

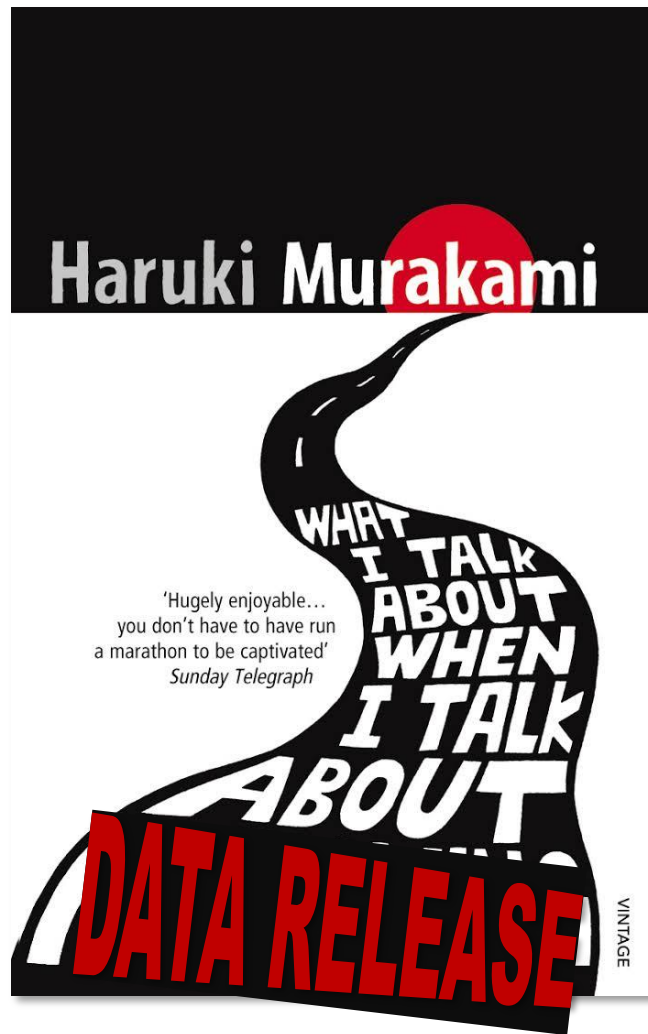


Public Health
England

Protecting and improving the nation's health

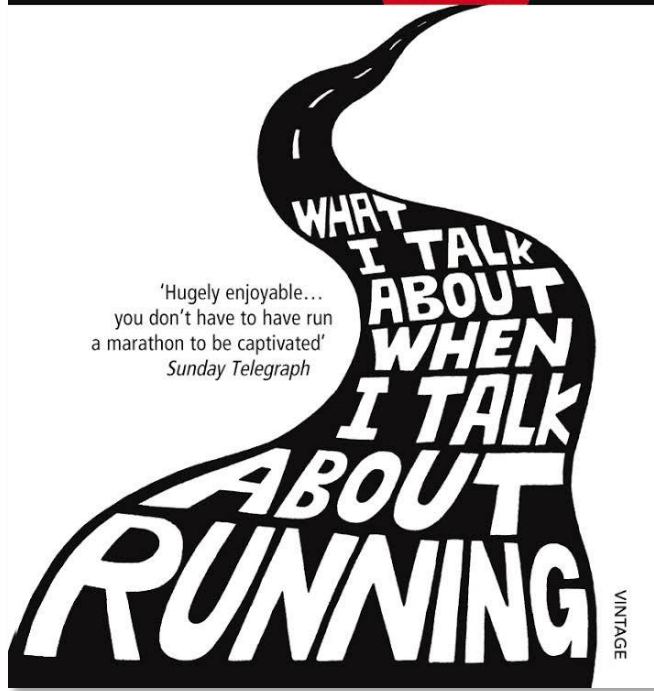
What I talk about when I talk about data release

Sean McPhail, Senior Analyst, National Cancer Intelligence Network



(With apologies to Haruki Murakami)

Haruki Murakami





Modern cancer data

Rewards of data release

The basics

Risks of data release

Controlling the risks

Summary



Modern cancer data

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Summary

Cancer Registration

Inpatient/Outpatient/A&E Hospital Episode Statistics:

HES

Cancer Waiting Times:

CWT

Radio-therapy Data Set:

RTDS

Systematic Anti-Cancer Therapy:

SACT

Cancer Patient Experience Survey:

CPES

Patient Reported Outcome Measures:

PROMS

Diagnostic Imaging Dataset:

DID



Cancer data – record level

| Unique Identifier | Demographic details | Clinical details |
|---------------------------|---|--|
| NHSnumber, Name & Address | Age, Gender, Ethnicity, Postcode, GP practice | Admission date, Diagnosis, Stage, Pathology, Treatment, etc... |

Cancer data – record level

| Unique Identifier | | Demographic details | | | | | Clinical details | | | | | |
|---------------------------|------------------|---|--------|-----------|----------|-------------|--|-----------|-------|-----------|---------------|--------|
| NHSnumber, Name & Address | | Age, Gender, Ethnicity, Postcode, GP practice | | | | | Admission date, Diagnosis, Stage, Pathology, Treatment, etc... | | | | | |
| NHSnumber | Name and Address | Age | Gender | Ethnicity | Postcode | GP practice | Admission date | Diagnosis | Stage | Pathology | Treatment | etc... |
| 6000000001 | John Smith | 77 | M | A | BS16 9AN | A8001 | 29/09/2015 | C61 | 1b | 80103 | M61.1 / Y76.5 | etc... |

