

# THE REWARDS OF CANCER DATA: Benefits to Cancer Patients – the CUP Case

**John Symons**  
Director

cancer of  
unknown  
primary  
foundation



Jo's  
friends



# Intelligence

“NEVER WAS SO MUCH  
OWED BY SO MANY  
TO SO FEW” *THE PRIME MINISTER*



# CUP IS A SIGNIFICANT - OFTEN UNRECOGNISED - PROBLEM

**5<sup>th</sup>** highest cause of cancer  
death in the UK. **30** people in  
the UK die *each day* from CUP.

CUP

CRUK 2013 data @ Jan 2016

**21%** in the  
most deprived  
socio-economic  
group. NCIN

Ratio of **1** male to **1.2** females

**57%** of patients  
diagnosed with CUP in  
the UK present as an  
emergency, compared  
with 23% for all cancers.  
NCIN 2006-2010

**50%** of UK CUP  
patients are aged 50-80  
(**45%** aged 80 and over ).  
NCIN 2006-2010

# Why 'Unknown' Primary?

Hypotheses:

- Primary the size of a grain of rice. Cancer spread (Metastasis) occurs very early when the primary is unusually small – often too small to be picked-up by present day tests including ultrasound, CT scans, MRI and PET - and the primary remains dormant.
- The primary shrinks or disappears:
  - Cancer growth is diverted to the seeding cells with the primary starved of nutrients
  - Pushed out of the body if, for example, hanging perilously to part of the digestive system after it has spread.
- Fallen on stony ground. The primary is successfully attacked by the immune system as it tries to get a toehold but has already shed cells that migrate through the body to find 'sanctuary' sites (where they can thrive and confuse or hide from the immune system.)

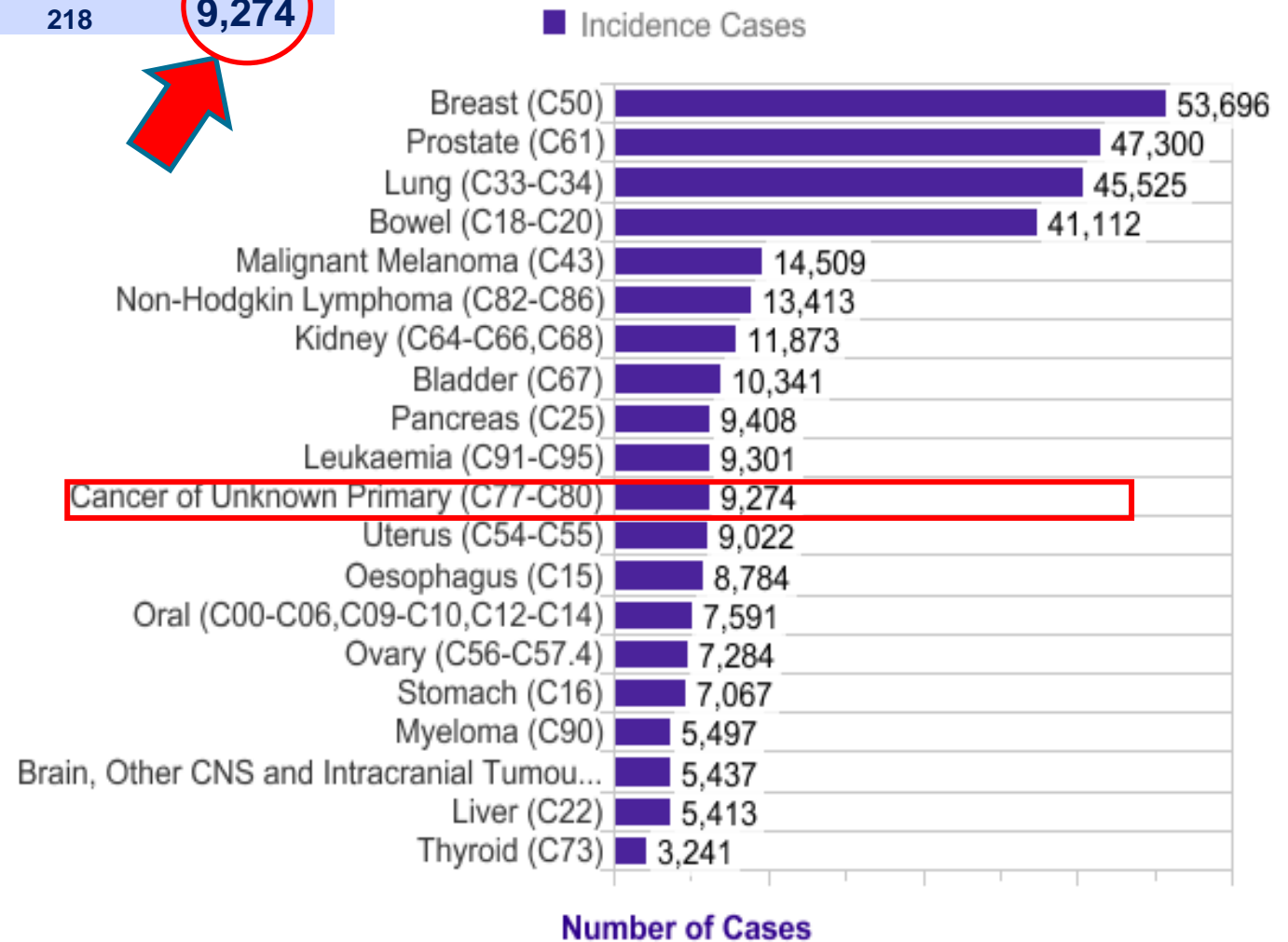
# CUP INCIDENCE, 2013 (3% of all cancer cases)

	England	Wales	Scotland	Northern Ireland	UK
Male	3,636	258	375	103	4,372
Female	4,021	306	460	115	4,902
Persons	7,657	564	835	218	<b>9,274</b>

**CUP is the 11<sup>th</sup> commonest cancer in the UK**

- 13<sup>th</sup> commonest in men
- 8<sup>th</sup> commonest in women

Cancer Site

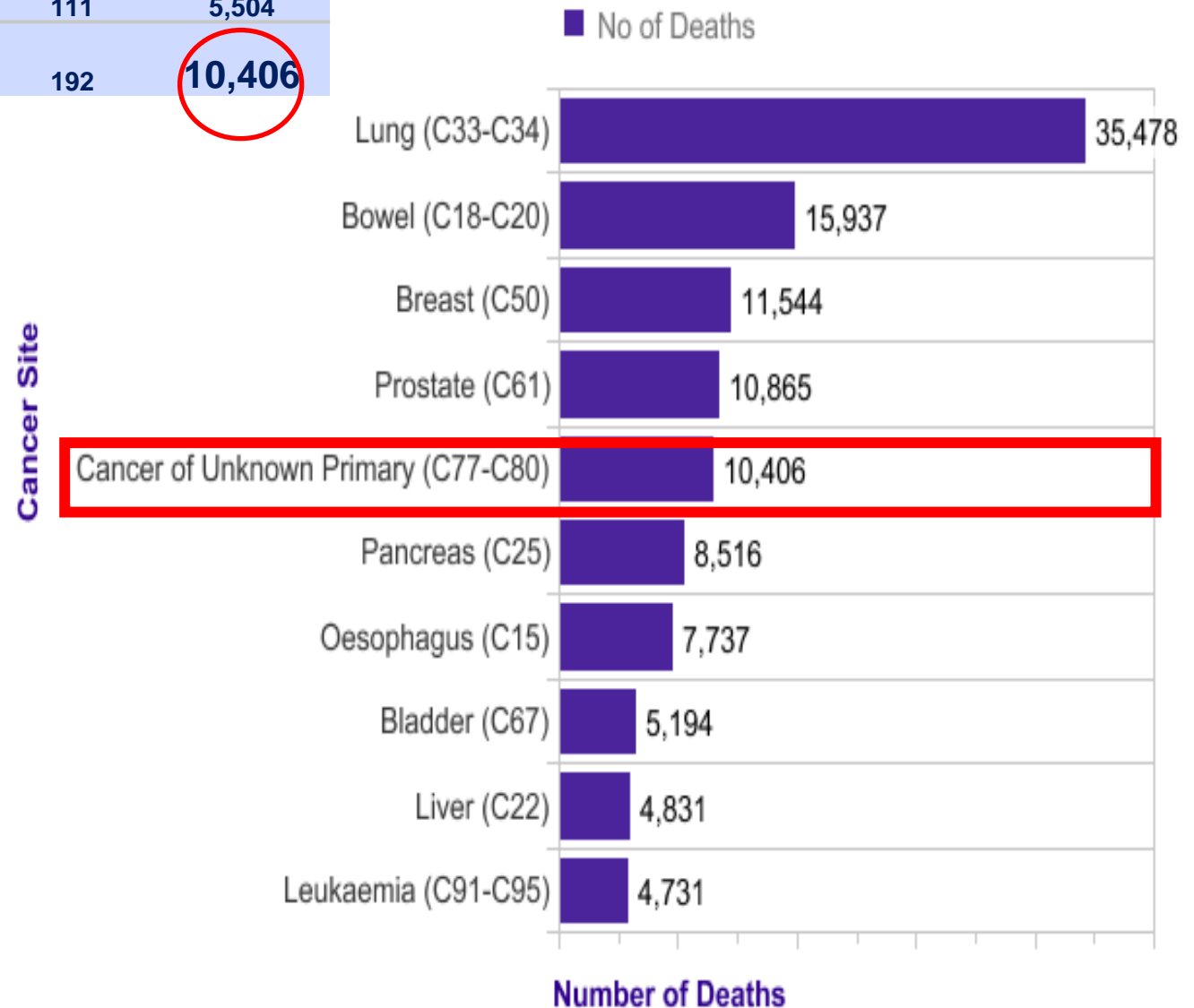


# CUP MORTALITY, 2013 (6% of all cancer deaths)

	England	Wales	Scotland	N Ireland	UK
Male	4,171	293	357	81	4,902
Female	4,612	338	443	111	5,504
Persons	8,783	631	800	192	<b>10,406</b>

**CUP is the 5<sup>th</sup> highest cause of cancer death in the UK**

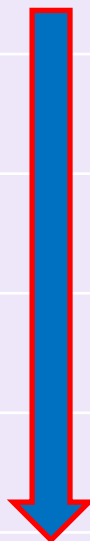
- 5<sup>th</sup> commonest in men
- 4<sup>th</sup> commonest in women






# SLOW FALL IN CUP (ICD10 C77-80) INCIDENCE AND MORTALITY AS DIAGNOSTIC TECHNIQUES IMPROVE

## UK INCIDENCE

Year	New Cases	Decline
1993	14,693	
2003	12,875	
2013	9,274	
		37%

## UK MORTALITY

Year	Deaths	Decline
1993	14,420	
2003	13,625	
2013	10,406	
		28%

UK (ICD-10 C77-80)				
Incidence			Mortality	
Year	No. of new cases	Rate* per 100,000	No. of deaths	Rate* per 100,000
1996	15,838	20.4	15,024	19.4
1998	14,972	19.0	15,259	19.3
2000	14,013	17.3	14,559	18
2002	13,428	16.1	14,058	16.7
2004	12,640	14.8	13,288	15.4
2006	11,566	13.1	12,267	13.7
2008	10,752	11.9	11,228	12.0
2010	9,585		10,472	10.7
2012	9,620		10,625	

\*Age-standardised to the European Population.  
Source: NCIN & CRUK

UK CUP Incidence by ICD code C77-80		
ICD Code:	2009	2008
<b>C77:</b> Secondary and unspecified malignant neoplasm of lymph nodes	972	854
<b>C78:</b> Secondary malignant neoplasm of respiratory and digestive organs	3,163	3,388
<b>C79:</b> Secondary malignant neoplasm of other sites	1,230	2,189
<b>C80:</b> Malignant neoplasm without specification of site	5,105	4,321
<b>Total (C77-80)</b>	<b>10,470</b>	<b>10,752</b>

