Transformational Change in Cancer through Intelligence

SCPN Annual Conference 4th February 2016
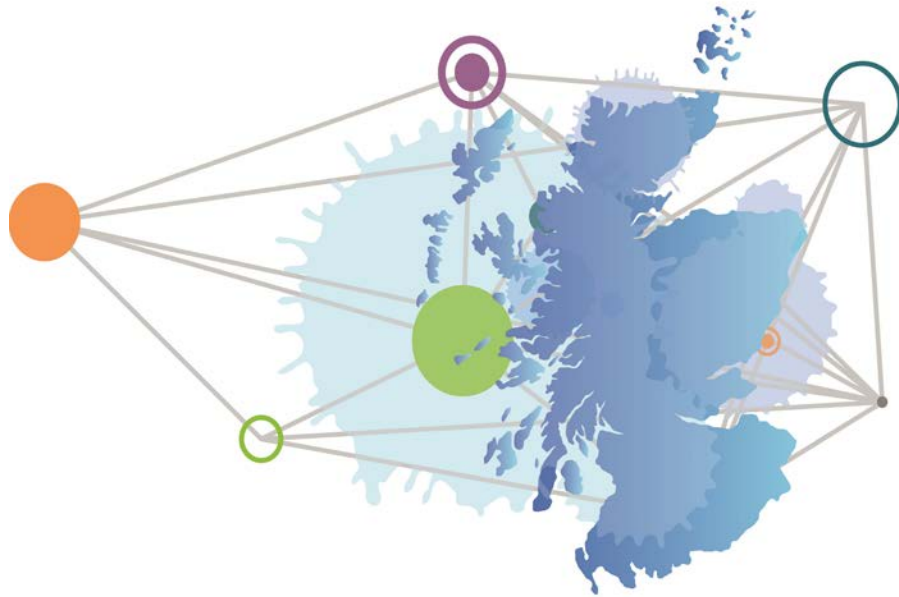
Dr Aileen Keel, CBE

Director,

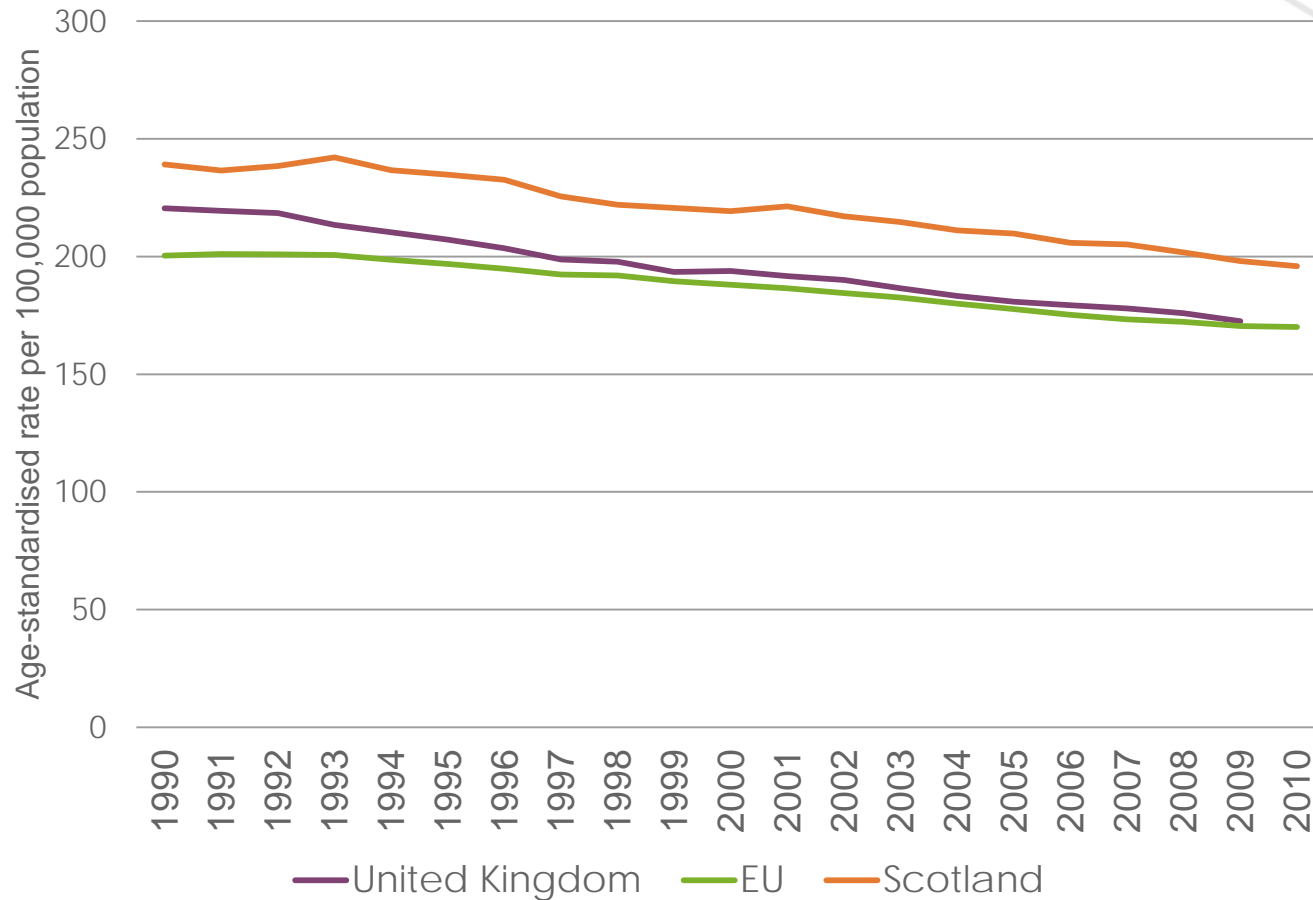Innovative Healthcare Delivery Programme,