Cancer data model

Unique Identifier

Unique Identifier

Demographic

Clinical details

NHSnumber, Name & Address

NHSnumber, Name & Address

Age, Gender, Ethnicity

Date, Diagnosis, Stage, Pathology, Treatment, etc...

| NHSnumber | Name and Address | Age | Gender | Ethnicity |
|-----------|------------------|-----|--------|-----------|
|-----------|------------------|-----|--------|-----------|

NHSnumber

Name and Address

| Diagnosis | Stage | Pathology | Treatment | etc... |
|-----------|-------|-----------|-----------|--------|
|-----------|-------|-----------|-----------|--------|

| | | | | |
|------------|------------|----|---|--|
| 6000000001 | John Smith | 77 | M | |
|------------|------------|----|---|--|

| | | | | |
|-----|----|-------|---------------|--------|
| C61 | 1b | 80103 | M61.1 / Y76.5 | etc... |
|-----|----|-------|---------------|--------|

6000000001

John Smith

Cancer

Demographic details

Unique Identifier

NHSnumber, Name & Address

Age, Gender, Ethnicity, Postcode, GP practice

| | |
|-----------|------------------|
| NHSnumber | Name and Address |
|-----------|------------------|

| | |
|------------|------------|
| 6000000001 | John Smith |
|------------|------------|

| Age | Gender | Ethnicity code | Postcode | GP practice |
|-----|--------|----------------|----------|-------------|
|-----|--------|----------------|----------|-------------|

| | | | | |
|----|---|---|----------|-------|
| 77 | M | A | BS16 9AN | A8001 |
|----|---|---|----------|-------|

Treatment etc...

M61.1 / Y76.5 etc...

Clinical details

Admission date, Diagnosis, Stage, Pathology, Treatment, etc...

| Admission date | Diagnosis | Stage | Pathology | Treatment | etc... |
|-----------------------|------------------|--------------|------------------|----------------------|---------------|
| 29/09/2015 | C61 | 1b | 80103 | M61.1 / Y76.5 | etc... |



