

Producing UK level reports for the NCIN work programme: challenges and opportunities

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Objective



- Overview of UK reports produced to-date by NCIN and lead teams
- Brief look at UK level data sources available
- Some of the methodological challenges experienced to date
- What is the scope for UK level reports?
- How should UK level reports be produced going forward?
- Try not to fall asleep!



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Background


- NCIN is a UK wide organisation
- Growing emphasis on UK wide outputs on lead KITs work programmes
- UK level data has become increasingly available over the last couple of years

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UK outputs to-date



Coming Soon ...

- Bone and Soft Tissue Sarcomas in the United Kingdom – West Midlands KIT
- Urological Cancer Factsheets – Incidence, mortality and survival in the UK – South West KIT

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UK data sources: What's available, what are the issues?

UK Cancer Information Service

Data for UK ranges from 1993 to 2010 diagnosis years/2011 mortality

National Cancer Data Repository 2010

Non-identifiable data for Celtic countries

- partial dates – problematic for survival analysis

- no sub-geographical data

- no deprivation data

Coding of tumours has been found to be inconsistent

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Methodological Issues:

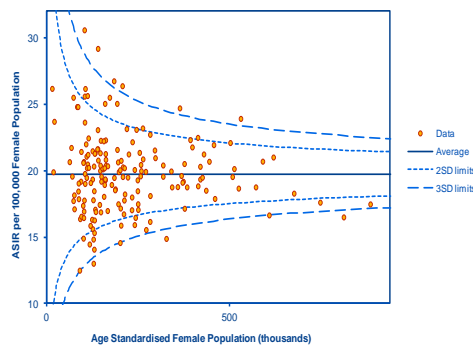
Sub-national analysis

Is it acceptable for lead registries to present sub-national analysis?

Could this lead to conflicting data?

How do we deal with outliers in UK reports?

- Does the guidance briefing need to add anything?



Uterine cancer incidence rates at health authority level, UK, 2007-2009

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Methodological Issues:

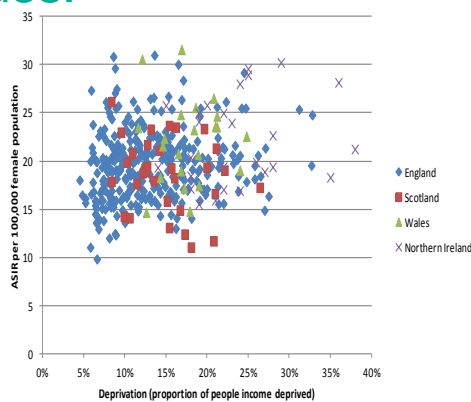
Deprivation

Deprivation has to be analysed by country

Can't compare across countries, only within countries

Can make general statements, "incidence rates tend to be highest in the most deprived areas within the UK"

What deprivation measures to use for each country?



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Collaboration/Communication

- Help needed to find and verify UK wide contextual information and data

What was the impact of the Campbell report on cancer services in NI?

Obesity Rates among Scottish women?

- Single analysis of treatment data at UK level an impossibility. This would require collaborative work between all countries
- **Avoid duplication of work and conflicting intelligence**
 - Communicate intention
 - Share initial results
 - Opportunity to comment

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What does this mean for the production of UK level reports?

- Do we need a more formal approach to producing UK level analysis?
 - Sub-analysis group? Steering group specific for UK level outputs?
 - Decide the scope of UK projects in relation to available data and planned work within specific countries
 - Share best practice, knowledge and findings.
- Who are the organisations that should be involved?
 - NCIN central team
 - NCDR team
 - England KITS, Scotland, Wales and NI intelligence teams
 - CRUK/ other charities
 - Ireland intelligence team?

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Discussion/Questions

- How can we improve the NCDR for next iteration?
- What is the consensus on sub-national analysis for UK countries?
- Should the guidance briefing on outliers include guidance on how to deal with outliers in different countries?
- Should we have a formal approach to producing UK level reports, lead by NCIN, as a steering group or analysis sub-group?
 - Decides scope of work
 - Forum for discussing and improving data issues
 - Share best practice, knowledge and findings
 - Who should be involved?

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