

Noah's Ark: A Global Database Success Story or What Might One Learn at a Zoo?



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National Cancer Intelligence Network (NCIN – est. 2008)

The NCIN is a UK-wide initiative, working to drive improvements in standards of cancer care and clinical outcomes by improving and using the information collected about cancer patients for analysis, publication and research.

www.ncin.org.uk

Aims and objectives:

- Promoting efficient and effective data collection throughout the cancer journey
- Providing a common national repository for cancer datasets
- Producing expert analyses, to monitor patterns of cancer care
- Exploiting information to drive improvements in cancer care and clinical outcomes
- Enabling use of cancer information to support audit and research programmes

International Species Information Systems (ISIS – est. 1973)

ISIS...maintains computer-based information systems used by the worldwide zoological community. It is the mission of ISIS to facilitate international collaboration in the collection and sharing of knowledge on animals and their environments for zoos, aquariums and related organisations.

www.isis.org

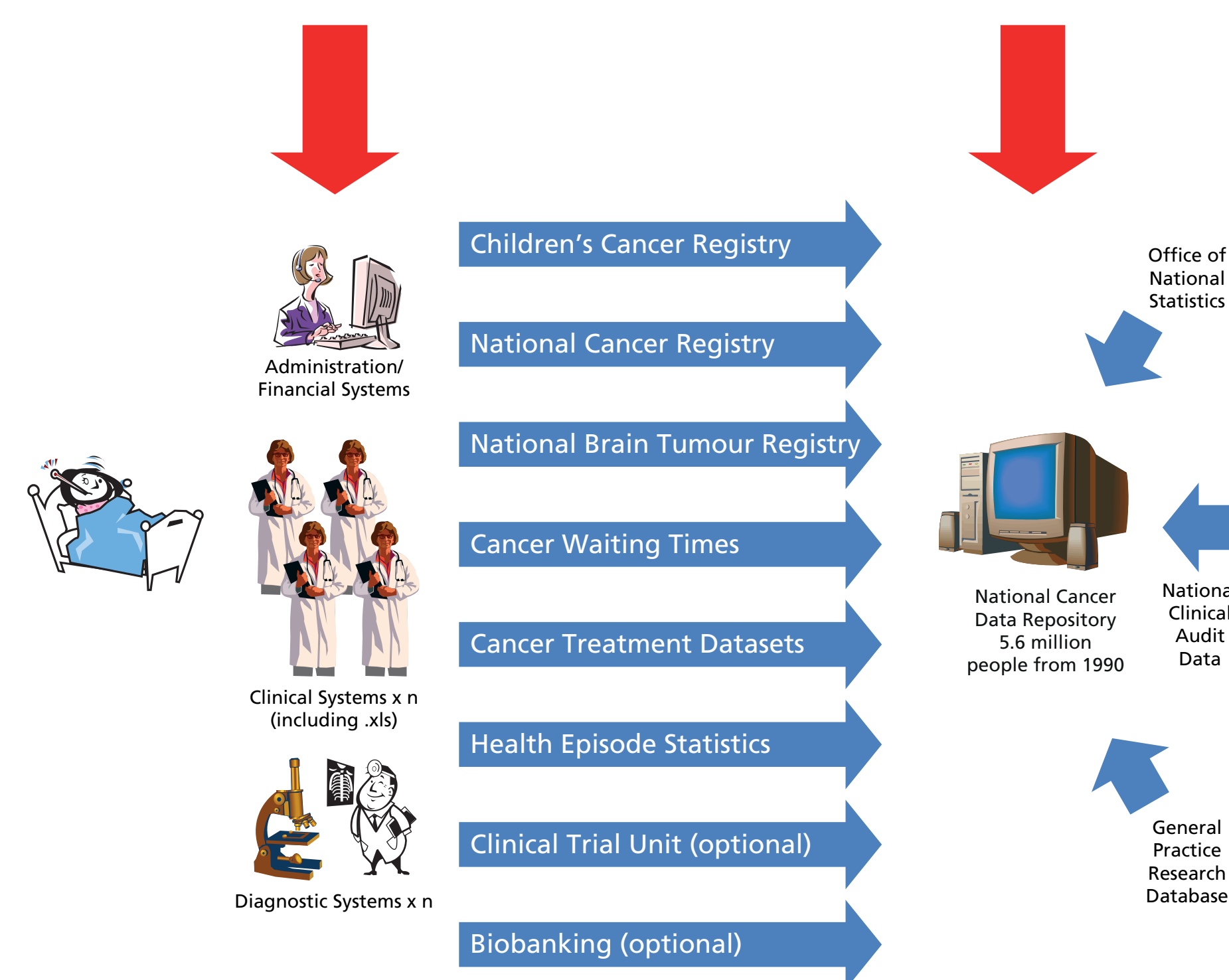
Goals:

