

The changing face of cancer: an alternative story

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The changing picture: some themes and implications

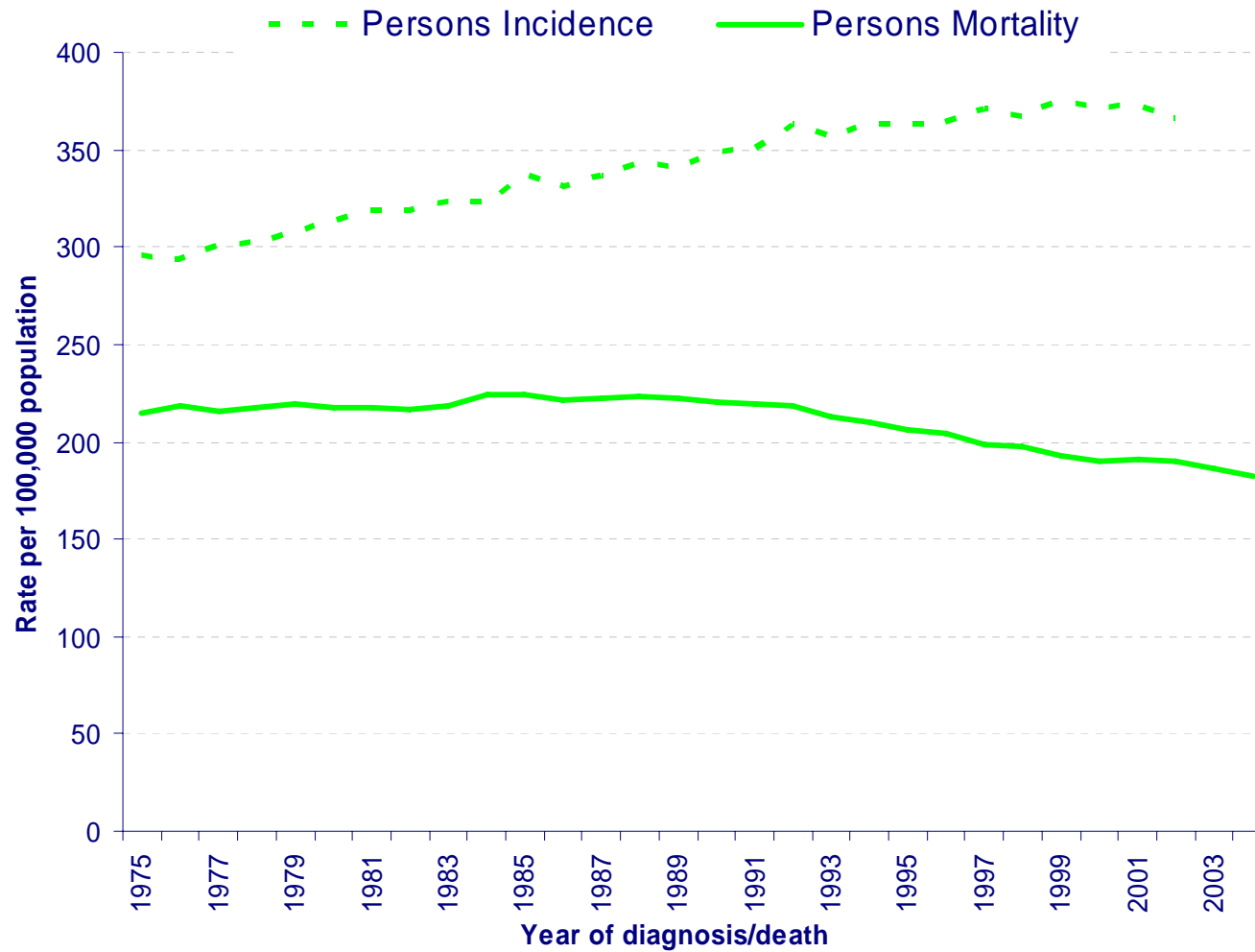
- **Chronicity**
- **Disability**
- **Inequity**
- **Identity**

Chronicity



Chronicity

Age standardised (European) incidence and mortality rates, all cancers (exc NMSC), Great Britain, 1975-2004



