What is the NCIN?

November 2009

"Quite simply, we want to have the best cancer information service in the world by 2012"

Mike Richards
Britain against Cancer
Dec 2007

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"The best cancer information service in the world"

- Build on current strengths of UK cancer registry system

- Collection of defined datasets on all cancer patients to be mandated through the national model contract. PCTs will be responsible for ensuring that this information is collected by MDTs and sent to cancer registries

- A new National Cancer Intelligence Network is being established to bring together relevant stakeholders and to act as a repository of cancer data.

Cancer Reform Strategy 2007

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NCIN Core Objectives

1. Promoting efficient and effective data collection throughout the cancer journey
2. Providing a common national repository for cancer datasets
3. Producing expert analyses, based on robust methodologies, to monitor patterns of cancer care
4. Exploiting information to drive improvements in standards of cancer care and clinical outcomes
5. Enabling use of cancer information to support audit and research programmes

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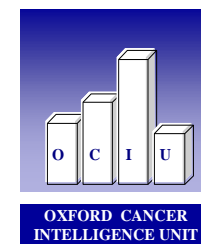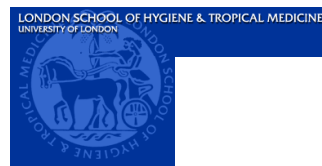
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NCIN Goal

In summary – to improve outcomes

- To provide data on performance and outcome to clinical teams

- To promote a stronger base for commissioning

- To improve choice for patients

- To capitalise on opportunities for health services research

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NCIN Collaborators

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NCIN Governance

- Part of the NCRI Initiative
- NCRI Board
- Cancer Programme Board
- NCIN Steering Group
- NCIN Coordinating Team
- Clinical Reference Groups
- Scientific Advisory Group

How are we doing this?

- Establishment of 12 site specific clinical reference groups to advise and progress key work streams

- Development of national data repository bringing together HES data, cancer registry data, and other sources such as cancer waits

- Undertaking expert analyses, and producing – eg The Cancer E Atlas

- Supporting audit and research

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SSCRGs - membership

- Colleges and professional groups
- Lead cancer registry
- Relevant national audit team
- NCRI Clinical Study Group
- Patients/consumers
- Voluntary sector groups
- The Cancer Network Director for the tumour site
- Representation from the 'national strategic team' (DH, NCAT, Peer Review Team, NHS Improvement)
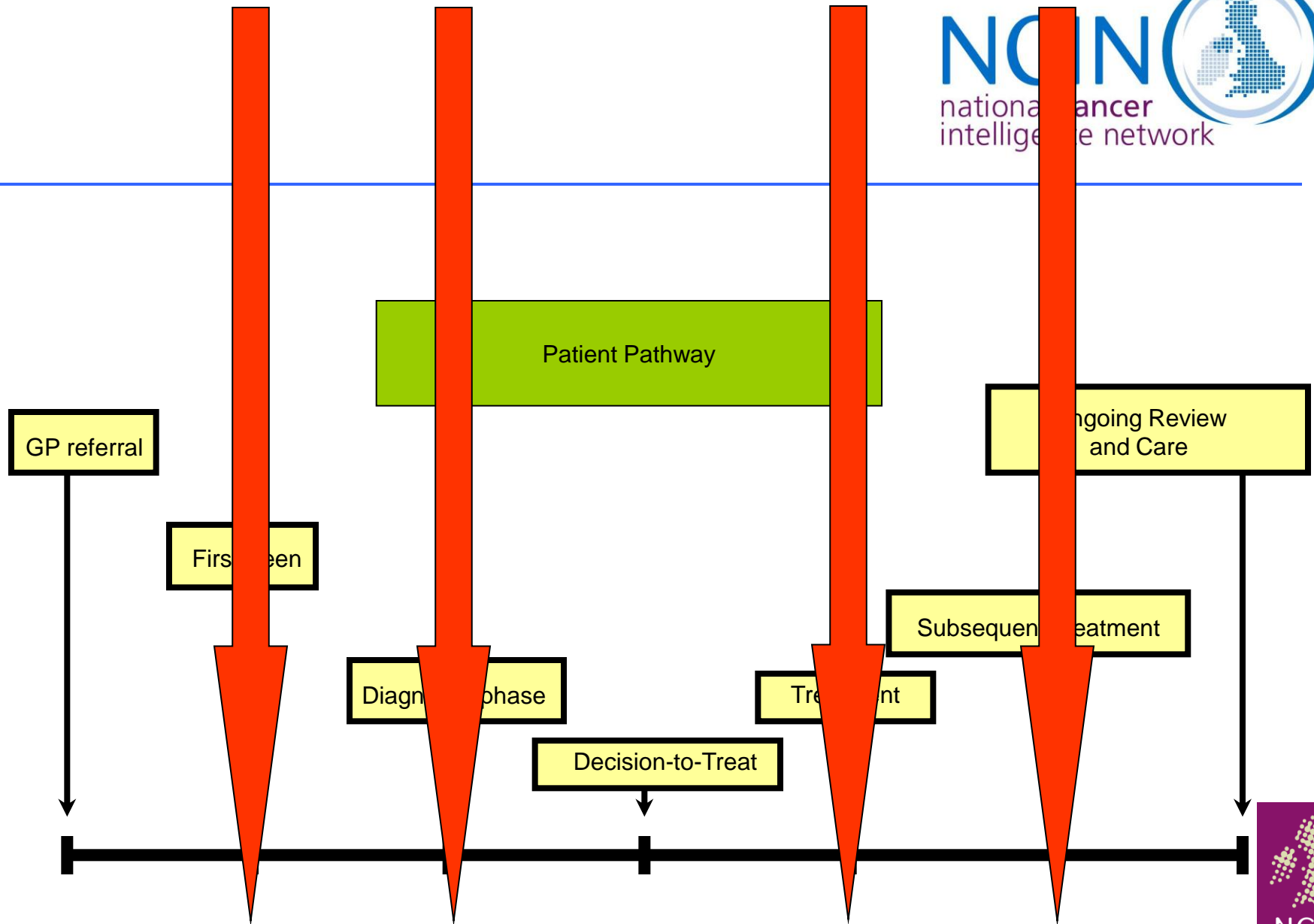- NCIN core management team.

CTYA (SS)CRG Membership

- Mike Stevens (Chair)
- Jill Birch
- Audrey Bradford
- Simon Davies
- