

Data to Insight to Change

**National Cancer Intelligence
Annual Conference June 2009**

Ciarán Devane - Chief Executive

A model partnership !

- **Five Funding Partners**

- CR-UK, Dept of Health, NCAT, Macmillan, MRC

- **20+ Collaborators**

Office for National Statistics
Scottish Cancer Registry
Northern Ireland Cancer Registry
Welsh Cancer Intelligence and Surveillance Unit
Northern and Yorkshire Cancer Registry
North West Cancer Registry and Information Service
Trent Cancer Registry
West Midlands Cancer Intelligence Unit
Oxford Cancer Intelligence Unit
Eastern Cancer Registry and Information Centre
Thames Cancer Registry

South West Public Health Observatory
National Registry of Childhood Tumours
National Cancer Services Analysis Team
Cancer Research UK Statistics Team
London School of Hygiene and Tropical Medicine
NHS National Cancer Action Team
Breakthrough Breast Cancer
Cancer Research UK
Macmillan Cancer Support
onCore UK
NHS Information Centre

- **Professional Associations**

UK Association of Cancer Registries (UKACR)
Association of Public Health Observatories

**WE ARE
MACMILLAN.
CANCER SUPPORT**

2 MILLION

Who are the two million cancer survivors?

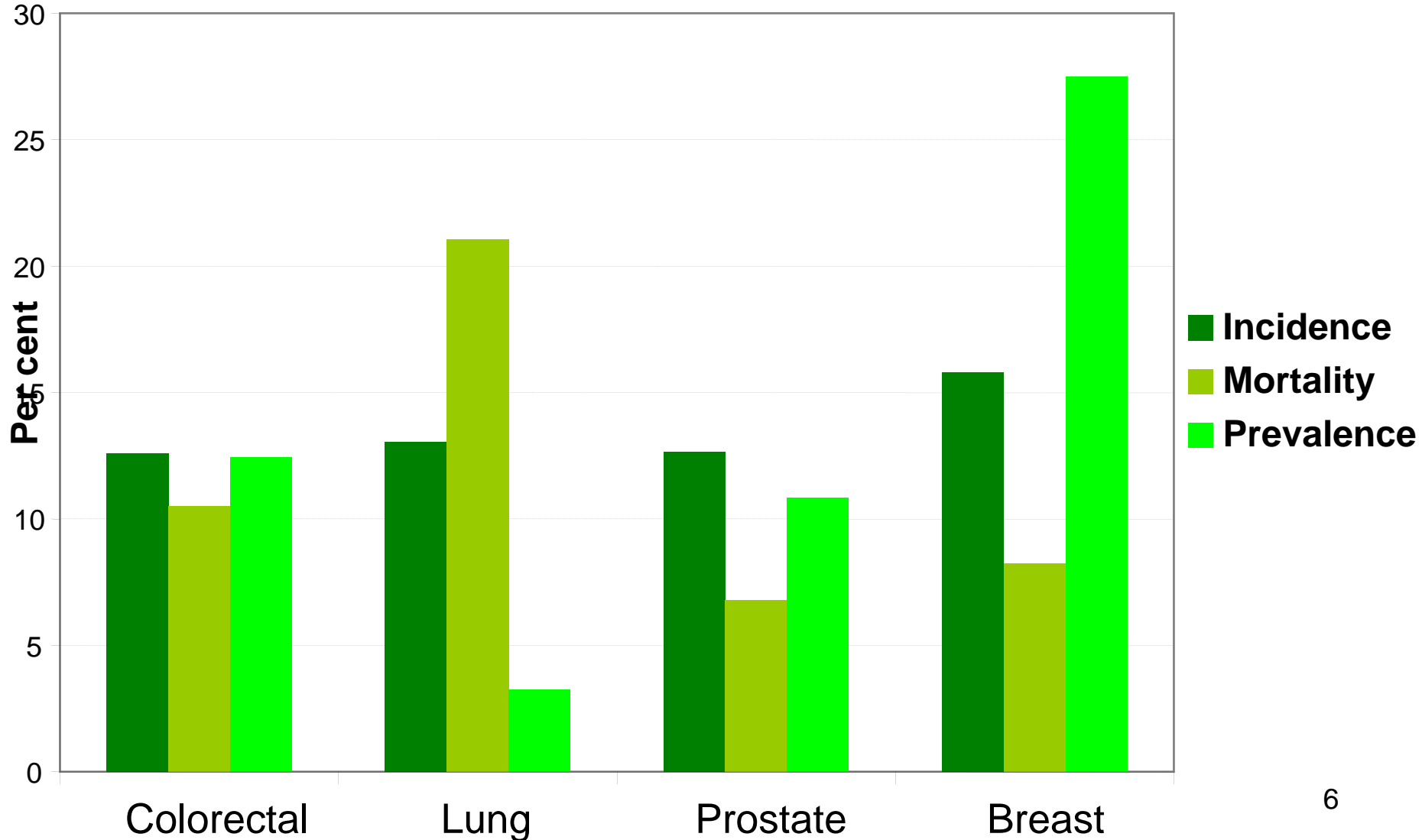
Sex	Cancer survivors	%
Male	800,000	40
Female	1,200,000	60

Age	Cancer survivors	%
0-17	16,000	0.8
18-64	774,000	38.7
65+	1,210,000	60.5

What cancers are they living with?

Cancer Site	Cancer survivors	%
Colorectal	250,000	12
Lung	65,000	3
Breast	550,000	28
Prostate	215,000	11
Other	920,000	46

Prevalence by site differs from incidence and mortality by site



The next stage is to link prevalence data with other data sets and insights . . .

- **90% survive early stage bowel cancer**
- **1.3 million people have made it past 5 years**
- **150 000 people die of cancer each year**
- **GP education doubles urgent referral for bowel cancer**
- **71% of people those in the 10+ years cohort report physical and emotional problems**
- **Community palliative care allows 80% to die where they choose**

2 MILLION

Ian's story – a success???

- **Aged 57, married with a son and lives in Surrey**
- **Headteacher**
- **Diagnosed in November 2003 with colorectal cancer + liver secondaries**
- **Chemotherapy, radiotherapy and surgery**
- **Is alive**



Some questions . . .

- How unusual is seven years of GP visits before diagnosis?
- When is endoscopy not offered with severe rectal bleeding at A&E?
- How prevalent is a parastomal hernia ?
- How many bowel cancer patients stop work because of severe fatigue ?
- What psychological support services reduce the distress of living with a colostomy ?

What are the NCIN priorities ??



Natural Histories

Variability

Compliance

The whole pathway

**The patient's view of
outcomes (as well as . . .)**

What are the NCIN priorities ??



Complete infrastructure

Produce outputs

**Think about, scrutinise,
link together . . .**

Promote transparency

Drive insight

Success is using that insight to get better care for 2 million people like Ian

- Diagnosed seven weeks not years
- Treatment does not require colostomy
- No consequent hernia
- Still at work
- Confident
- A real success



THANK YOU

