

# Helen M Morement

**CEO**

**AMMF – The Cholangiocarcinoma Charity**

**07 December 2018**

**London**



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THE CHOLANGIOCARCINOMA CHARITY



## THE FACTS:

- Cholangiocarcinoma is the second most common primary liver cancer in the world
- In 2013 it caused 2,161 deaths in England alone\*

\* *Figures published June 2015 by the National Cancer Intelligence Network*

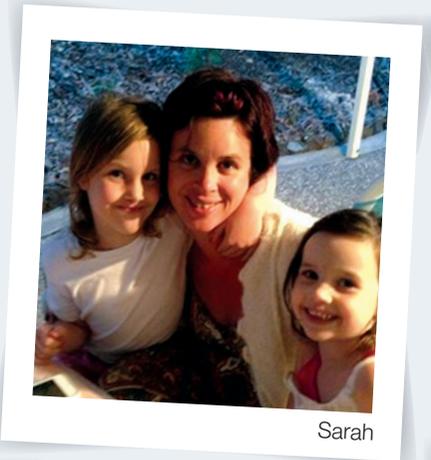
## THE FACTS:

- Cholangiocarcinoma is the second most common primary liver cancer in the world
- In 2013 it caused 2,161 deaths in England alone\*
- Fewer than 5% will survive one year from diagnosis
- The incidence is increasing, and we don't know why
- The age of those affected is getting lower, and we don't know why

*\* Figures published June 2015 by the National Cancer Intelligence Network*



Lucy-May



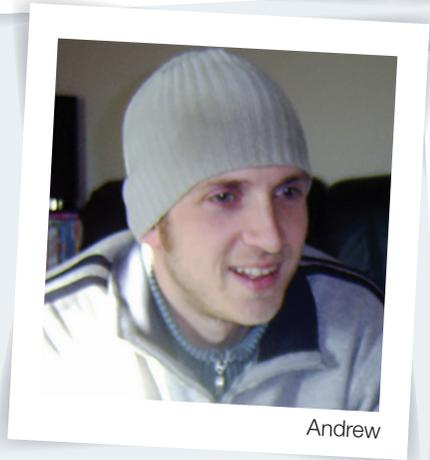
Sarah



Nicola



Greig



Andrew



Nick



Charlotte



Veronica

# THE MAJOR PROBLEMS

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- Most are diagnosed too late for potentially curative surgery
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- **There's a lack of robust data ...**

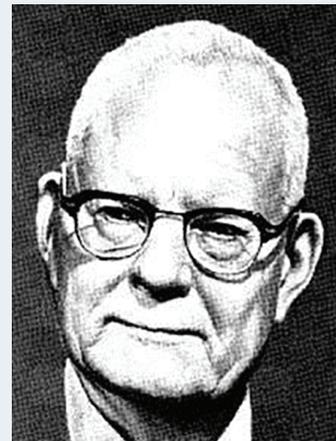
# THE MAJOR PROBLEMS

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)



# ICD-10

**ICD-10 Version:2010**

Search  [ Advanced Search ]

ICD-10 | Versions - Languages | Info

- ▼ ICD-10 Version:2010
  - ▶ I Certain infectious and parasitic diseases
  - ▼ II Neoplasms
    - ▼ C00-C97 Malignant neoplasms
      - ▼ C00-C75 Malignant neoplasms, stated or presumed to be primary, of specified sites, except of lymphoid, haematopoietic and related tissue
        - ▶ C00-C14 Malignant neoplasms of lip, oral cavity and pharynx
        - ▼ C15-C26 Malignant neoplasms of digestive organs
          - ▶ C15 Malignant neoplasm of oesophagus
          - ▶ C16 Malignant neoplasm of stomach
          - ▶ C17 Malignant neoplasm of small intestine
          - ▶ C18 Malignant neoplasm of colon
          - ▶ C19 Malignant neoplasm of rectosigmoid junction
        - C20 Malignant neoplasm of rectum
        - ▶ C21 Malignant neoplasm of anus and anal canal
        - ▼ C22 Malignant neoplasm of liver and intrahepatic bile ducts
          - C22.0 Malignant neoplasm: Liver cell carcinoma
          - C22.1 Malignant neoplasm: Intrahepatic bile duct carcinoma
          - C22.2 Malignant neoplasm: Hepatoblastoma
          - C22.3 Malignant neoplasm: Angiosarcoma of liver
          - C22.4 Malignant neoplasm: Other sarcomas of liver
          - C22.7 Malignant neoplasm: Other specified carcinomas of liver
          - C22.9 Malignant neoplasm: Liver, unspecified
        - C23 Malignant neoplasm of gallbladder
        - ▶ C24 Malignant neoplasm of other and unspecified parts of biliary tract
          - C24.0 Malignant neoplasm: Extrahepatic bile duct
          - C24.1 Malignant neoplasm: Ampulla of Vater
          - C24.8 Malignant neoplasm: Overlapping lesion of biliary tract
          - C24.9 Malignant neoplasm: Biliary tract, unspecified

**C22 Malignant neoplasm of liver and intrahepatic bile ducts**  
*Excl.:* biliary tract NOS ([C24.9](#))  
 secondary malignant neoplasm of liver ([C78.7](#))

**C22.0 Liver cell carcinoma**  
 Hepatocellular carcinoma  
 Hepatoma

**C22.1 Intrahepatic bile duct carcinoma**  
 Cholangiocarcinoma

**C22.2 Hepatoblastoma**

**C22.3 Angiosarcoma of liver**  
 Kupffer cell sarcoma

**C22.4 Other sarcomas of liver**

**C22.7 Other specified carcinomas of liver**

**C22.9 Liver, unspecified**

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**C23 Malignant neoplasm of gallbladder**

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**C24 Malignant neoplasm of other and unspecified parts of biliary tract**  
*Excl.:* intrahepatic bile duct ([C22.1](#))

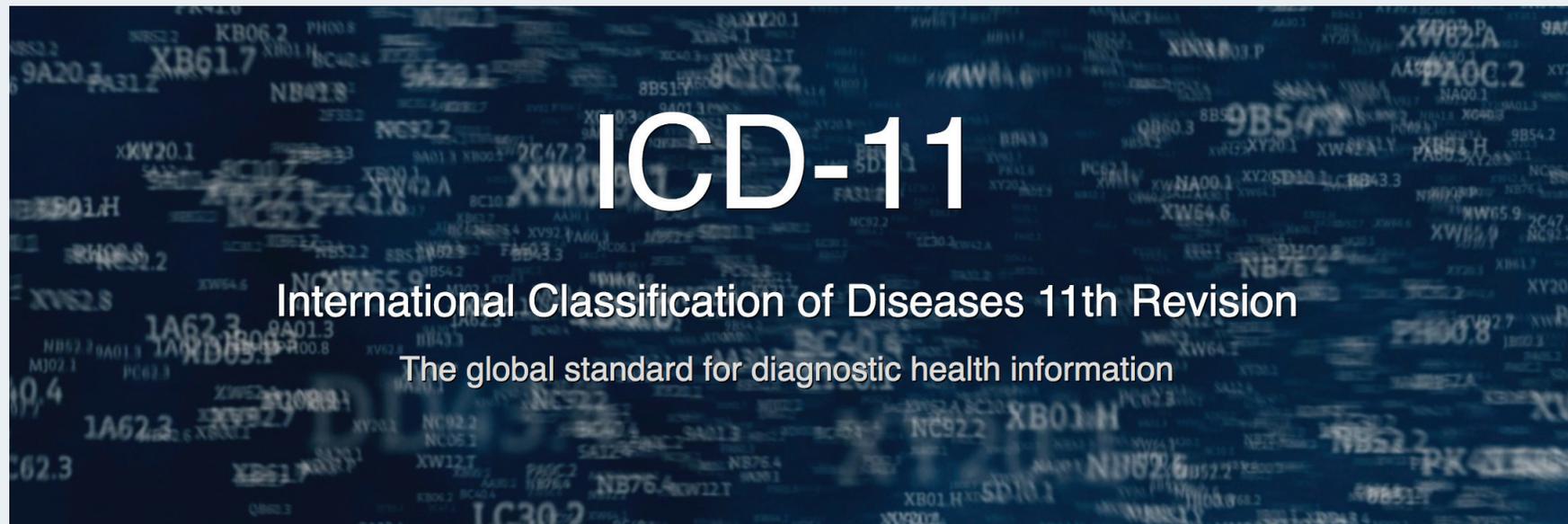
**C24.0 Extrahepatic bile duct**  
 Biliary duct or passage NOS  
 Common bile duct  
 Cystic duct  
 Hepatic duct

**C24.1 Ampulla of Vater**

**C24.8 Overlapping lesion of biliary tract**  
 [See note 5 at the beginning of this chapter]  
 Malignant neoplasm involving both intrahepatic and extrahepatic bile ducts  
 Malignant neoplasm of biliary tract whose point of origin cannot be classified to any one of the categories C22.0-C24.1

**C24.9 Biliary tract, unspecified**

# INTERNATIONAL CLASSIFICATION OF DISEASES 11TH REVISION



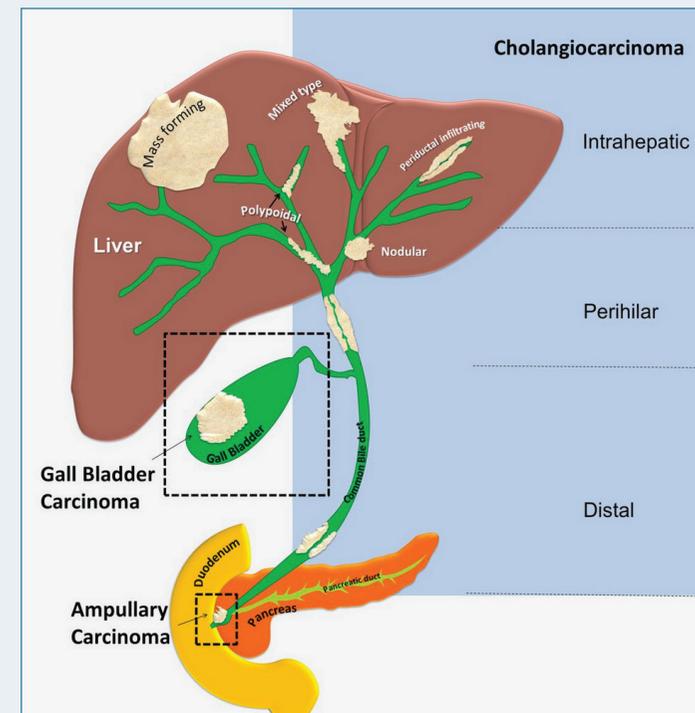
<https://icd.who.int>

# ICD-11 HAS RE-CODED CHOLANGIOCARCINOMA:

2C12.10 Intrahepatic cholangiocarcinoma

2C18.0 Hilar Cholangiocarcinoma

2C15.0 Extrahepatic cholangiocarcinoma:  
Adenocarcinoma of biliary tract,  
distal bile duct





**CHOLANGIOCARCINOMA**  
**UK**



# Thank you