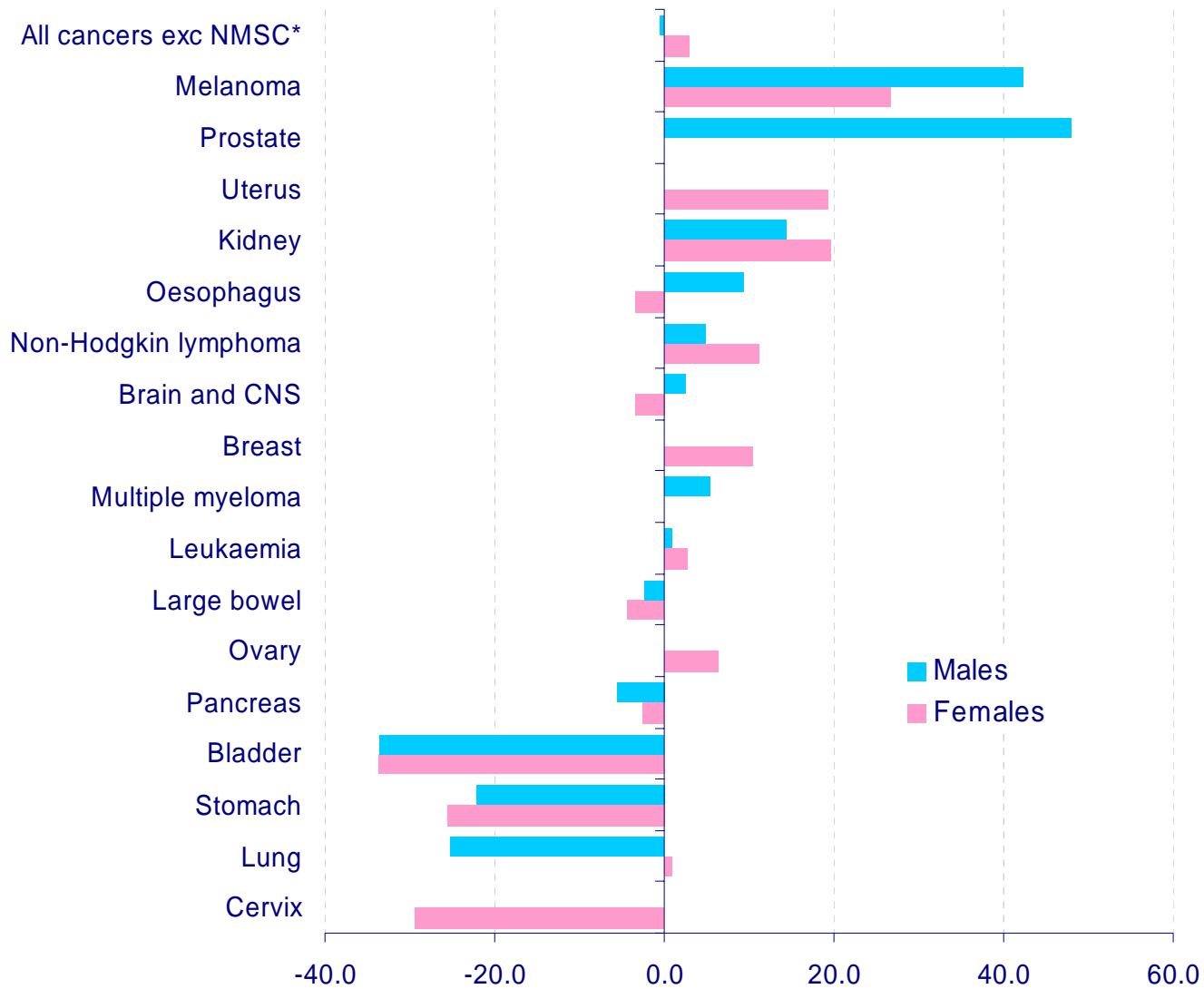
Cancer prevalence

UK 2000 estimates of total prevalence from EUROPREVAL study (2002)

Breast (female)	172,000
Large bowel	77,000
Lung	32,000
Prostate	31,000
Melanoma	31,000
All cancers	1,207,000

