Why the use of cancer data is so important, and why the current model is so valuable

LONDON SCHOOL of HYGIENE &TROPICAL MEDICINE

Cancer Research UK Cancer Survival Group

National Consent Model Workshop
London, 21 April 2016

UICC World Cancer Declaration 2013

"One overarching goal"

There will be major reductions in premature deaths from cancer, and improvements in quality of life and cancer survival.

www.uicc.org/world-cancer-declaration, 25 November 2013

Private autonomy *vs.* public interest

How do we balance the individual's right to privacy with society's right to understand the health risks we all face, and how effectively those risks are being controlled?

Data protection and sharing for research

Potential risks
Societal benefits
Threats to data sharing for research
A way forward …

Use of identifiable data: public interest

Risks and benefits

Potential risk to individuals
- Some loss of autonomy
- Very low risk of breach of confidentiality

Proven benefit to individuals *and* society
- Causes of cancer – prevention
- Incidence – planning
- Survival – effectiveness of health system
- Survivorship – quality of life, rehabilitation, care

The individual and society

From the general to the particular
Search data about individuals to select someone for action (tax, arrest, …)

From the particular to the general
Analyse data about individuals to inform society, but not to identify any person

Population-based cancer registry

Attempts to record information on all new cases of cancer in a defined population

Person:	***habitual resident***
Place:	***defined territory***
Time:	***continuous***

"…the most valuable data are, undoubtedly, the rates obtained by the occurrence of *every* case of cancer over a specified period"

Doll *et al.* Cancer Incidence in Five Continents Vol. 1. 1966

A registry "records all new cases of cancer in a defined population"

Jensen *et al.* Cancer Registration: Principles and Methods, 1991

Measures of cancer burden – definition

- **Incidence – new cases (number, rate)**
- **Survival – probability alive at time "*t*"**
- **Prevalence – survivors (number, %)**
- **Mortality – deaths (number, rate)**

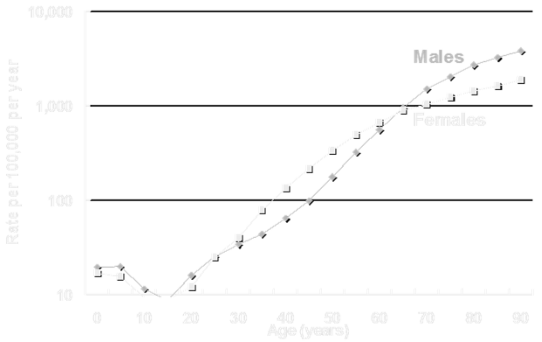
Measures of cancer burden – for me

- **Incidence – what's my risk?**
- **Survival – what are my chances?**
- **Prevalence – how many of us are there?**
- **Mortality – those we have lost ...**

Measures of cancer burden - application

- **Incidence – prevention, planning**
- **Survival – effectiveness of health care**
- **Prevalence – care, survivorship**
- **Mortality – priorities**

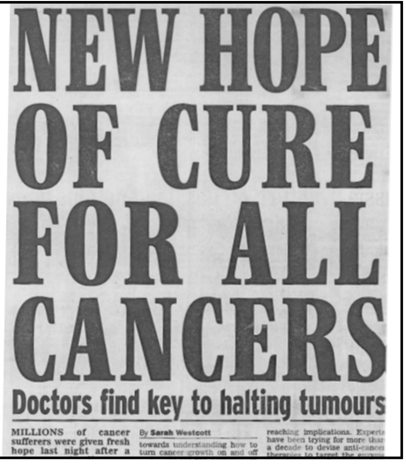
Cancer incidence by age, sex ...