Farr Institute @ Scotland

Vision

- To develop a national cancer data infrastructure for Scotland, linking primary, secondary, and ultimately social, care data to improve patient outcomes

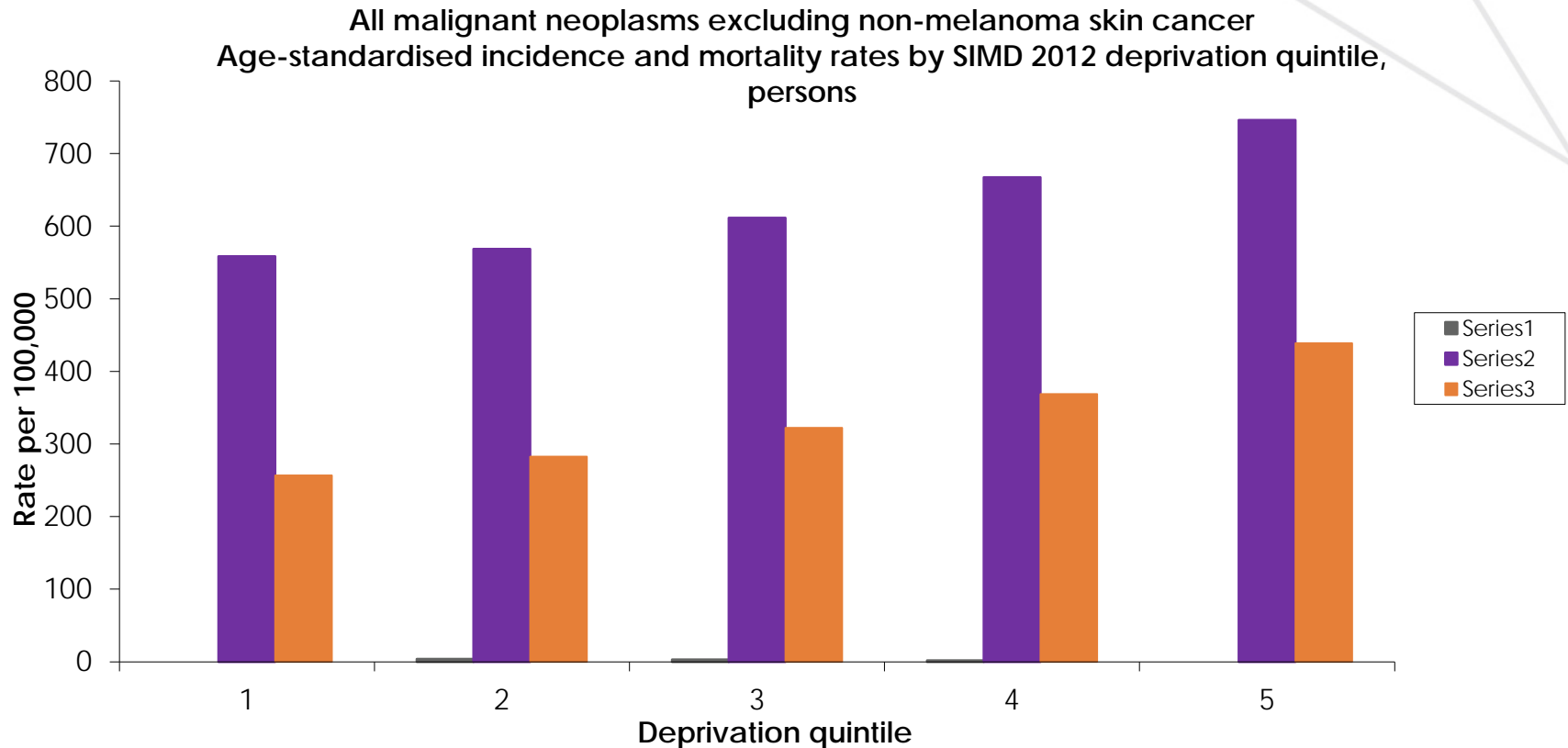# Cancer mortality[1] in Scotland, UK and EU 1990-2010