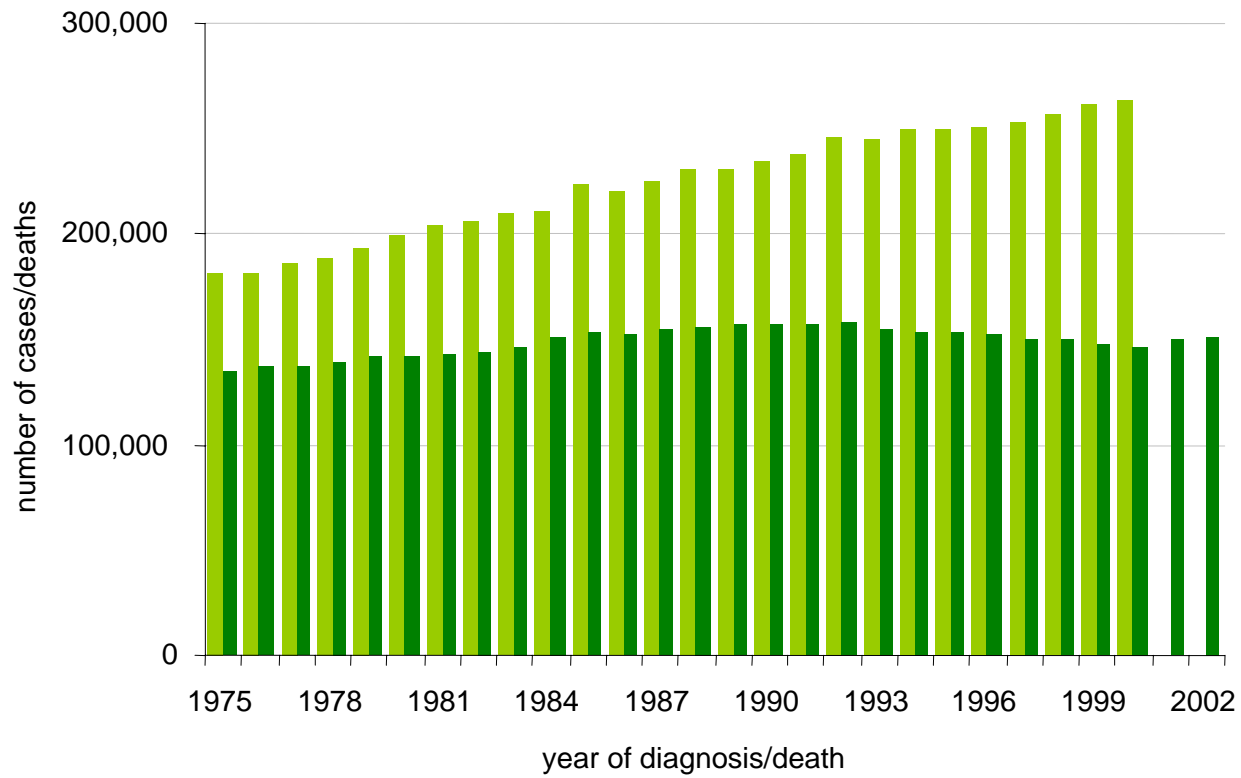
Cancer trends

Percentage change in the age standardised (European) incidence rates, major cancers, UK, 1993-2002



A growing gap

Numbers of cases and numbers of deaths from cancer in Britain 1975-2002



Cancer Survivors in the US: The National Health Interview Study

Hewitt et al, 2003. Journal of Gerontology: 58(1) 82-91)

- 95,000 people – 4,878 reported a history of cancer
- Comparison of cancer survivors with those without a history of cancer. Current status at time of interview:
 - Psychological problems
 - Limitations in activities of daily living (ADL)
 - Instrumental ADL
 - Functional limitations
 - Health-related limitations in ability to work

survivorship

- 29 million adult survivors of cancer in the US – 4.8% of the population
- Respondents who were cancer survivors were:
 - Older
 - More likely to be female (breast, cervix, uterus or ovarian cancer)
 - To have chronic medical conditions
 - To have lower educational attainment
 - Ranged from within 2 years of diagnosis to >20 years

disability



Is a history of cancer a risk factor for poor health and disability?

- Cancer survivors significantly more likely to:
 - Report poor health
 - Have 3 or more chronic conditions
 - Have psychological problems
 - Have one or more limitations of ADL or IADL
 - Be unable to work through health problems (for those under 65)

(Controlled from socio-demographics and health characteristics, eg other chronic illnesses)

Characteristics associated with poor health and disability

- Lung cancer, leukaemia, lymphoma
- Younger people (diagnosed before 45 years) – increased risk of psychological problems
- Co-morbid conditions – increased risk of poor health
- Current or former smokers

Service use

- Physician consultations double that of those without cancer
- Greater use of therapy services, physio, OT etc
- >1/3 reporting psychological problems – had seen a mental health professional in the last year

- Likelihood of poor health and disability 5-10 times higher than expected among those with another chronic illness
 - Late effects of treatment
 - Consequences of underlying risk factors for cancer
 - Even among younger cancer survivors cardiovascular disease, functional and work limitations are high
 - 1 in 6 cancer survivors of working age unable to work
 - Risk of psychological problems not lowered by time from diagnosis

inequity



inequity

- The 'deprivation gap' –
 - Coleman et al (2004) the gap in survival between rich and poor wider for patients diagnosed in the late 1990's than in the late 1980's
- Geographical inequalities – Jack et al (2003) the proportion of patients receiving active treatment for lung cancer varied between health authorities
 - 5% and 17% (investigations)
 - 8% and 30% (chemotherapy)
 - 15% and 42% (radiotherapy)
 - 1 year survival (11% - 34%)

Vulnerable groups and access to health care

(SDO briefing paper)

- People more likely to access services they think are high quality
- People less likely to use services that make them feel a burden or time waster
- To make use of health services people need knowledge, information and language resources practical resources(cars, childcare, telephones and time away from work)
- Professional decisions can disadvantage people of BME groups, older people and poorer people
- High levels of non attendance is a signal that the service is difficult to use

identity



identity

- Self-narrative – part of all our worlds: these are inherent to our sense of identity
- These are disrupted and need to be re-negotiated in illness
 - Threats to identity
 - Bodily areas
 - Relationships under stress
 - Encounters with medical institutions
- A diagnosis of cancer challenges self narratives and motivates the search for newer narratives that incorporate the meaning of illness

How is narrative/identity work to be supported in cancer care?

(Mathieson and Stam, 1995 Sociology of Health and Illness, 17(3) 283-306)

- Psychosocial framework should focus on need for continual readjustment of identity:
 - Using a narrative approach to people's experience
 - Does not superimpose a professional model on such experience
 - Rejects the idea that an individual can 'manage' adjustment to cancer

What does this mean for cancer networks?

- Need to organise services around the long-term consequences of cancer
- Address all phases of illness
- Give priority to issues of chronicity, disability, inequity and identity



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