- *Become affiliated to relevant major national organisations*
- *Facilitate basic science and clinical research as well as sample collection, including for biomarker development*
- *Improve the pathway to collaborative clinical trials and opportunities for research funding*
- *Update national guidelines and advise on policy and best practice*
- *Optimise and standardise clinical management across the country*
- *Monitor epidemiological trends accurately*

The Cholangiocarcinoma UK Committee organised its first Cholangiocarcinoma UK Conference, held at Friends House, Euston Road, London on 7th December 2018. Invited attendees were from a cross faculty group of clinicians, scientists and academics with a specialist interest in cholangiocarcinoma from around the UK and who are default members of Cholangiocarcinoma-UK. The intention was for this meeting to be interactive, collaborative and open. Rather than being a one-off event, the hope was for this meeting to focus agreement on prioritising unmet needs and be the beginning of a long-term sustainable movement which would lead to meaningful change in the future.

ATTENDANCE

Capacity at the venue was 64, and 64 people registered to attend the meeting, of whom 54 attended on the day. Attendees were from a broad range of specialties, including HPB surgery, HPB Medicine/Endoscopy, Medical and Clinical Oncology, Basic Science, Pathology, Radiology, Specialist Clinical Nursing, Patient Advocacy, Grant Funding Bodies and Industry.

PROGRAMME

The full conference programme is given in Appendix 1. The morning session consisted of a series of 15 to 30 minute lectures highlighting the priorities of cholangiocarcinoma with respect to Patient advocacy, Epidemiology and Aetiology, Diagnosis & Biomarkers, Endoscopic Management, a national IPNB database, Ensuring Quality with Centres of Excellence/Expertise, Transplantation, Basic Science Research, Medical Oncology and Clinical Oncology. The afternoon consisted of round table, multi-disciplinary afternoon workshops. Delegates were split into six groups and asked to address three areas: Onco-policy, Service Development, Research and Innovation (Appendix 2).

EVALUATION of the CONFERENCE

Out of 54 delegates, 33 (61%) completed an evaluation form. Delegates were asked to rate their satisfaction with three key aspects of the meeting, event organisation, the morning session (presentations) and the afternoon session (workshops & feedback). The following scale was used: Very Satisfied / Satisfied / Dissatisfied / Very Dissatisfied. All respondents were either Very Satisfied or Satisfied with these three aspects of the meeting. A breakdown of responses is given in Appendix 3.

CONSENSUS MESSAGES & OUTCOMES

An open round up of feedback from all workshop groups was held at the end of the conference and notes taken. Furthermore, in the feedback forms delegates were asked the question: “*What one thing would you like Cholangiocarcinoma-UK to achieve?*” Respondents’ comments related to three broad areas: raising awareness; collaboration, in order to promote standards of care, and access to data, samples and other resources; and the facilitation of multi-partner research.

There was broad agreement on all these areas, i.e. what Cholangiocarcinoma UK should aim to take forward. The consensus outcomes are summarised below.

1: Onco-policy:

a) How best to highlight the increasing burden of cholangiocarcinoma as a cancer of unmet need?

- Accurately monitor epidemiological trends with updated data on mortality and incidence rates, nationally and regionally, including data on treatments, outcomes, risk factors
- Continue to lobby WHO/IARC/COSD (NCRAS, UK) for more accurate ICD coding
- Increase public awareness; consider engaging celebrity champions and art forms (“biliary tree”); engage social media, reach out to main media, charities and funders – that cholangiocarcinoma is a growing problem internationally
- Increase awareness amongst GPs re. rising cholangiocarcinoma: lower threshold for investigations
- Engage politicians e.g. via an All Party Parliamentary Working Group
- Liaise with other rare cancer groups for collaboration and learning opportunities

b) What should be the role(s) and structure of Cholangiocarcinoma UK going forward?

- Cholangiocarcinoma UK should be the “go to” professional voice for cholangiocarcinoma in the UK and should develop updated guidelines and standards of clinical care.
- Be an information source for the Public and Specialists, including for trial information which we should publicise widely
- Fight for funding: establish collaborative clinical trials alongside multi-platform research grant applications, multi-trial designs
- Consider a national database of cases and virtual biobank of tissue and biofluids

- Regarding the structure of Cholangiocarcinoma UK going forward:
 - Keep current working Chair and Committee stable for another 1-2 years
 - During 2019/2020, the committee should also work towards establishing Terms of Reference for the group, a formal Membership list, affiliation to relevant organisations (e.g. BSG, BASO) and election of subsequent Chair and full Committee
 - This meeting was mostly funded by BASL with some support from Sirtex and BTG. Future meetings should not rely on Industry sponsorship and we should move to charging a fee to attendees of future meetings

2: Service development:

a) Should the UK be moving towards centres of expertise/excellence, based on the premise that these centres provide quality assured multi-modality therapies including surgery (including transplantation)?