- Supporting, maintaining and ensuring the continuous development of comprehensive software systems and tools
- Serving as an independent, impartial body which promotes the development of standards and practices that enhance the integrity and usefulness of data on animals and their environments
- Obtaining the broadest possible participation in data collection and sharing for zoos, aquariums and related organisations worldwide
- Promoting the general scientific usage of the knowledge beyond animal management

Convergent in purpose – Divergent in strategy

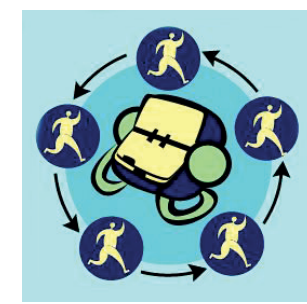
Cancer Information Management

Consider the reporting requirements for a Trust in England caring for a child diagnosed with a brain tumour



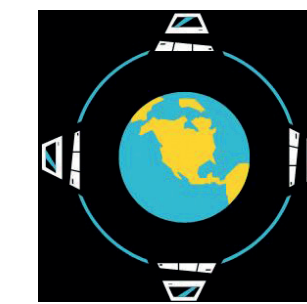
NCIN

- National
- 1 country
- 168 Acute NHS Trusts
- 168 (x n²) hospital information management systems (£££)
- MULTIPLE Datasets



