Public Health
England

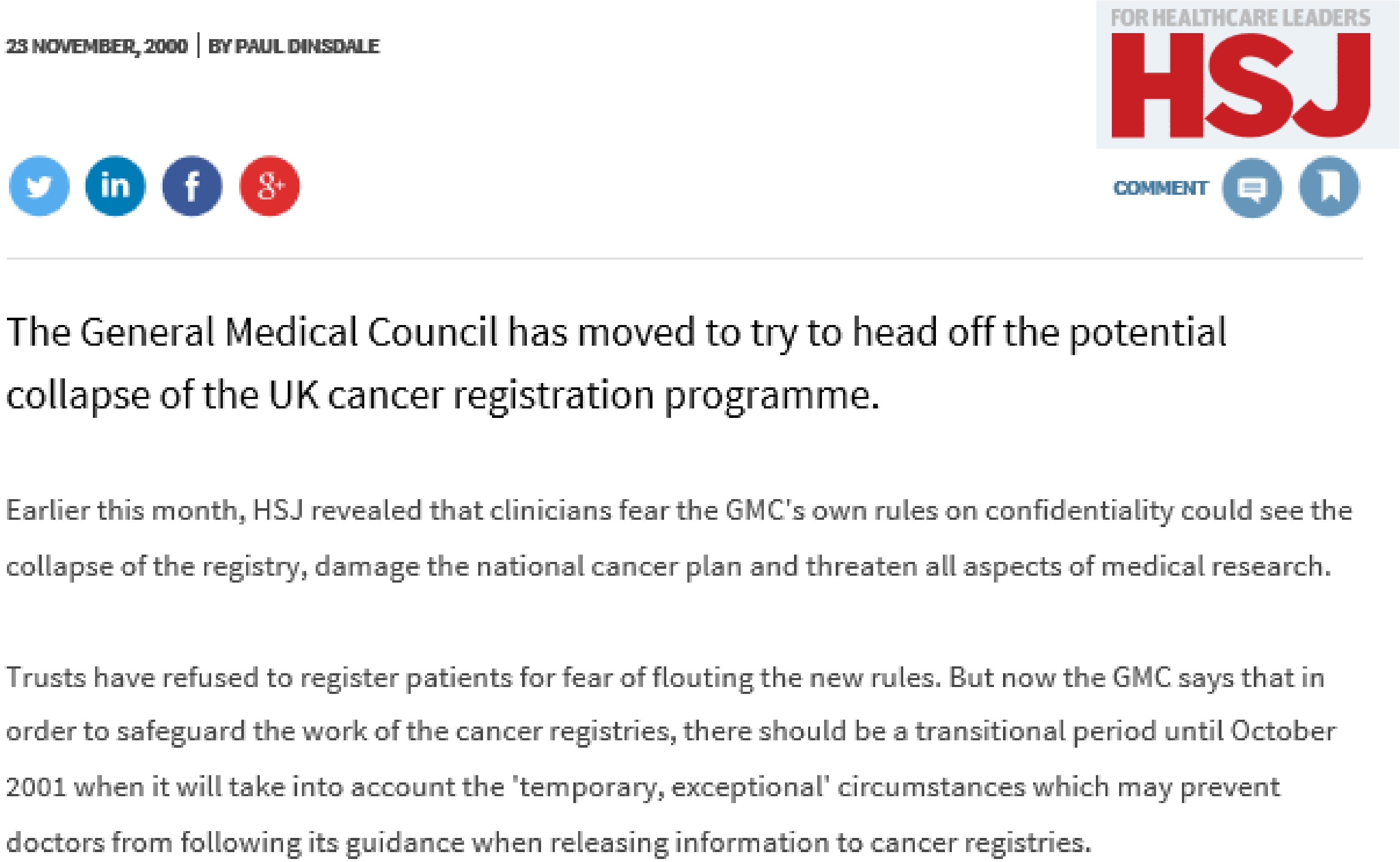
Protecting and improving the nation's health

Cancer registration – how will it change if consent is needed?

Chris Carrigan
National Cancer Registration and Analysis Service
Public Health England (PHE)

We’ve been here before….

