



# AMMF

The UK's only Cholangiocarcinoma Charity

*Helen M Morement*  
*CEO*



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THE CHOLANGIOCARCINOMA CHARITY

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- Most are diagnosed too late for potentially curative surgery
- The cause here in the West is generally unknown  
(it's sporadic)

## THE MAJOR PROBLEMS

- It's difficult to diagnose clearly and accurately
- Most are diagnosed too late for potentially curative surgery
- The cause here in the West is generally unknown (it's sporadic)
- Cholangiocarcinoma has one of the worst prognoses of any cancer, and this hasn't changed for decades



## AMMF'S MAIN AIMS:

- To raise the awareness of cholangiocarcinoma
- To encourage and support research
- To provide information to those who need it

## LACK OF ROBUST DATA: A MAJOR PROBLEM

There is a lack of robust data to prove what we are seeing.

And...

*“Without data you’re just another person with an opinion.”*

W. Edwards Deming,  
Data Scientist (1900 – 1993)



# PARTNERSHIP BETWEEN PUBLIC HEALTH ENGLAND AND AMMF



Public Health  
England

National Cancer Registration and Analysis Service – analysis proposal

**Name of project**

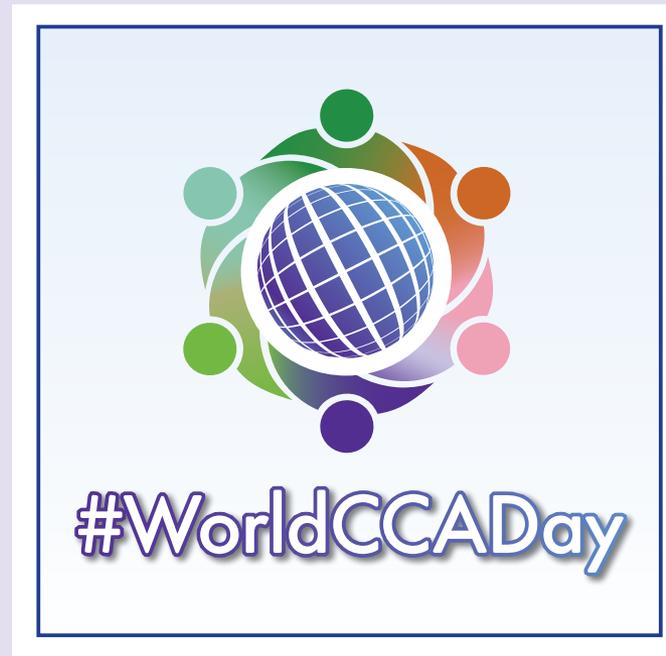
**Analysis of the Epidemiology of Cholangiocarcinoma in England**

**Authors: Shahid A Khan, Helen Morement, Mireille B Toledano  
(February 2018)**

This project should answer many of the questions we currently have relating to the epidemiological trends of cholangiocarcinoma, and provide some very useful and robust data, at last...



## WORLD CHOLANGIOCARCINOMA DAY



[www.worldccaday.org](http://www.worldccaday.org)

## INTERNATIONAL CCA WORKSHOP



Cholangiocarcinoma experts from around the world meet in London to uncover and discuss current challenges and unmet needs.



## GLOBAL CHOLANGIOCARCINOMA ALLIANCE

Sharing the same vision with closer global collaboration

“This multidisciplinary group is much-needed in tackling cholangiocarcinoma. It’s not something one organisation can do; it needs gifted people from a variety of backgrounds to make a difference.”

*Professor Shahid A Khan,  
Imperial College London*

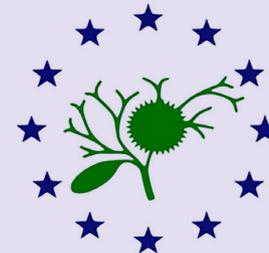


Global  
**Cholangiocarcinoma**  
Alliance



## THE EUROPEAN NETWORK FOR THE STUDY OF CHOLANGIOCARCINOMA

ENS-CCA is an association of research groups from thirteen European countries, actively working on basic, translational and clinical research into cholangiocarcinoma.



European Network for the Study  
of Cholangiocarcinoma

# THE EUROPEAN NETWORK FOR THE STUDY OF CHOLANGIOCARCINOMA



Next ENS-CCA Congress – Edinburgh 2020



## CHOLANGIOCARCINOMA-UK

A multi-disciplinary group of clinicians, scientists and patient advocates whose purpose is to facilitate collaborative research, enhance service development and raise the awareness of cholangiocarcinoma.



## AMMF AWARDS FOR RESEARCH



Since its inception in 2002, AMMF has awarded in excess of £1.5m to support cholangiocarcinoma research at many of the UK's leading research institutions, and internationally

In the words of Mr Leonard Cohen:

*“...there is a crack in everything,  
that’s how the light gets in ...”*





In the words of Mr Leonard Cohen:

*“...there is a crack in everything,  
that’s how the light gets in ...”*

Let’s start letting the light in today.





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**Thank you**