Modern cancer data

Rewards of data release

The basics

Risks of data release

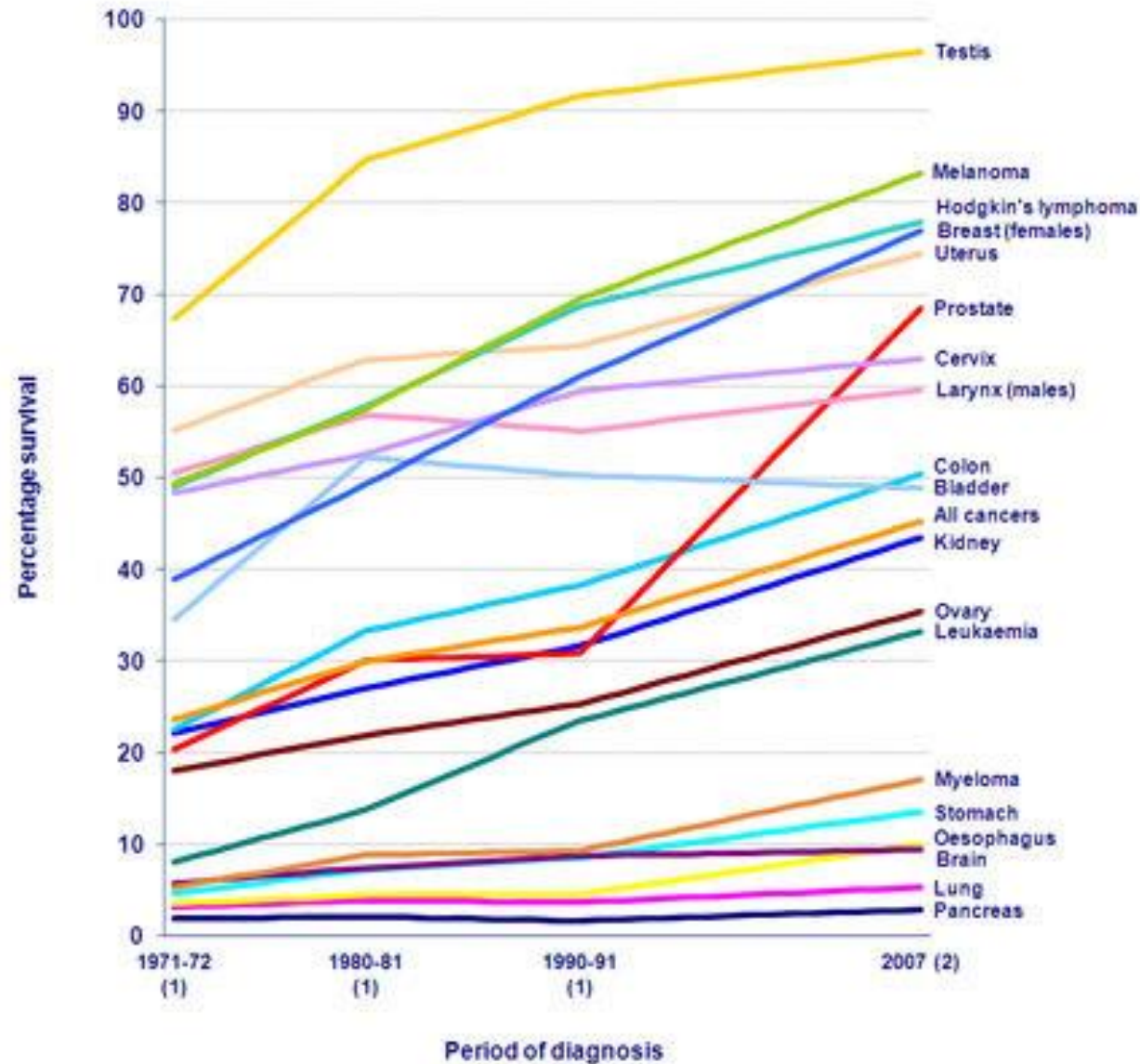
Controlling the risks

Summary

The Reward

Figure 1.2: Ten year relative survival (%), adults (15-99 years), selected cancers, England and Wales: survival trends for selected cancers 1971-2007

10-year cancer survival is increasing, in many cancers, by up to about 1% a year.