Age-standardised mortality rate per 100,000 population (using ESP1976[2])

Cancer incidence and mortality by deprivation

All malignant neoplasms excluding non-melanoma skin cancer
Age-standardised incidence and mortality rates by SIMD 2012 deprivation quintile, persons

Why?

- Scotland's cancer outcomes lag behind those of our counterparts in Northern Europe

- NHS Scotland is awash with cancer data – but it's not joined up

- High performing health care systems internationally are supported by systematic data collection, collation, analysis and **sharing**

- Linked and aligned data are fundamental to improving cancer outcomes

- Many other benefits will flow....

Benefits

- Direct clinician access to data in near real time

- Patient access to their own data to help supported self management

- Quicker/slicker audit leading to continuous quality improvement

- Informed performance management

- Better service planning

- Benchmarking of Scotland with rUK and more widely

- Enhanced research and innovation opportunities

- **? Better Prevention**

Barriers

- Multiple heterogeneous datasets

- Technical

- Organisational

This is complex stuff!

But…

- Technical barriers have fallen dramatically in last 10 years

- Progress++ in interoperability/management of complex datasets

- Advanced capability in (safe) use of "big" data

- Numerous examples of where organisational/governance issues have been overcome

Innovative Healthcare Delivery Programme (IHDP)

Aims to harness the power of informatics to deliver value rapidly to patients, health care professionals and the wider NHS through collaboration with academia, industry and the third sector.

IHDP Team

- Dr Aileen Keel
  Director

- Dr Jem Rashbass (Director for National Disease Registration, PHE)
  Senior Clinical Adviser

- David Cline
  Chief Operating Officer

- Fiona Clark
  Programme Administrator

- Amanda Sammarco
  Personal Assistant to Dr Aileen Keel and Programme Assistant

How?

- Data mapping and intelligence gathering
- Identification of information gaps
  - MDTs
  - Primary care / **prevention**
- Scoping of "barriers"
- Learning from experience in England

Prevention data

- Environment (e.g. radon, UV etc.) ➡️ HPS

- Vaccinations (e.g. HCV, HPV) ➡️ HPS

- Screening (Cervical, Breast, Bowel) ➡️ NSS

- Life style risk factors
  - Smoking
  - Obesity
  - Alcohol
  - Physical Activity