- The UK should be moving towards badged centres of expertise/excellence for cholangiocarcinoma care as there is unsatisfactory variability in the management of this cancer currently
- There should be set evidence based standards for all aspects of cholangiocarcinoma care, including surgery (pre and post-operative care), ERCP, EUS, interventional (e.g. PTC, ablation, embolisation) and diagnostic radiology, histopathology (including tissue/cytology acquisition, molecular profiling as standard), radiation and medical oncology, palliative care and Clinical Nurse Specialist expertise
- We need to ensure equitable and easy access for patients, most of whom present with advanced disease, to trials across the UK including for neoadjuvant treatments as well as to evidence based therapies via the NHS/NICE
- The aim should be to raise standards across the whole UK as many patients cannot travel long distances regularly for management

b) What are the clinical priorities in surgery, endoscopy and oncology?

- Surgery
 - Defining and offering operability in a timely fashion
 - Monitoring R0 resections and outcomes e.g. operative mortality, morbidity and recurrence, referral practices
 - Reconsider liver transplantation for select cases of CCA
- Endoscopy
 - Avoid local biliary intervention prior to specialist HPB MDT review
 - Ensure adequate expertise and access to stenting, brushings, spyglass, RFA
- Oncology/other aspects
 - Establish a standardised level of MDT including for data recording
 - Consider a national MDT for a rapid second opinion
 - Pathology: digital imaging for networks and maximising diagnostic yield

- Access to trials and biobanking of patient samples
- Consider the ENETS model
- Training: consider dedicated cholangiocarcinoma fellowships
- There should be continued mentoring beyond consultant level, including training abroad at centres with greater experience of cholangiocarcinoma

3: Research and innovation:

a) How best to develop a national database and virtual tissue bank?

- Cholangiocarcinoma UK may be best placed to develop this, with affiliated groups
- A virtual tissue bank should be supported by the UK Tissue Authority with SOPs for tissue and biofluids (serum, urine, bile) collection inc fresh tissue, tissue microarrays (include “normal” background tissue and appropriate controls/at risk individuals)
- Infrastructure for this may be achievable through a grant or award such as the CRUK Accelerator Award and in parallel with establishing collaborative clinical trials alongside multi-platform research grant applications, multi-trial designs inc basic science and translational medicine
- Establish a library of current databases in existence in the UK and Europe
- Fight for funding: establish collaborative clinical trials alongside multi-platform research grant applications, multi-trial designs

b) How to increase participation in clinical trials around the UK?

- Consider novel trial designs rather than simple RCTs which patients often do not like, preferring inclusivity of therapy
- Practice inclusive collaboration including recognition, authorship etc.

c) What are the basic science priorities?

- Production of a relevant model based on tissue collection
- Understanding the mechanisms of cholangiocarcinogenesis (inc the cell of origin), resistance, prognosis
- How to make a “cold” tumour “hot”
- Consider a dedicated cholangiocarcinoma basic science annual meeting

GOING FORWARD

This summary report of the Cholangiocarcinoma UK Meeting, including consensus messages & outcomes, will be reviewed by the Committee and shared with all members of Cholangiocarcinoma UK as well as being made available in the public domain. The Committee will consider how best to take forward the outcomes from this meeting.

Appendix 1: Cholangiocarcinoma UK Conference - 7th December, Meeting Programme

08:45 *Tea/Coffee/Registration*

09:15 **Welcome:** Cholangiocarcinoma UK: What and Why? *Shahid Khan*

Session 1: Chair - Derek Manas

09:30 The Patient/Healthcare Professional Partnership. *Helen Morement*

09:45 Epidemiology & Aetiology: What we don't know & how can we find out. *Shahid Khan*

10:00 Diagnosis & Biomarkers: The unmet needs and how we meet them. *Simon Rushbrook*

10:15 Endoscopic Management: what else do we need? *Steve Pereira*

10:30 IPNB database, *Michael Silva*

10:45 Tea/Coffee Break

Session 2: Chair – Nigel Heaton/Hassan Malik

11:15 Ensuring Quality: Centres of “Excellence/Expertise”? *Derek Manas, Hassan Malik*

11:30 Transplantation for CCA: should we and how could we deliver it nationally? *Nigel Heaton*

11:45 The basic science research priorities in CCA and how to address them. *David Bates & Simon Rushbrook*

Session 3: Chair - Maria Hawkins

12:30 Medical Oncology: The unmet needs and how we meet them. *John Bridgewater & Juan Valle*