The Reward

| NCIN Analysis Work Programme | | RAGU rating: | Geographical granularity: | | Key to colour coding: | | | | | | | | | |
|------------------------------|--|--------------------------------------|-----------------------------------|-----------------------------------|---------------------------------|----------------------|------------------|--------|--------|--------|--------|--------|--------|-------------|
| | | R Significant risk to project | At Area Team | | INT: International | | | | | | | | | |
| July 2015 | | A Some risk to project | CCG: Clinical Commissioning Group | | L: London | | Doing | | | | | | | |
| | | G Project on track | CN: Cancer Network | | LA: Local Authority | | Write-up or QA | | | | | | | |
| | | U Under consideration | E: England | | MDT: Multi-disciplinary team | | Publication prep | | | | | | | |
| | | | E&W: England & Wales | | P: Provider | | Communication | | | | | | | |
| | | | GP: General Practitioner | | SCN: Strategic Clinical Network | | | | | | | | | |
| | | | | | SE: South East England | | | | | | | | | |
| Area | Project title | RAGU | Status | Geographical granularity | Lead | Support | Comms? | Jul-15 | Aug-15 | Sep-15 | Oct-15 | Nov-15 | Dec-15 | Date update |
| Epidemiology | Upper GI: Incidence and survival data briefing | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| General | Cancer Analysis System (CAS) development | G | In progress | E | Sean | tbc | No | | | | | | | |
| General | Cancer Patient Experience Survey | G | In progress | E | Lucy | Bella | Yes | | | | | | | |
| General | CCG Outcomes Indicator Set | G | In progress | E | Sean | LEB | No | | | | | | | |
| General | Information Governance and data release | G | In progress | E | Sean | tbc | No | | | | | | | |
| General | What cancer statistics are available and where can I find them? (u) | U | Consideration | E | GP | tbc | Yes | | | | | | | |
| General | Lung: ICBP M5 influence of comorbidity on early death (UK) | G | In progress | INT | Margreet | Vicki & Daniela | Yes | | | | | | | |
| General | Public facing data: tools update | G | In progress | E | Sean | KITs | Yes | | | | | | | |
| Inequalities | Cancer in GB and Ireland: similarities and differences (UK) | G | In progress | UK nations | Nicola | tbc | Yes | | | | | | | |
| Inequalities | NCEI report 2015 | U | In progress | UK, E, E&W | Ruth | Sam | Yes | | | | | | | |
| Inequalities | Upper GI: Socioeconomic deprivation and survival | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| Local | London: One year relative survival estimates (with 2013 data) | G | In progress | L | Viv | Catherine, Tom | No | | | | | | | |
| Local | London: Analyses with 2013 data for Cancer Intelligence Priorities for London Steering Group | G | In progress | L | Viv | Catherine, Tom | No | | | | | | | |
| Local | London: Emergency presentation data for all tumour types | R | In progress | L | Viv | Catherine, Tom | No | | | | | | | |
| Local | London: Enquiries | A | In progress | L | Viv | Catherine, Tom | No | | | | | | | |
| MDT | Metastatic Spinal Cord Compression analysis | G | In progress | E | Sean | LEB | No | | | | | | | |
| MDT | Provider level survival (proxy) for Bruce Keogh | G | Agreed | P | Sean | Viv | Yes | | | | | | | |
| MDT | Service Profiles: Hepatic, pancreatic and biliary indicators | R | On hold | old-CN | Vicki | tbc | Yes | | | | | | | |
| MDT | Service Profiles: Lung | A | In progress | E,MDT | Margreet | tbc | Yes | | | | | | | |
| MDT | Service Profiles: Oesophageal and gastric cancer update | R | On hold | n/a | Vicki | tbc | Yes | | | | | | | |
| Methodology | Big HES data application | G | In progress | E | Sean | tbc | No | | | | | | | |
| Methodology | Clinical Headline Indicators for Cancer (COSD level 4) | G | In progress | E | LEB | Jackie, Carl, Nicola | Yes | | | | | | | |
| Methodology | Upper GI: Linking data to a Barrett's oesophagus register | U | In progress | n/a | Vicki | tbc | No | | | | | | | |
| Methodology | Upper GI: Linking data to a diabetes register | U | On hold | n/a | Vicki | tbc | No | | | | | | | |
| NAEDI | Be Clear on Cancer - evaluation for oesophageal cancer | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| NAEDI | Emergency Presentations (proxy indicator in CCT) | A | In progress | CCG | Sam | Sean | Yes | | | | | | | |
| NAEDI | GP & CCG Pres 2014 (reflex) | A | In progress | GP | Sam | Sean | Yes | | | | | | | |
| NAEDI | Impact of early diagnosis on survival H2 | R | In progress | E | Bella | Claudia | Yes | | | | | | | |
| NAEDI | Lung: Early lung cancer diagnosis | G | In progress | Leeds vs E | Margreet | Vicki & Ruth | Yes | | | | | | | |
| NAEDI | Lung: Effect of emergency presentation on surgery and survival | G | In progress | E | Margreet | Daniela | Yes | | | | | | | |
| NAEDI | Routes to Diagnosis 4 (update for 2013 data) | G | Agreed | E,SCN,CCG | Sean | Sam | Yes | | | | | | | |
| NAEDI | Routes to Diagnosis: Intervals | G | Agreed | E | Bella | Claudia | No | | | | | | | |
| NAEDI | Routes to Diagnosis by stage | G | Agreed | E | Bella | Claudia | Yes | | | | | | | |
| NAEDI | Routes to Diagnosis: Treatments H1 | A | In progress | E | Claudia | Bella | Yes | | | | | | | |
| NAEDI | Upper GI: Surgery, routes to diagnosis and survival | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| Rarer cancers | Granular breakdown of rarer cancers (UK) | R | In progress | UK nations | Sam | Nicky | Yes | | | | | | | |
| Research | Association of depression and bipolar disorder with breast cancer | G | In progress | SEE | Ruth | tbc | No | | | | | | | |
| Survivorship | Costings (partnership project with Imperial) | G | In progress | E | Lucy | tbc | No | | | | | | | |
| Survivorship | Local Cancer Intelligence (UK) | A | In progress | E | Lucy | tbc | Yes | | | | | | | |
| Survivorship | Cancer and mental health | U | Consideration | E | Lucy | James | Yes | | | | | | | |
| Survivorship | Progressive cancers | G | In progress | E | Lucy | tbc | Yes | | | | | | | |
| Survivorship | Segmentation of 2 million (prevalence) | A | In progress | LA, CCG, GP, NHS, Local Authority | Sarah | Lucy | Yes | | | | | | | |
| Treatment | Comorbidity: agreement of methodologies (paper) | A | On hold | E | Sean | tbc | No | | | | | | | |
| Treatment | Lung: Effect of comorbidity on surgery and survival | G | In progress | E | Margreet | tbc | Yes | | | | | | | |
| Treatment | Lung: hospital volume and risk of readmission | G | In progress | E | Margreet | Henrik | Yes | | | | | | | |
| Treatment | Lung: Linkage between registrations and summary RTDS | G | In progress | E | Margreet | Daniela | Yes | | | | | | | |
| Treatment | RTDS: Reporting and analysis | G | In progress | E | Margreet | Daniela | No | | | | | | | |
| Treatment | Staging data (update for 2013 data) | G | Agreed | E,CCG | Sean | Sam | Yes | | | | | | | |
| Treatment | Treatment dataset mapping | G | In progress | E | Sean | Sam | No | | | | | | | |
| Treatment | Upper GI: Pancreatic resections, procedure volume & mortality | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| Treatment | Upper GI: Surgery for oesophageal and gastric cancer | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| Treatment | Upper GI: Surgery for pancreatic cancer | G | In progress | E | Vicki | tbc | Yes | | | | | | | |
| Treatment:SAC | Data ascertainment | A | In progress | P | Mike | Raph | | | | | | | | |
| Treatment:SAC | 30 day post-chemotherapy mortality | G | In progress | P | Mike | Raph | Yes | | | | | | | |
| Treatment:SAC | CR: UK Geographical analysis | U | Consideration | CCG | Mike | Raph | | | | | | | | |
| Treatment:SAC | Body Mass Index in cancer | U | Consideration | E | Mike | Raph | | | | | | | | |
| Treatment:SAC | Use of chemotherapy in sarcoma | U | Consideration | P | Raph | | | | | | | | | |
| Treatment:SAC | Survival of patients with colorectal cancer treated with CDF drugs | G | In progress | P | Mike | Raph | | | | | | | | |
| Treatment:SAC | Uptake of chemotherapy at CCG or provider or area team level | U | Consideration | CCG | Raph | | | | | | | | | |
| Treatment:SAC | Distance to treatment | U | Consideration | P | Raph | | | | | | | | | |
| Treatment:SAC | Relationship between volume and outcome | U | Consideration | P | Mike | Raph | | | | | | | | |
| Treatment:SAC | Early treatment discontinuation | U | Consideration | P | Mike | Raph | | | | | | | | |
| Treatment:SAC | Current patterns of care | U | Consideration | E | Mike | Raph | | | | | | | | |
| Treatment:SAC | Top Regimens (routine report, quarterly) | G | In progress | E,AT,P | Raph | | | | | | | | | |
| Treatment:SAC | Regimen Benchmarking (routine report, six-monthly) | G | In progress | E,AT,P | Mike | Raph | | | | | | | | |