### Not counted as CUP:

**C76** (Malignant neoplasm of other & ill-defined sites),

**C26** (Malignant neoplasm of other & ill-defined digestive organs),

**C39** (Malignant neoplasm of other & ill-defined sites in the respiratory system and intrathoracic organs)



**INTELLIGENCE: My weapons**  
**DATA: My ammunition**

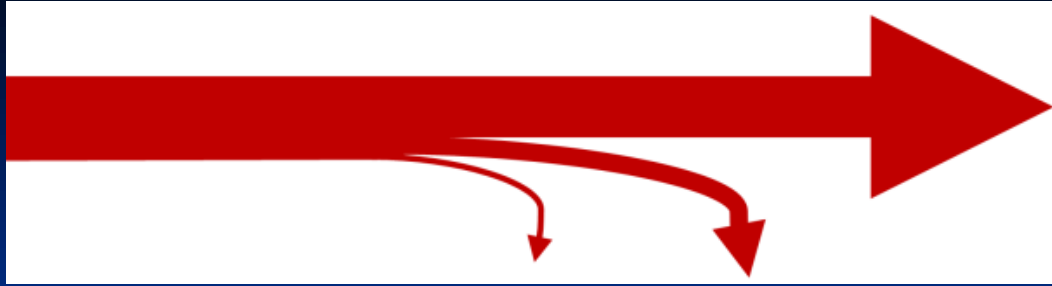
Processed CUP data give us:

- knowledge and understanding; what we know, and don't know, about the burden of the disease
- the evidence we need to communicate effectively, in particular the analytical frameworks to argue logically for action: (research , resources etc.)



**METASTATIC SITE**

Liver  
(14)



**cCUP 71% (10)**

Small Bowel 7% (1)

Pancreas 21% (3)

**cCUP** Lung Pancreas  
**25% (3)** 25% (3) 17% (2)

Bone  
(13)



Renal 17% (2)

Ovarian 8% (1) Prostate 8% (1) Haem 8% (1)

Peritoneal  
(9)



**cCUP 67% (6)**

Lung 11% (1)

Ovarian 22% (2)

**Metastatic Site at final diagnosis.**  
**From POOLE HOSPITAL Annual Report 2014**

# FROM NIHILISM TOWARDS SOLUTIONS

The data framework for communication and logical argument to help power change



# Making the unknown, known



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www.ncin.org.uk/publications/data\_briefings/cancer\_of\_unknown\_primary

home > Publications > Data Briefings > Cancer of unknown primary

**NCIN**  
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Using information to improve quality & choice

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**PUBLICATIONS**

- Reports
- Data Briefings
- Guidance Documents
  - Local Awareness and Early Diagnosis Baseline Guide
- Peer Reviewed Publications

**Cancer of Unknown Primary**

**What is Cancer of Unknown Primary?**

This briefing looks at individuals whose tumour is recorded to one of the secondary or unspecified ICD-codes. Patients are recorded as having Cancer of Unknown Primary (CUP) if the primary site of the malignancy cannot be established or the tumour has been registered without specification of site. Most patients have relatively poor outcomes. The uncertainty of the primary site of the tumour at time of treatment often severely impedes the management and treatment of patients. The statistics presented here are our best current understanding of the incidence of CUP.

CUP is open to different definitions. Although there is not a specific classification in the International Classification of Disease (ICD) nomenclature, the 2010 NICE Guideline (<http://www.nice.org.uk/CG104>) proposed that the majority of CUP can be covered by the ICD tenth revision (ICD-10) codes C77-C80. Descriptions and the number of newly diagnosed cases (incidence) for CUP by ICD-10 code in the UK in 2009 are shown below.

**KEY MESSAGE:**

*CUP accounts for 3.3% of all newly diagnosed cancers in the UK, and 7.1% in those aged 85+. Incidence rates have fallen by around 40% since the mid 1990s due to improved registration practice and advances in diagnostic methods. Further analyses are needed to improve diagnosis and treatment for these patients.*

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Order Confirmation x www.cupfoundjo.org/wp-content/uploads/2014/01/Routes-to-diagnosis-briefing-note.pdf

www.cupfoundjo.org/wp-content/uploads/2014/01/Routes-to-diagnosis-briefing-note.pdf

Apps National Rail Enqui... First Great Western ... Classic FM BBC NEWS National Rail Enqui... Cancer Research UK... CUP Imported From IE BBC - Radio

**Routes to Diagnosis: Cancer of Unknown Primary**

**NCIN Data Briefing**

**Background**

The Routes to Diagnosis (RTD) study has been updated to include all patients diagnosed in 2006-2010, covering 1.3 million newly diagnosed tumours. The methodology has remained the same as the previous RTD publication.<sup>1</sup> An improvement in the completeness of Hospital Episode Statistics (HES) data linked to cancer registrations has led to HES data being available for more tumours than in the previous iteration of RTD.

