
The National Cancer Intelligence Network: Where now? Where next?

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NCIN: Where now? Where next?

- Who needs cancer intelligence?
- What information do they need?
- What progress are we making on providing the intelligence required?
- Where next?

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NCIN: Who needs cancer intelligence?

- A wide range of interested parties, including:
 - Policymakers
 - Commissioners
 - Patients, carers and patient advocates
 - Providers of cancer services
 - Researchers
 - Industry (e.g. Pharma)
 - The media

NCIN: What information do people need?

Perspective 1: The policymaker

- Trends: e.g. in incidence/mortality of difference cancers – to assess impact of previous policies (e.g. tobacco) and to predict future demand for services
- Quality and outcomes from current services: How do they vary (Inequalities)?
- International comparisons: Are we doing as well as others? If not, why not?
- Costs: Are we getting good value for money?
- Research: How could we do better?

NCIN: What information do people need?

Perspective 2: The patient/carer

- Where can I get the care I need?
- How soon will I be seen?
- How will I know whether the service is good?
- How do service X's outcomes compare with those elsewhere?
- Is there a Which guide to cancer services?
- [How much will I have to pay?]

NCIN: What information do people need?

Perspective 3: The commissioner

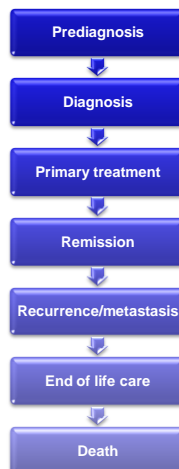
- What services am I buying for my population?
- Are they meeting national standards? (structure and process)
- Are they delivering the required outcomes?
- Am I getting value for money?
- How should I be planning services for the future?

NCIN: What information do people need?

- Much of the information required by different stakeholders is the same – though the formats may vary
- We all need patient-level data (anonymised) relating to the whole care pathway – from before diagnosis to long term recovery or death
- Individual patient-level data then needs to be aggregated to relevant levels (e.g. MDT, PCT, CCG, SHA, national)

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Information across the care pathway (1)



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Information across the care pathway (2)

Prediagnosis: Risk factors (e.g. Smoking)
Illnesses/comorbidity
Nature and duration of symptoms
Attendances in primary care
Waiting times

Diagnosis: Investigations
Cancer type
Stage
Date of diagnosis

Information across the care pathway (3)

Treatment: Surgery
Radiotherapy
Chemotherapy
Length of stay

Post treatment: Experience of care
Quality of life
Hospital attendances
GP attendances

Information across the care pathway (4)

Recurrence/	Date/type
Metastasis:	Treatment
	Patient experience
	QOL

End of life care:	Specialist palliative care services
	Social care
	Place of death
	Date of death

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Information across the care pathway (5)

	Source
Prediagnosis: Risk factors (e.g. Smoking)	GP records
Illnesses/comorbidity	GP records
Nature and duration of symptoms	GP records
Attendances in primary care	GP records
Waiting times	CWT

	Source
Diagnosis: Investigations	DID/Path
Cancer type	CR
Stage	CR
Date of diagnosis	CR

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Information across the care pathway (6)

		Source
Treatment:	Surgery	HES
	Radiotherapy	RTDS
	Chemotherapy	SACT
	Length of stay	HES

		Source
Post treatment:	Experience of care	CPES
	Quality of life	PROMs
	Hospital attendances	HES
	GP attendances	GP records

Information across the care pathway (7)

		Source
Recurrence/	Date/type	?
Metastasis:	Treatment	HES/RTDS/SACT
	Patient experience	?
	QOL	?

		Source
End of life care:	Specialist Palliative care services	?
	Social care	?
	Place of death	ONS
	Date of death	ONS

Information across the care pathway (5)

- A very wide range of information is needed to build a complete picture of activity and outcomes
- The data required came from multiple sources
- These datasets need to be linked effectively
- Datasets need to be standardised if the linked information is to be meaningful
- Once collected, the data need to be collated, analysed and presented in ways which are useful to different stakeholders

➤ **These are all key tasks for NCIN**

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NCIN: What progress are we making?

- Where were we a decade ago?
- Where are we now?

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Cancer Intelligence: A decade ago

- Cancer registries
 - Reasonably complete case ascertainment
 - Timeliness – quite poor
 - Staging – decidedly incomplete
- Office for National Statistics
 - Collated information on incidence, survival and mortality at national and sub-national levels
- Waiting times database
 - Reasonably reliable for 2ww
 - Poor recording of 31 and 62 day waits
- Intermittent surveys, including
 - Patient experience (2000)
 - Radiotherapy (Royal College of Radiologists)

Cancer Intelligence: Where are we now?

- Massive progress on:
 - Collecting the information needed
 - Linking patient-level data
 - New analyses
 - New outputs: 'profiles'

Where are we now? Data collections

- Cancer registries – improving on all parameters
- Some new data collections are fully established
e.g. cancer waits; radiotherapy
- Other new data collections have now commenced
e.g. imaging and chemotherapy
- Collection of Quality of life data (PROMs) has been
successfully piloted
- Data on quality of services (structure and process
measures) e.g. peer review

Where are we now? Linkages

- Linkage of datasets is now seen as routine (It was not
always thus!)
- Hospital Episode Statistics (HES) is now linked to
cancer registry data to form the backbone of the
National Cancer Data Repository (NCDR)
- Linkage to primary care records can be made for
around 8% of the population (GPRD) – but this is set
to rise
- ENCORE – is bringing this all together

Where are we now? Novel analyses

Linked datasets are being used for a variety of purposes e.g.

- Routes to diagnosis (supporting the National Awareness and Early Diagnosis Initiative)
- Routes from diagnosis (supporting the National Cancer Survivorship Initiative)
- Studies of Major surgery/radiotherapy in different patient groups (supporting the National Cancer Equality Initiative)

Where are we now? New outputs

- Cancer commissioning toolkit
- GP practice profiles – supporting NAEDI
- PCT profiles – supporting commissioning
- Service profiles – supporting providers and patients (informed choice)

NCIN – Where next? (1)

- Can we now rest on our laurels? – NO
- Although work is in progress, there are still gaps e.g.
 - Staging
 - Chemotherapy
 - Primary care
 - Specialist palliative care
 - Social care
 - Quality of life
 - Pathology (other than histopathology)
 - Recurrences
- It is still not easy for commissioners and patients to find the information they want/need
- We still have relatively little data on costs or value for money

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NCIN: Where next? (2)

- NCIN will move into Public Health England (PHE), but will remain the main supplier of information on cancer to DH, PHE and the NHS
- Existing gaps in intelligence should be rectified as soon as possible
- New challenges/opportunities will arise and will need to be met (e.g. collection of genetic information)
- Most importantly – cancer intelligence will be THE primary driver of improved outcomes – as a lever in itself and as the bases for other incentives (e.g. financial)

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