Cancer in Europe 2002-2020

Annual change in incidence rates	New cases per year	Increase from 2002
No change	3,300,000	+ 20 %
1% rise	4,000,000	+ 40 %
2% rise	4,800,000	+ 70 %

Bray, 2008



NEW HOPE OF CURE FOR ALL CANCERS

Doctors find key to halting tumours

MILLIONS of cancer sufferers were given fresh hope last night after a

By Sarah Westcott

towards understanding how to turn cancer growth on and off

reaching implications. Experts have been trying for more than a decade to devise anti-cancer

Daily Express
1 Sep 2008, page 1

Clinical research and public health

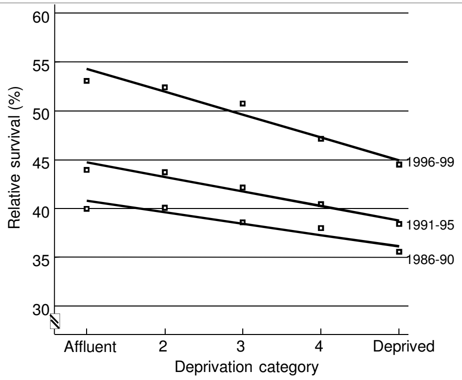
Clinical trials	**highest *achievable* survival**
Public health	**average survival *achieved***

Translational research to reduce the difference

Cancer strategy in England

1995 Reorganisation of treatment services
2000 NHS Cancer Plan
2007 Cancer Reform Strategy
2011 Improving Outcomes: Strategy for Cancer
2015 Achieving world-class outcomes

Rectal cancer survival, men, England and Wales



Use of identifiable information in cancer registration is *unavoidable*

- Quality assurance (validity)
- Eliminate duplicates (inflation of incidence)
- Clinical data not routinely captured (scope)
- Linkage of events (cause, outcome)
- Assessment of survival
- Small area analyses (clusters)
- Assessment of genetic risks
- Surveillance, audit and research

Opt-out from registries will not work

Unquantifiable loss of information

- Most patients would consent, some would not
- Many patients would not be asked
- Complete, unbiased coverage would be lost
- True disease burden would be unknown
- Comparisons would become unreliable:
  - time, geographic area, population sub-group
- Projections of future burden unreliable
- Health inequalities no longer reliably measured

Can governments formulate rational policy *without* key indicators ?

Policy-makers would be “flying blind”

- Policy-vital information: unreliable or unavailable
- Burden of new cancers: unknown
  Age, sex, region, population sub-groups ...
- Future projections: unreliable
- Health inequalities: not reliably measured

Informed consent will not work

No effective cancer registry with informed consent

- West Germany – informed consent, 1990-
  - Hamburg and Saarland registries closed for 2 years
- East Germany – informed consent, 1990-
  - Closure of largest European cancer registry (1953-)
- Hungary – Personal Data Protection Act 1992
  - Cancer registration stopped until 1999
- UK – General Medical Council guidance 2000
  - Emergency legislation required to protect registries

- Nordic countries – statutory, no consent
  - Efficient, complete, productive cancer registries

The “principle” of informed consent in public health

> “I doubt whether informed consent can be a feasible general principle in public health. It is the fundamental principle in clinical ethics, in the clinical encounter. It never has been the fundamental principle in public health, where we have always had to look to other principles of legitimation.”

Baroness O'Neill of Bengarve. Health Service Regulations 2002.
Lords Hansard **21 May 2002**: c746-7

UK survey of public attitudes

- Heard of National Cancer Registry – 17% yes
- Screening invitation invades privacy – 96% no
- Postcode in Registry invades privacy – 89% no
- Invitation for research invades privacy – 88% no
- Support law on cancer registration – 83% yes

Barrett et al., Br Med J 2006

Messages for the media …

- **Medical records are vital for research**
- **Identifiable data are used anonymously**
- **Unblemished record on confidentiality**
- **Vast, beneficial medical research output**
- **Confidential research is in everyone’s interest**
- **Medical research is *already* being prevented**

The Government should...

- **Explain to the public why, despite the underlying principle of consent for data collection, identifiable data must for some purposes be collected without consent, for research that harms no-one and benefits everyone.**
- **Make cancer registration a statutory requirement**

Medical research is threatened by insistence on patient consent

“I don’t expect patients just to tolerate the kind of work that cancer registries and epidemiologists do: I believe they would be astonished if it weren’t done.”

Ben Traynor* Consenting adults *Guardian 12 April 2001

Cancer patients want their data to be shared for research

Margaret Grayson*, a breast cancer survivor in Northern Ireland, explains why sharing cancer patient data for ethical medical research is so important for the benefit of future patients.

**National Cancer Intelligence Network Conference, Belfast, June 2015*

Margaret Grayson
speaks in Belfast, June 2015