

The National Brain and CNS Registry

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A National Registry for Brain, CNS, Skull-base and Pituitary tumours

- National population-based tumour registry
- With 100% ascertainment
- Covering all tumours in these groups
- Containing quality assured data
- Including details of treatment, outcome, co-morbidity and long term follow-up

It will be the national resource underpinning clinical care, audit and research for this group of tumours

reasons why this won't work

"the systems aren't there to collect the data"

"data in the NHS is rubbish"

"there is no money"

"I already have my own database, thanks"

"nice idea – but you are mad if you think it can be achieved"

"we all do things differently"

"we are all too busy"

"I have been here before – it didn't work last time and won't this time."

"we don't have the IT expertise in our Trust"

"it isn't allowed – it breaches patient confidentiality"

National Cancer Registration in England

- 8 Regional cancer registries
- Information Governance framework for identifiable patient data
- 18-month completion time
- Incidence, mortality, survival
- Data on ~250,000 tumours/year
 - Works quite well for common tumours
- Limited treatment & outcome data
- Limited direct feedback to clinical groups
- Timeliness and consistency is an issue for a wider dataset

For brain and CNS tumours

- ~6,000 tumours / year in the England
- Large number of different tumour types
 - ~134 histopathological types
 - 4 account for >50% cases; 19 for 90%
 - 60% of types <10 cases /year
- Highly specialised diagnoses
- Increasingly diagnosed and graded with radiology
 - Outpatient follow-up; palliative care

Options – for Brain, CNS etc

- Do nothing new
 - 2.5% of all cases per year
 - Use existing CR and HES data etc
- Concentrate on the big five/top nineteen
 - Ignore the rest
- Aim for “perfection”
 - Constrained by cost, time, effort etc

The case for perfection

- Relatively small work-load
- Limited number of expert centres
- Cohesive expert professional groups
 - Neurosurgery, oncology, pathology, radiology, specialist nurses etc
- Timely
 - IOG and neuroscience MDTs
- Has the potential to deliver significant benefits

The Brain and CNS SSCRG has permission from the NCIN to run a national pilot to implement new data collection for a national site specific registry.

This project will act as an exemplar for “rare” tumour groups.

Designs for a perfect world

- Secure buy-in and commitment from everyone
- Ensure sufficient time, money, expertise etc
- Reach a consensus on what to do, how and when
- Define the data items and system interoperability standards
- Mandate national data and interoperability standards
- Modify existing systems to support new path/pacs/pas/mdt feeds
- Make sure data is entered consistently
 - Train and teach staff
 - Modify working practices
- Audit and QA data; systems; people
- Begin to collect data (from the early adopters)
- Audit and QA data; systems; people
- Roll-out nationally

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- Work from what you can do now, not from what you like to do eventually (80/20 rule)
- Apply the KISS principle:
 - Keep it simple, stupid
- Provide expert input to help get data flowing
- Only address the real show-stoppers
- Share best practice
- Provide timely and relevant feedback and audit of data to improve quality etc

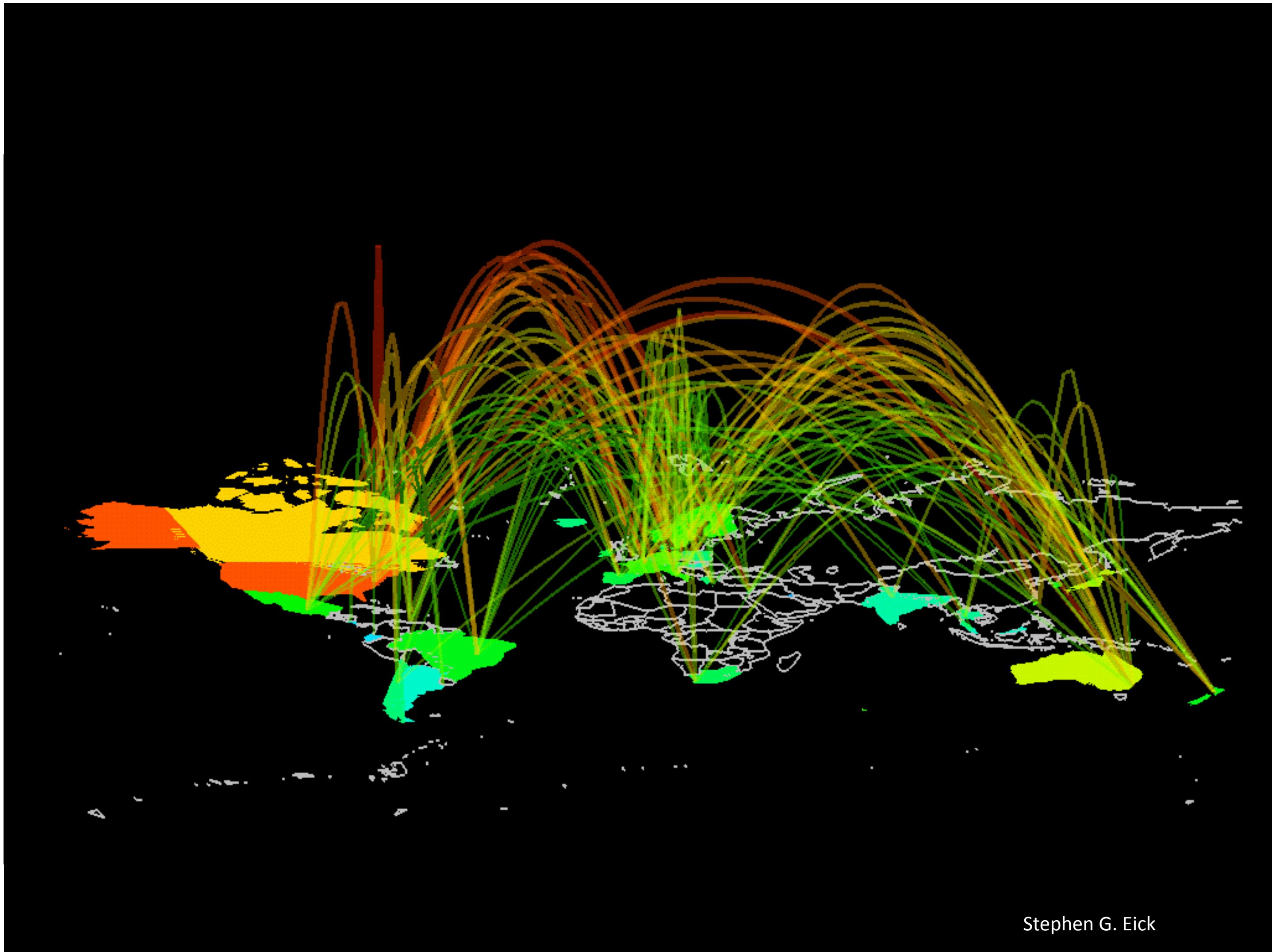
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- has a registry database and processing system
- is be able to hold all the data items in existing and new cancer datasets
- has expertise in CNS tumour classification
- has expertise in electronic data processing methods
- is covered by the Information Governance framework for English cancer registries

Today is...

- about input from the expert community.
- a reality check
 - Is this what the community wants?
 - can it be made to happen?
 - If it can, then how do we start?
- to identify the champions and early adopters.

This is a remarkable opportunity, but it can only happen with your support and input.



Stephen G. Eick