GMC stuff leads to Section 60



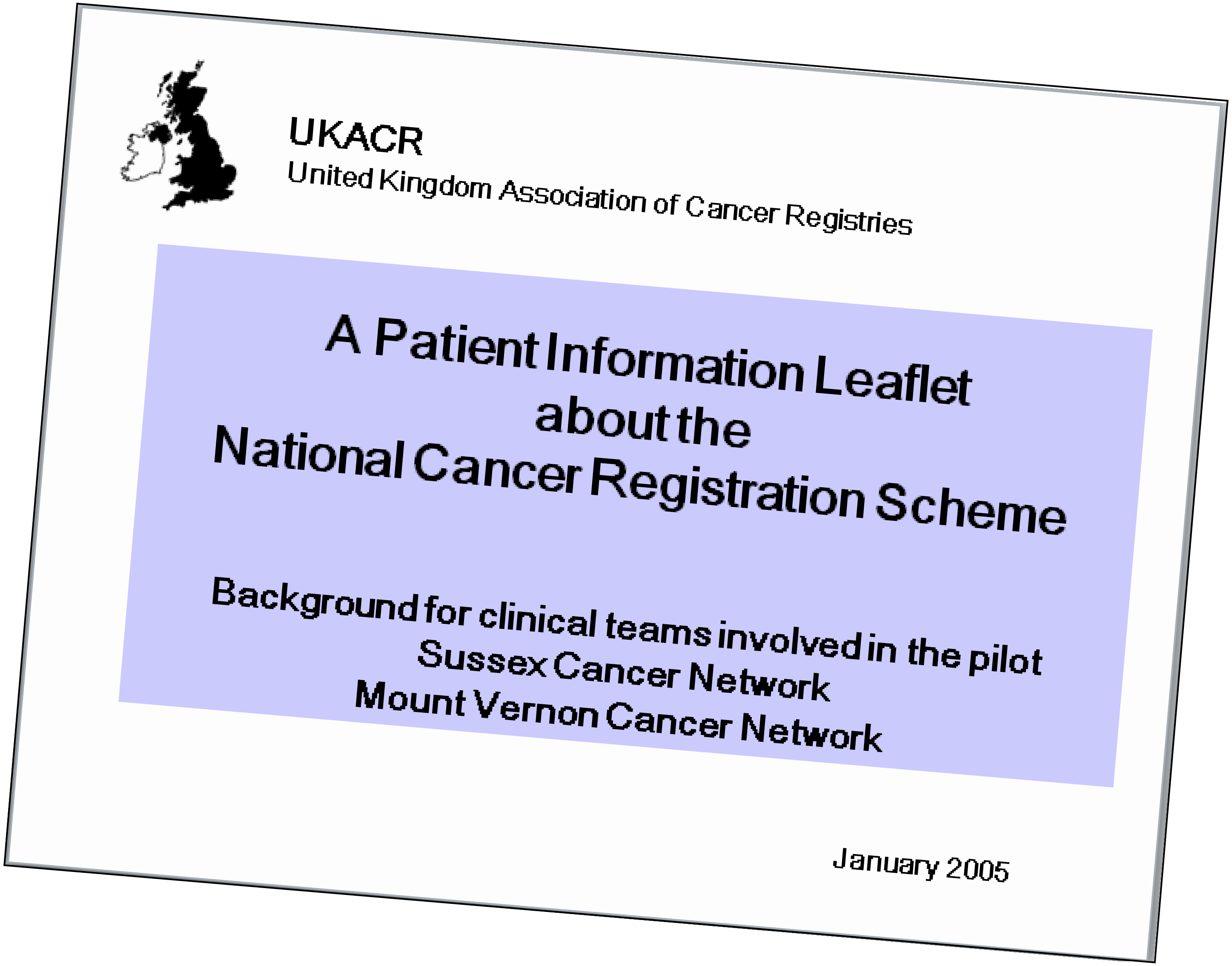
23 NOVEMBER, 2000 | BY PAUL DINSDALE

The General Medical Council has moved to try to head off the potential collapse of the UK cancer registration programme.