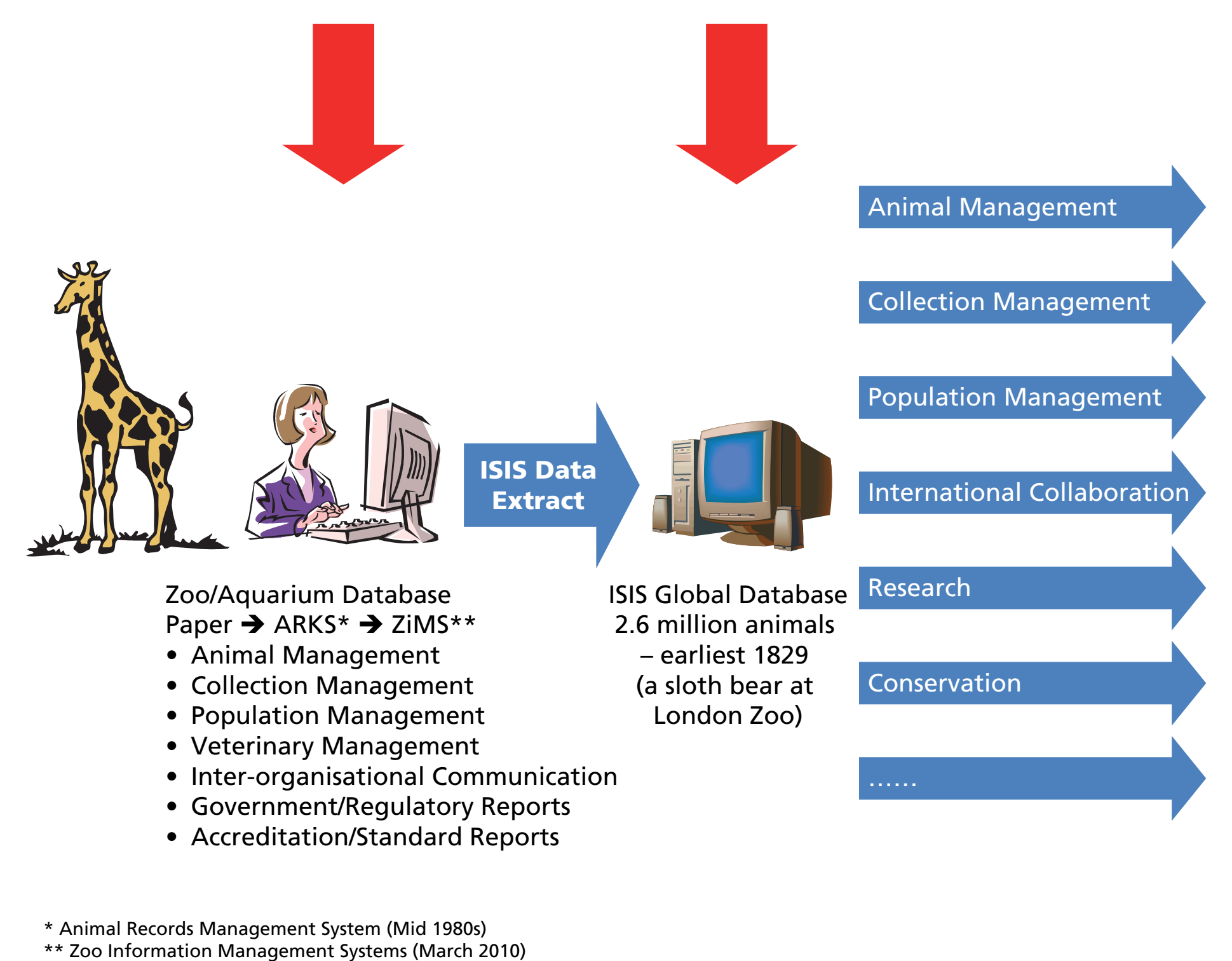
ISIS

- International
- 80 countries
- 6 continents
- >800 zoos & aquaria
- ONE information management system
- ONE global dataset
- Pooled resources (\$) → shared benefit



Zoo Information Management

Consider the reporting requirements for any ISIS zoo



* Animal Records Management System (Mid 1980s)
** Zoo Information Management Systems (March 2010)

What, if anything, is wrong with this picture?
What, if anything, might cancer information, service and research networks learn from the experiences of other industries?

Which is a more efficient use of resources?
Which might yield higher quality data?

Might this model be more efficient?
Might the result be higher quality data?

Cancer Management – Success Stories?

Data quality, gaps and caveats

- Current gaps in clinical outcomes data include critical information a factors that impact on treatment options such as stage, co-existing illness and cancer sub-type. This prevents case-mix adjustment and limits interpretation of the data.
- Incomplete data and differences in how data are coded by different Trusts and cancer registries will account for some of the variation in outcomes.
- ...no direct conclusions should be drawn from the data provided without additional analysis. (Cancer Research UK website)

MPs slam PCT "failures" on cost-effectiveness of cancer care

"The key driver of further improvements is the need for high-quality, comprehensive and timely data that is understood and used to make decisions about how services should be configured." (UK News March 01, 2011/Pharmatimes website)

One year cancer survival rates in England remain poor despite national strategies

- The committee found a lack of information on aspects of cancer care that it considered important for monitoring quality of services. "It is very disappointing that, a decade after publication of the NHS Cancer Plan, there is still not enough good quality and timely information on such important aspects of cancer services."
- The report recommended developing a cancer information strategy including common standards for the quality and timeliness of data on cost, activity and outcomes.
- The report also pointed out that the Department of Health cannot yet measure the impact of the cancer strategy on key outcomes, such as survival rates. And it does not know if cancer services are being commissioned cost effectively because of poor data on costs, and because outcomes data are not sufficiently timely. (BMJ 2011)

Cancer Strategy goals "at risk from poor information"

Delivery of improved patient care through the 2007 Cancer Reform Strategy for England is at risk unless there is considerable improvement in the quality of information used to support it, the National Audit Office (NAO) has warned. (UK News November 18, 2010/Pharmatimes website)

Report reveals 'shocking' variation in cancer survival in the UK

"...eight 'priorities for action' designed to close the gap in survival rates and boost cancer outcomes, and its key recommendations include: ...improved data collection to help primary care trusts plan effectively for their local populations. (UK News December 03, 2009/Pharmatimes website)

Data Standards

Registry data collected in the absence of shared standards contribute little beyond anecdotal data towards case management or cancer control. Shared standards ensure clarity of communication, protect the integrity of data when pooled or compared across multiple sources... (NCI website)

National Brain Tumour Registry (NBTR)

We do not have a fixed list of data items and/or prescriptive list of definitions to impose on any MDT. (NBTR website)

Captive Animal Management – Success Stories

SAVED FROM EXTINCTION – CAN YOU IDENTIFY THESE ANIMALS?



Recommendation

NCIN should adopt the ISIS strategy: focus resources on facilitating an inter-Trust collaborative approach – using a pooled budget – to provide a single solution to be used by all cancer treatment centres to manage patient care which feeds a single database from which all information requirements can be met.