Information in the new world: *can we make cancer data count?*

Brian Cottier Invitation Lecture

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**About me**

- Managing Director, MHP Health Mandate
- Multi-award-winning specialist health policy consultancy
- Role in supporting the development of *Improving Outcomes: a Strategy for Cancer* and the *Cancer Reform Strategy*
- Work closely with the NCIN
What I’ll cover

• Why information matters in the new world

• Do we need a supply or demand side information revolution?

• Translating intelligence into action

Why information matters in the new world
Information is critical to *Improving Outcomes: A Strategy for Cancer*

A supply or demand side revolution?

Improving outcomes requires a supply and demand side revolution

**Supply**
- Data collection
- Data quality
- Linking data sets
- Clinical audit

**Demand**
- Informed choice
- Stronger commissioning
- Professional improvement
- Clearer accountability

Using the information cycle to improve cancer outcomes

- Activity
- Data
- Intelligence
- Information
- Action
Good progress has been made on many aspects of information – but we need to translate this to action.

Translating intelligence into action
Making data count – some examples

Commissioners
finding the 5,000 lives to save

Providers
improving patient experience

Patients
enabling informed choice

Why commissioners need information

To:
• Identify priorities
• Scrutinise the performance of providers (quality and cost)
• Respond to the needs of patients / the public
• Enable informed scrutiny
Commissioning prioritisation works – but can we use data to get the next generation of commissioners to prioritise the right issues?

Finding the 5,000 (cancer types)

* Analysis does not include prostate cancer

Source: MHP Health Mandate, Commissioning in the new world, August 2010

Source: Data derived from Abdel-Rahman et al, BJC Supplement December 2009; ONS, registrations of cancer deaths, 2009
Targeting action where it is needed most

Where do excess deaths occur?

- Geography
- Age
- Socioeconomic status
- Ethnicity
- Gender
- Sexuality
- Disability
- Religion

Why providers need information

To:

- Monitor quality
- Learn from good practice
- Target improvements (quality and cost)
- Respond to the needs of commissioners and patients
Most providers have examples of good and poor practice – can we use data to enable them to target improvements in the right areas?

Source: MHP Health Mandate analysis of National Cancer Patient Experience Survey 2010

Some providers are incentivised on improving patient experience – can we use this as a tool to encourage improvement amongst the ‘reds’?

Source: MHP Health Mandate analysis of ProvIT database and National Cancer Patient Experience Survey 2010
Why patients need information

To:

• Learn more about what happened to patients like them

• Assess their options

Make informed choices based on what matters to them

Source: MHP Health Mandate analysis of ProvIT database and National Cancer Patient Experience Survey 2010

What do patients want to know?

What clinical outcomes for my type of cancer are achieved here compared with other hospitals? [Would I have a better chance of surviving somewhere else?]

Source: focus groups conducted by Joanne Rule (unpublished)
What do patients want to know?

**How well do patients with my type of cancer rate their experience of care?**
[No point telling me about general satisfaction levels]

Source: focus groups conducted by Joanne Rule (unpublished)

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What do patients want to know?

**How will this diagnosis affect the rest of my life? What kind of back up will there be when I go home?**

"I’LL BE PERFECTLY FRANK WITH YOU, WE NEED THAT BED!"

Source: focus groups conducted by Joanne Rule (unpublished)
What do patients want to know?

Will the doctor listen to me? Will a nurse actually come if I use my call button?

Source: focus groups conducted by Joanne Rule (unpublished)

What do patients want to know?

Do the professionals communicate well with each other? Will I be able to attend when they discuss my case?

Source: focus groups conducted by Joanne Rule (unpublished)
How can we apply intelligence to inform patients about what they want to know?

Information on service quality is currently:

- Too general
- Out of date
- Available only from disparate sources
- Not contextualised
- Not easily comparable
- Presented poorly

The work of the NCIN provides a platform to change this

Source: MHP Health Mandate, Accounting for quality, September 2010

In summary

- Cancer has led the Information Revolution, but there is a long way to go
- The NCIN has helped deliver a leap forward in terms of the intelligence available
- We all have a role to play in translating intelligence into action to improve outcomes

Let’s work together to make data count
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