Earlier this month, HSJ revealed that clinicians fear the GMC's own rules on confidentiality could see the collapse of the registry, damage the national cancer plan and threaten all aspects of medical research.

Trusts have refused to register patients for fear of flouting the new rules. But now the GMC says that in order to safeguard the work of the cancer registries, there should be a transitional period until October 2001 when it will take into account the 'temporary, exceptional' circumstances which may prevent doctors from following its guidance when releasing information to cancer registries.

We’ve been here before….



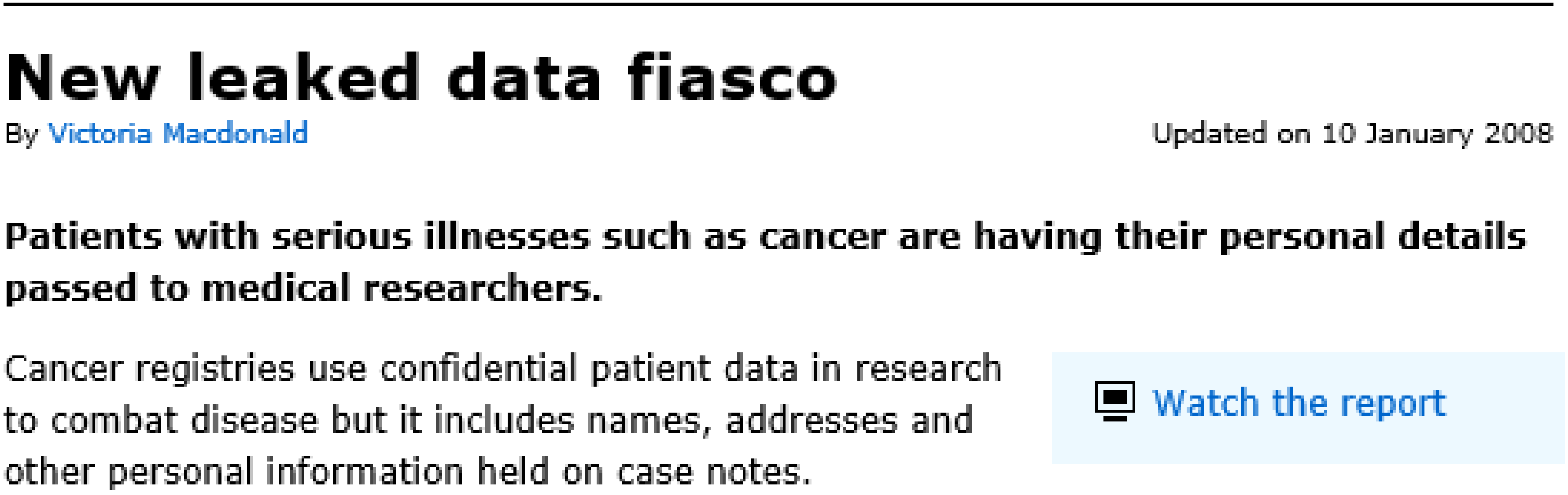
UKACR
United Kingdom Association of Cancer Registries

A Patient Information Leaflet about the National Cancer Registration Scheme

Background for clinical teams involved in the pilot
Sussex Cancer Network
Mount Vernon Cancer Network