➡️ Primary Care ➡️ No systematic national collection
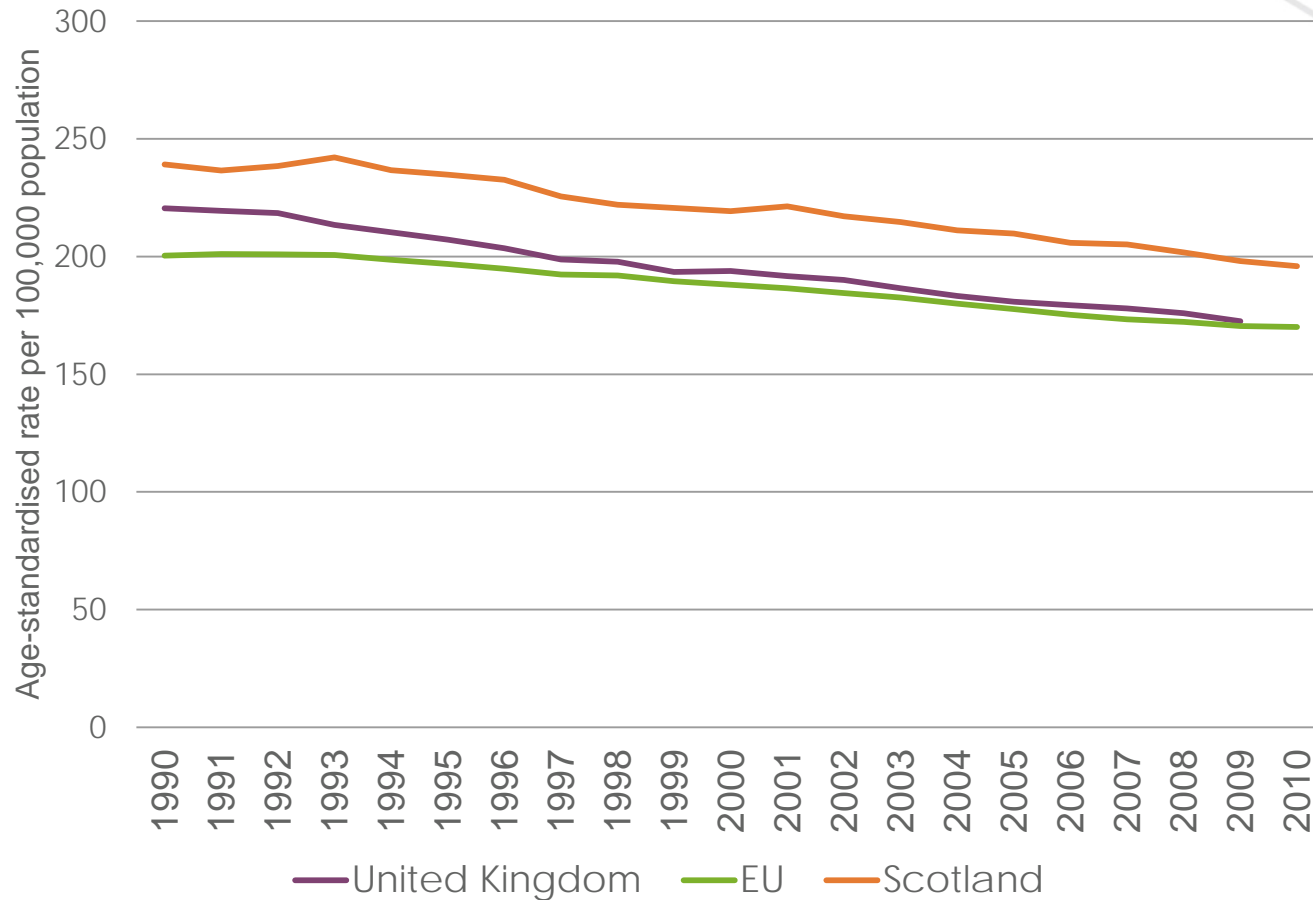
Cancer Patients' Views

- They want their data to be used/shared to improve outcomes

- They want to be partners in clinical research and practice (Independent Cancer Patient Voices)

- useMYdata (cancer patient movement)

Progress to date

- Scottish Cancer Challenge Fund (£1M – SFC)

- Completed visits to 5 Cancer Centres early December

- Further discussions with NSS/ISD on next steps

    - Is SPIRE the solution to the primary care cancer data gap?

Cancer mortality[1] in Scotland, UK and EU 1990-2010

Age-standardised mortality rate per 100,000 population (using ESP1976[2])

Source: WHO/Europe and ScotPHO, Scotland and European HfA Database 2012
1. All cancers (ICD-10 C00-C97)
2. 1976 version of the European Standard Population