13:00 Clinical Oncology: establishing novel roles in CCA therapy. *Maria Hawkins*

13:15 Lunch

14:00 to 16.00 (inc 15:00 Tea/Coffee Break)

Session 4: Round-Table MDT Workshops (6 groups) – meeting unmet needs: the ways forward

16.00 Feedback from workshops

16:45 Close *Shahid Khan*

*Cholangiocarcinoma UK is a Special Interest Group of BASL, which has provided funding for this meeting
Additional sponsorship for the meeting provided by BTG and Sirtex*

Appendix 2: Afternoon Workshop Groups

<u>Group 1</u> <u>start with Onco-policy</u>	<u>Group 2</u> <u>start with Service</u> <u>development</u>	<u>Group 3</u> <u>start with Research</u> <u>and innovation</u>	<u>Group 4</u> <u>start with Onco-policy</u>	<u>Group 5</u> <u>start with Service</u> <u>development</u>	<u>Group 6</u> <u>start with Research and</u> <u>innovation</u>
<u>Juan Valle (F)</u>	<u>John Bridgewater (F)</u>	<u>Maria Hawkins (F)</u>	<u>Shahid Khan (F)</u>	<u>Simon Rushbrook (F)</u>	<u>Steve Pereira (F)</u>
<u>Helen Morement (F)</u>	<u>Hassan Malik (F)</u>	<u>Geri Keane (F)</u>	<u>Derek Manas (F)</u>	<u>Nigel Heaton (F)</u>	<u>David Bates (F)</u>
<u>Matthew Cramp</u>	<u>Graeme Alexander</u>	<u>Anna Grabowska</u>	<u>BTG 2nd representative</u>	<u>Micol Damiani</u>	<u>Eman Alabaswy</u>
<u>Brian Davidson</u>	<u>Ahmed Al-Mukthar</u>	<u>Simon Harper</u>	<u>Anya Burton</u>	<u>Mariana Delfino-Machin</u>	<u>Thomas Armstrong</u>
<u>Andrew Fowell</u>	<u>Luke Boulter</u>	<u>Charles Imber</u>	<u>Shijie Cai</u>	<u>Rahul Deshpande</u>	<u>Muhammad N Iftikhar</u>
<u>Abhik Mukherjee</u>	<u>Chiara Braconi</u>	<u>Sheela Jayaraman</u>	<u>Rachel Guest</u>	<u>Roopinder Gillmore</u>	<u>John Issac</u>
<u>Manmohan Pabla</u>	<u>Helen Bungay</u>	<u>Nagappan Kumar</u>	<u>Syed Asim Ahmed Jafri</u>	<u>Rob Goldin</u>	<u>Kevin Gaston</u>
<u>Paul Ross</u>	<u>Dhanny Gomez</u>	<u>Debs Sarker</u>	<u>John Primrose</u>	<u>Keith Roberts</u>	<u>Michael Silva</u>
<u>John Scott</u>	<u>Mairéad McNamara</u>	<u>Nehal Shah</u>	<u>Ian Pope</u>	<u>Dinesh Sharma</u>	<u>Glyn Snowdon</u>
<u>Sian Thomas</u>	<u>Ankit Rao</u>	<u>Ajith Siriwardena</u>	<u>Douglas Thorburn</u>	<u>David Vass</u>	<u>Richard Syms</u>
<u>Hayley Whitaker</u>	<u>Jackie Whitlow</u>	<u>Roger Williams</u>			

Delegates were split into the above six groups and asked to address three areas:

1: Onco-policy:

- a) How best to highlight the increasing burden of this disease as a cancer of unmet need?
- b) What should be the role(s) and structure of CCA-UK going forward, including with this meeting?

2: Service development:

- a) Should the UK be moving towards centres of expertise/excellence, based on the premise that these centres provide quality assured multi-modality therapies including surgery (inc transplantation)?
- b) What are the clinical priorities in surgery, endoscopy and oncology?

3: Research and innovation:

- a) How best to develop a national database and virtual tissue bank?
- b) How to increase participation in clinical trials around the UK?
- c) What are the basic science priorities?

Appendix 3: Breakdown of Evaluation Responses

How satisfied were you with event organisation?

Very Satisfied 25; Satisfied 8; Dissatisfied 0; Very Dissatisfied 0

How satisfied were you with the morning session (presentations)?

Very Satisfied 25; Satisfied 8; Dissatisfied 0; Very Dissatisfied 0

How satisfied were you with the afternoon session (workshops & feedback)?

Very Satisfied 20; Satisfied 11; Dissatisfied 0; Very Dissatisfied 0; No reply 2