January 2005

Channel 4, January 2008



New leaked data fiasco

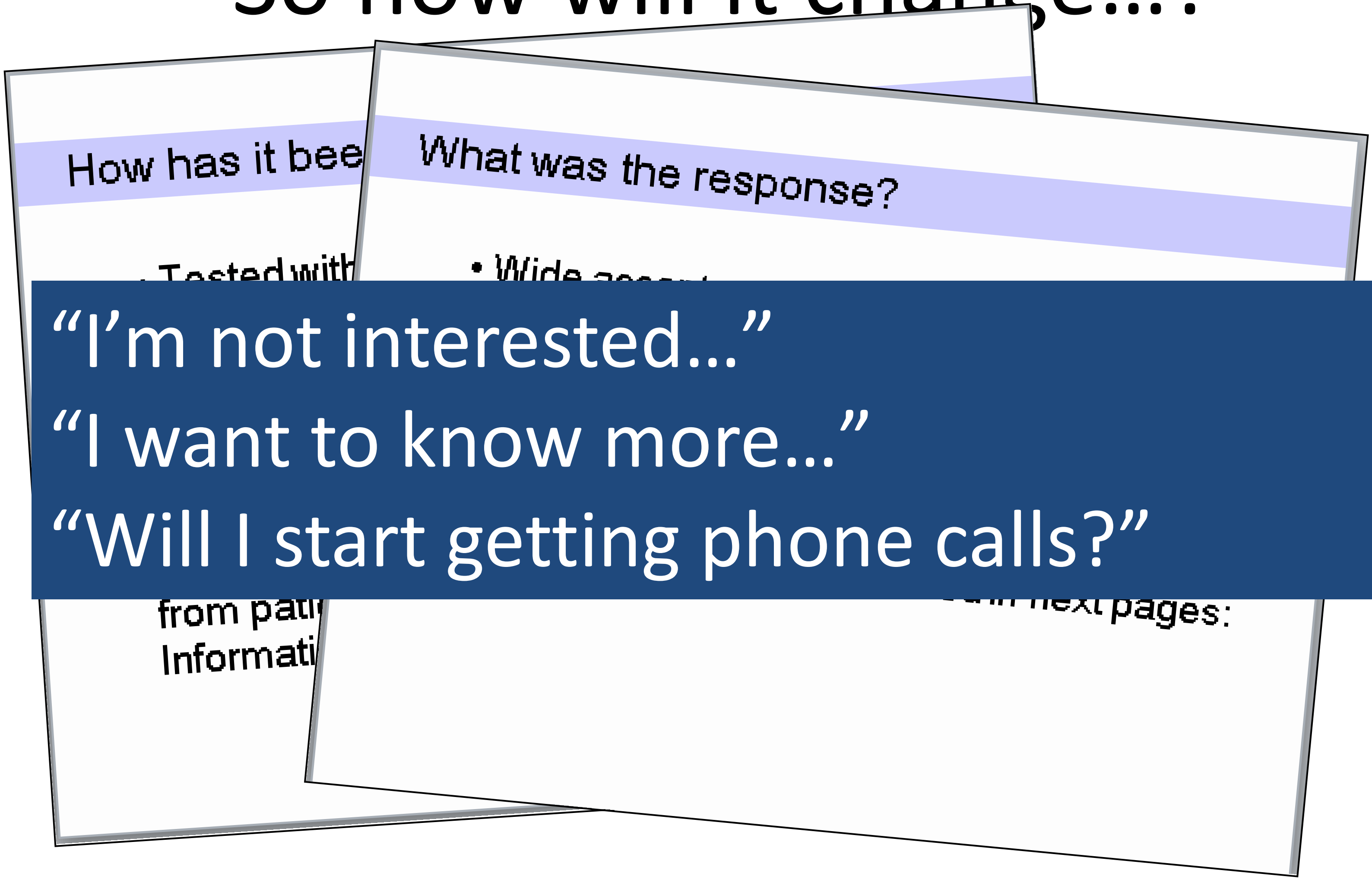
By Victoria Macdonald

Updated on 10 January 2008

Patients with serious illnesses such as cancer are having their personal details passed to medical researchers.

Cancer registries use confidential patient data in research to combat disease but it includes names, addresses and other personal information held on case notes.

So how will it change…?



How has it bee

• Tested with

from pati

Informati

What was the response?

• Wide accep

next pages:

“I’m not interested…”

“I want to know more…”

“Will I start getting phone calls?”

The flows of data….

- Registration relies on a wide and varied set of clinical data:
  - Referrals for tests
  - Test results
  - Screening results
  - Pathology results
  - Hospital attendances
  - Treatment
  - Ongoing visits

Consent asked for what, by who, at what point?
Too Busy?
Uncertain?
Insensitive?
Personal bias?
Organisational bias?

How would registration change?

- Less reliable
- Less complete
- Potentially biased (ethnicity, age, gender?)
- Less useful for analysis
  - Hospital comparisons?
  - Trends?
  - Patient outcomes?
- Incomplete for researchers

- Is that what patients want?