This five year cohort enables overall Routes to be calculated for less common cancer sites, which previously had too few cases to produce meaningful results. This data briefing looks at the results for "Cancer of Unknown Primary", included for the first time, with breakdowns available by sex, age and deprivation.

**Cancer of Unknown Primary**

Patients are recorded as having Cancer of Unknown Primary (CUP) if the primary site of the malignancy cannot be established or the tumour has been registered without specification of site. In the period under study, CUP was a term applied to a spectrum of conditions ranging from "malignancy of undefined origin (MUO)", where metastatic disease has been identified without an obvious primary site, but prior to full investigation, and "confirmed CUP (cCUP)" when metastatic malignancy has been confirmed (usually) histologically and all relevant investigations have failed to determine the origin. It is believed that cases conventionally recorded as CUP fall predominantly into the latter category. CUP accounted for 3% of all tumours in this cohort. There were 44,100 cases of CUP diagnosed in 2006-2010, with a ratio of 1 male to 1.2 females; 5% of patients were aged under 50 and nearly 40% were aged 80 and over. There was a statistically significant difference in the proportion of CUP patients by socio-economic gradient, with 17% in the least deprived compared to 21% in the most deprived group.

**KEY MESSAGES:**

- 57% of patients diagnosed with Cancer of Unknown Primary presented as an emergency, which reflects the non-specific symptoms experienced by these patients.
- One-year survival for Cancer of Unknown Primary for managed Routes is above 24%, whereas for those who present as emergencies it is 5%.

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# Routes to Diagnosis

# Briefing Sheet



# Making the unknown, known

- NICE guidelines [CG104] Published date: July 2010
- NCIN annual conferences
  - 2011. NCIN conference Poster CUP – a study of data inequality.
  - 2012. NCIN conference Poster CUP – a rare disease?
  - 2013, NCIN Brighton. Chair of opening plenary
  - 2014. NCIN Birmingham. *The Challenges of Coding Cancer Of Unknown Primary (CUP) – A Survey Of Current Practices in the UK, Ireland and Australia.* Claire Vajdic, Claudia Oehler, Nicola Cooper, John Symons.

## NCIN SSCRGs

Breast cancer  
Children & TYA cancers  
CNS cancers  
Colorectal cancer  
Gynaecological Cancers  
Haematological cancers  
Head & neck cancers  
Lung cancer  
Sarcomas  
Skin cancer  
Upper GI cancers  
Urological cancers

Where  
does CUP  
fit in?