40+ people

100++ projects

Plus... CRUK & Macmillan, dozens of academic groups, 100s of researchers.

Public domain?

The Reward – Routes to Diagnosis

Routes to Diagnosis, 2006-2008
NCIN information supplement



Routes to Diagnosis, 2006-2008
NCIN information supplement



www.ncin.org.uk



Protocol

**Cancer Diagnosis in the Acute Setting
(CaDiAS)**

A study on behalf of the London Cancer Alliance

Protocol version: v2.4
Date: 11 January 2013

An NRCN approved study, sponsored by Chelsea and Westminster Hospital, funded by the Department of Health and carried out on behalf of the London Cancer Alliance.

43 citations.

Dozens of
secondary
projects.

Change of
policy direction
at a national
level.



Modern cancer data

Rewards of data release

The basics

Risks of data release

Controlling the risks

Summary

Categorising data releases

Safe?

Anonymous?

Un-safe?

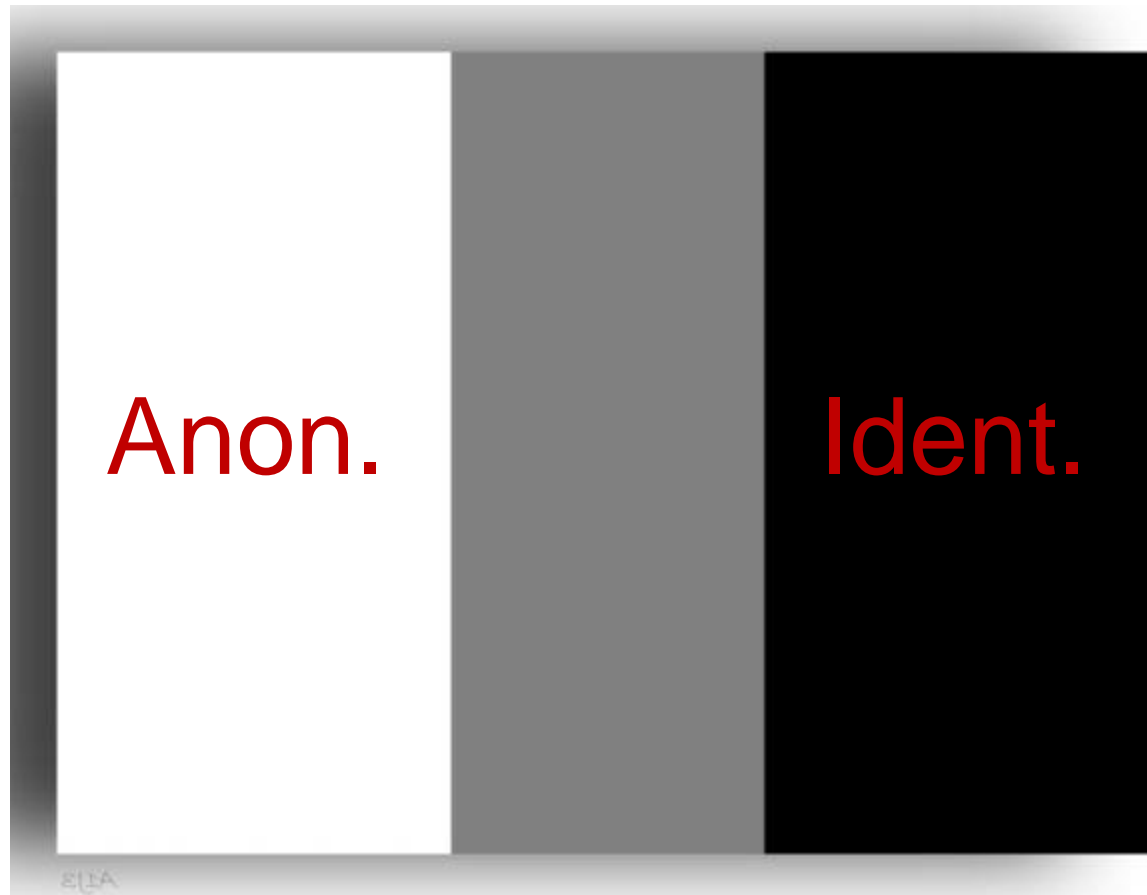
Identifiable?

Categorising data releases



(<http://pictify.saatchigallery.com/336790/the-grey-between-black-and-white>)

Categorising data releases



(<http://pictify.saatchigallery.com/336790/the-grey-between-black-and-white>)

Categorising data releases



(<http://pictify.saatchigallery.com/336790/the-grey-between-black-and-white>)

Cancer data – identifiable

| Unique Identifier | Demographic details | | | | | | Clinical details | | | | | |
|---------------------------|---|-----|--------|-----------|----------|-------------|--|-----------|-------|-----------|---------------|--------|
| NHSnumber, Name & Address | Age, Gender, Ethnicity, Postcode, GP practice | | | | | | Admission date, Diagnosis, Stage, Pathology, Treatment, etc... | | | | | |
| NHSnumber | Name & Address | Age | Gender | Ethnicity | Postcode | GP practice | Admission date | Diagnosis | Stage | Pathology | Treatment | etc... |
| 6000000001 | John Smith | 77 | M | A | BS16 9AN | A8001 | 29/09/2015 | C61 | 1b | 80103 | M61.1 / Y76.5 | etc... |

Cancer data – anonymous

| Unique Identifier | Demographic details | | | | Clinical details | | | | | | |
|---------------------------|---------------------|--------|-----------|---------------|------------------|----------------|-----------|------------|------------|-----------|---------|
| NHS number, Name, Address | Age | Gender | Ethnicity | Postcode, CCG | Admission date | Diagnosis | Stage | Patient ID | Treatment | Outcome | |
| NHS number | Name and Address | Age | Gender | Ethnicity | Postcode, CCG | Admission date | Diagnosis | Stage | Patient ID | Treatment | Outcome |
| 60000000 | John Smith | 75+ | M | White | London, CCG | 29/01/15 | C61 | I | Surgery | D | D |

Cancer data – shades of grey

| Unique Identifier | Demographic details | | | | Clinical details | | | | | |
|---------------------------|---------------------|-----------|--------------------|----------|------------------|----------------|-----------|-----------|-----------|--------------|
| NHS number, Name, Address | Gender | Ethnicity | Priority, Postcode | CCG | Admission date | Diagnosis | Stage | Pathology | Treatment | |
| NHS number | Name and Address | Gender | Ethnicity | Priority | Postcode CCG | Admission date | Diagnosis | Stage | Pathology | Treatment |
| 60000000 | John Smith | M | White | Priority | E10 CCG | 29/01/15 | C61 | 1b | Surgery | Chemotherapy |



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Summary

Hazard and risk

Hazard : the danger

Risk : the chance that that hazard occurs

The hazard here

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Risk and compliance

NHS Trust receives largest ever data breach fine

Brighton and Sussex University Hospitals NHS Trust fined £325k after hard drives with highly-sensitive patient data were sold on eBay, but will appeal

Posted by Information Age on 1 June 2012

An NHS Trust in Brighton has been served with the largest ever fine issued by the Information Commissioner, after hospital hard drives containing sensitive patient data were sold on eBay.

Share article

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The hard drives contained medical records, home addresses and National Insurance numbers of "tens of thousands" of patients, the ICO said today, including children and patients treated by the Trust's HIV and Genito

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The Register *Setting the hazard that feeds IT*

DATA CENTRE SOFTWARE NETWORKS SECURITY INFRASTRUCTURE BUSINESS HARDWARE SCIENCE BOOTNOTES FORUMS WEEKEND

Business > **Government**

Right, opt out everybody! Hated Care.data paused again

Is it time to put down this terminally ill scheme?



8 Sep 2015 at 11:37, Kat Hall

More like this: Nhs, Uk, Care.Data

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- Bletchley Park remembers 'forgotten genius' Gordon Welchman
- The nuclear derby punch: FI

Intruders



Heat magazine & re-identification

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World

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Phone hackers 'sought details of Kylie Minogue's cancer treatment'

August 12, 2014 ☆ Read later

Nick Miller
Europe Correspondent
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Email article Print

London: British private investigator Glenn Mulcaire hacked the voicemails of Kylie Minogue's siblings, Dannii and Brendan, so *News of the World* could write intimate details about the pop star's cancer treatment in Melbourne in 2005.

Details of the hack were revealed in one of two new books published after the phone-hacking trial, both of which shed new light on the scandal that engulfed Fleet Street over the past half-decade.

Hack Attack, by Nick Davies of the *Guardian*, covers six years of his reportage and investigation.

And *The News Machine*, by the *Independent's* James Hanning, is co-written by Glenn Mulcaire, the *News of the World's* private investigator who was twice convicted for phone hacking, and whose notes and emails were vital evidence in convicting four senior *News of the World* editors on phone hacking charges.