# Research into Coding Issues



CRUK-NCIN  
Partnership Project



## Registries:

Australia 8

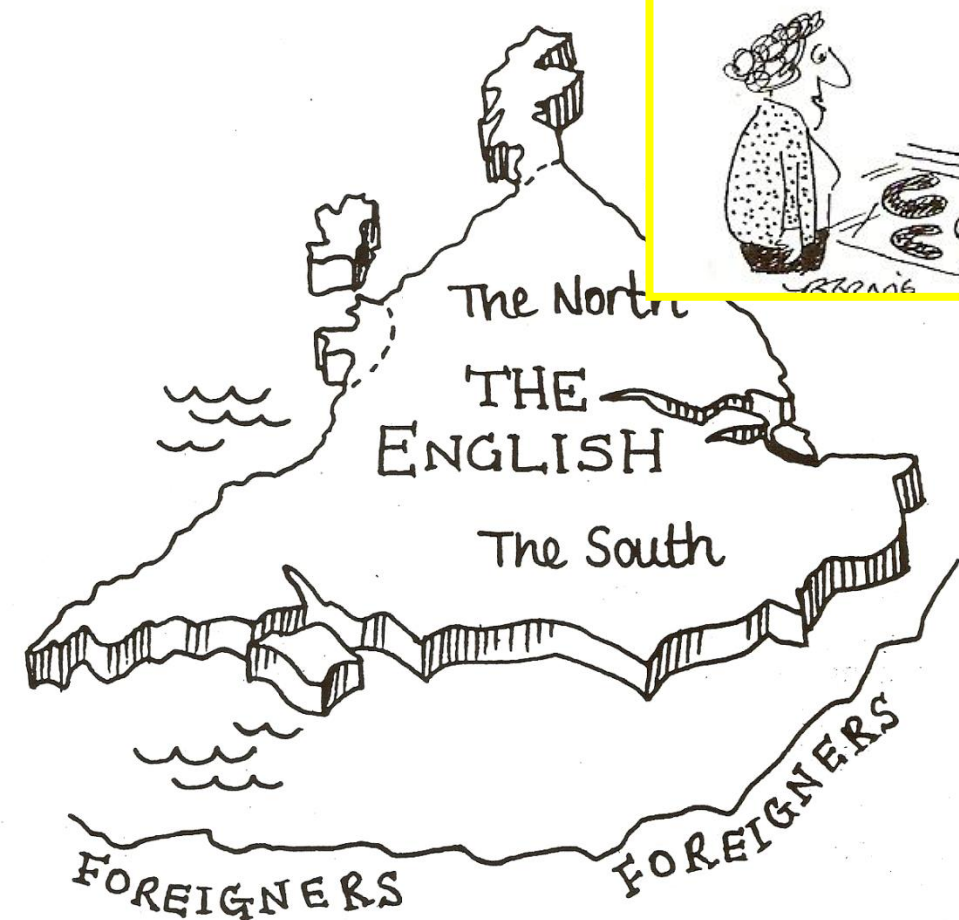
Ireland 1

England 8

Scotland 1

Wales 1

N Ireland 1





## The challenges of coding Cancer of Unknown Primary (CUP)

A survey of current registration and reporting practices in the UK, Ireland and Australia

Claudia Oehler<sup>1</sup>, Claire Vajdic<sup>2</sup>, Nicola Cooper<sup>1</sup> and John Symons<sup>3</sup>

1. National Cancer Intelligence Network, Public Health England  
2. University of New South Wales, Australia  
3. Cancer of Unknown Primary Foundation, UK

- **No consistent national or international coding guidance** for registering and reporting CUP resulting in varied cancer registration practices.
  - **Reporting practices vary** with some registries using ICDO3 codes and others using different ICD10 codes to represent CUP.
- Differing interpretations of: ICDO3 and ICD10 codes, the investigation of death certificate only notifications, electronic notifications, consideration of prior registrations of site-specific cancers, and the types of notifiers.
  - Variation in coding practices for tumours with non-epithelial morphologies such as melanoma and sarcoma, and the use of ill-defined primary site codes such as 'gastrointestinal' cancer.



# Our Weapons: INTELLIGENCE underpinned by DATA



**DATA GIVE PATIENTS, &  
THEIR ADVOCATES, POWER**



# www.cupfoundjo.org

The image shows a screenshot of a web browser displaying the CupFoundJo website. The browser's address bar shows the URL www.cupfoundjo.org. The website's navigation menu includes links for Home, What is CUP?, Diagnosis, Treatment, Support, Forum, Research, News, and Contact. The main header features the text "CANCER OF UNKNOWN PRIMARY FOUNDATION" and the "Jo's friends" logo. Below the header, there is a large banner image of a woman sitting in a field of purple flowers, reading a book. Overlaid on this image is the text "Information & support for people affected by CUP". Below the banner, there are four blue circular buttons labeled "Diagnosis", "Treatment", "Support", and "Research". At the bottom of the page, the text "Cancer Of Unknown Primary (CUP)" is visible on the left, and a quote "A valuable website that has" is partially visible on the right.

Navigation: Home, What is CUP?, Diagnosis, Treatment, Support, Forum, Research, News, Contact

Header: CANCER OF UNKNOWN PRIMARY FOUNDATION, Jo's friends, About Jo's friends +, Support our work +

Banner: Information & support for people affected by **CUP**

Buttons: Diagnosis, Treatment, Support, Research

Footer: Cancer Of Unknown Primary (CUP), "A valuable website that has"

**CUP**

cancer of  
unknown  
primary  
foundation