Kylie Minogue's siblings were hacked for news about the pop-star's cancer treatment. Photo: Getty



Slivers



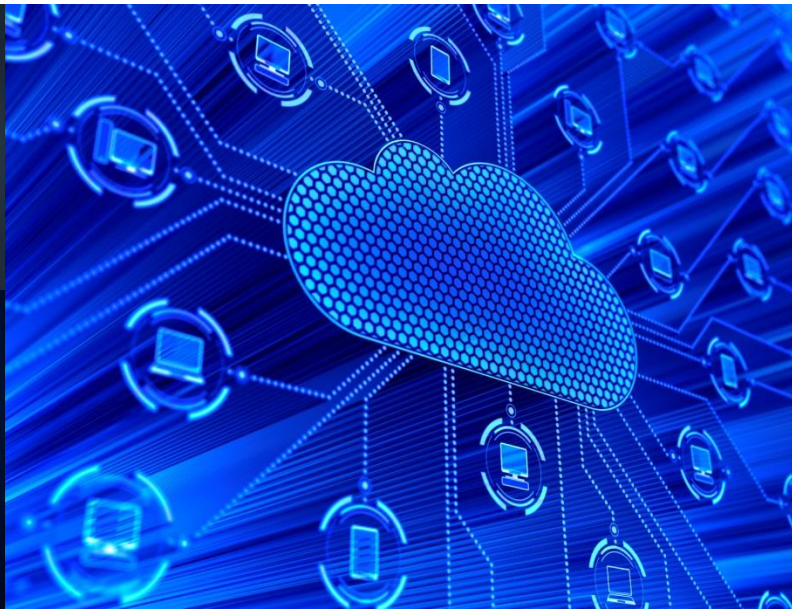
Existing data in the public domain



When it's gone, it's gone



The cloud





Modern cancer data

Rewards of data release

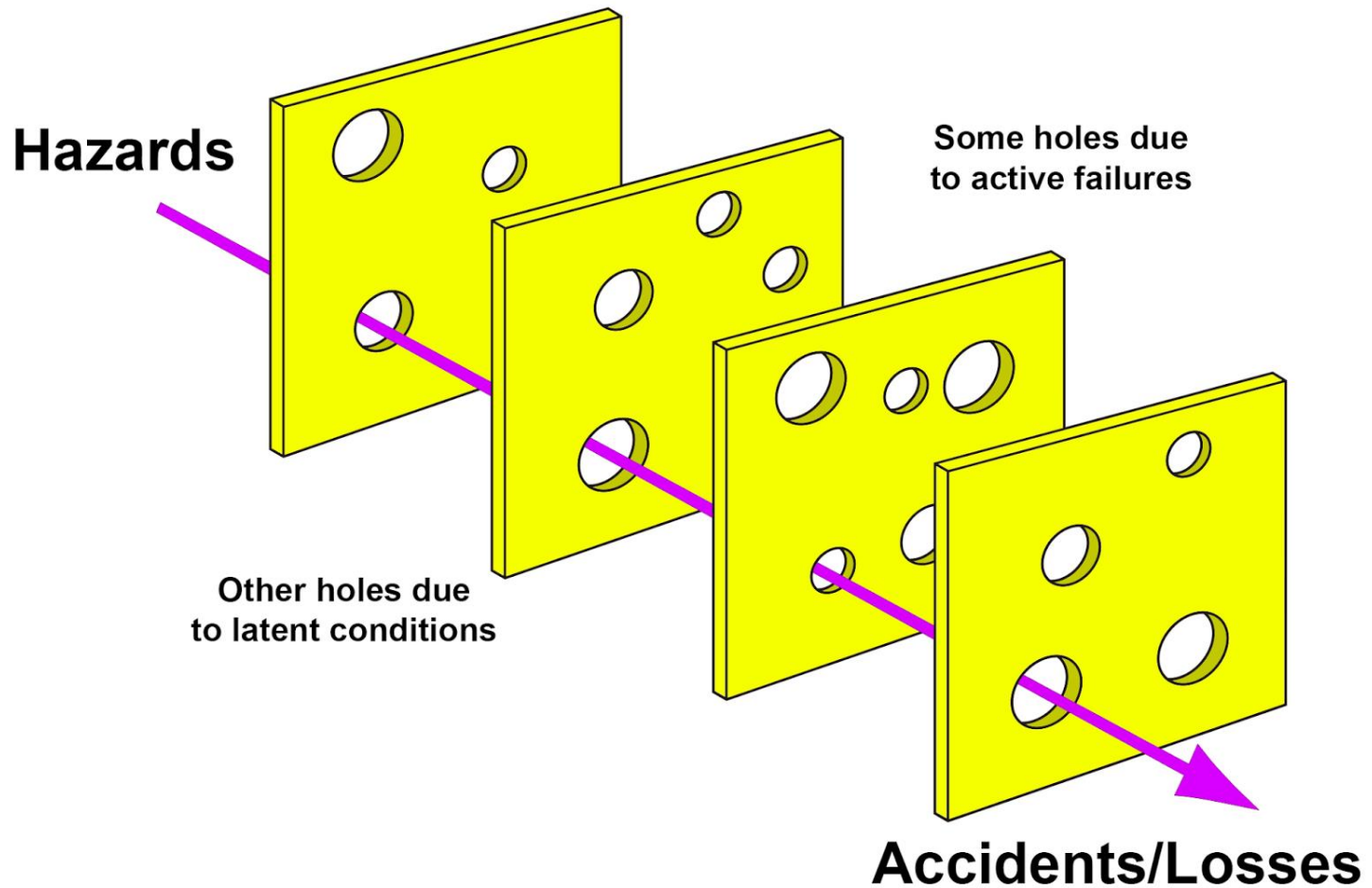
The basics

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Swiss cheese accident model



Controls - Isolation



Controls - Aggregation



Controls – Anonymisation

| Unique Identifier | Demographic details | | | | | Clinical details | | | | | | |
|---------------------------|---|-----|--------|-----------|----------|--|----------------|-----------|----------|-----------|-----------|-----------|
| NHS number, Name, Address | Age, Gender, Ethnicity, Postcode, GP practice | | | | | Admission date, Diagnosis, Severity, Pathology, Treatment, Outcome | | | | | | |
| NHS number | Name and Address | Age | Gender | Ethnicity | Postcode | GP practice | Admission date | Diagnosis | Severity | Pathology | Treatment | Outcome |
| 60000000 | John Smith | 77 | M | White | BN1 1AN | A8001 | 29/01/15 | C61 | Severe | Biopsy | Surgery | Recovered |

Controls – Anonymisation

| Unique Identifier | Demographic details | | | | Clinical details | | | | | | |
|---------------------------|---------------------|--------|-----------|---------------|------------------|----------------|---------------------|---------------------|-----------------|-----------|-----------|
| NHS number, Name, Address | Age | Gender | Ethnicity | Postcode, CCG | Admission date | Diagnosis | Secondary diagnosis | Patient history | Treatment | Outcome | |
| NHS number | Name and Address | Age | Gender | Ethnicity | Postcode, CCG | Admission date | Diagnosis | Secondary diagnosis | Patient history | Treatment | Outcome |
| 60000000 | John Smith | 75+ | M | White | E10 1AN CCG | 29/01/15 | C61 | Hypertension | Medication | Stable | Discharge |

Controls - Pseudonymisation

**Unique
Identifier**

**NHSnumber,
Name & Address**

| | |
|------------------|-----------------------------|
| NHSnumber | Name and Address |
|------------------|-----------------------------|

| | |
|-------------------|-------------------|
| 6000000001 | John Smith |
|-------------------|-------------------|

Controls - Pseudonymisation

**Unique
Identifier**

**NHSnumber,
Name & Address**

NHSnumber

**Name and
Address**

E93E1102-BF3E-4729-A735-2836993D1070



Modern cancer data

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Summary

Risk vs reward

As the reward increases...so does the risk.

Risk vs reward

As the reward increases...so does the risk.

1£ reward = 1\$ risk?

Risk vs reward

As the reward increases...so does the risk.

~~1£ reward = 1\$ risk?~~

10£ reward = 1\$ risk?

Risk vs reward – applying controls

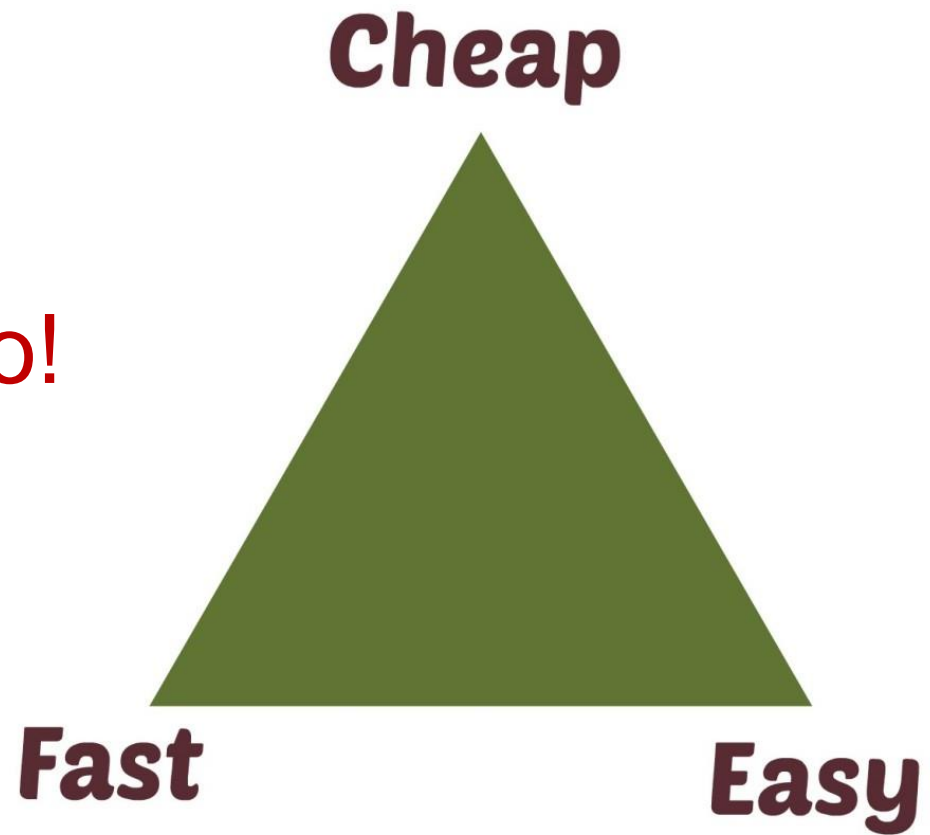
As the controls increase the risk decreases...

but

As the controls increase the reward decreases...

Summary

Choose any two!



Summary

~~Choose any two!~~
Find the optimum



Thank you for listening



sean.mcphail@phe.gov.uk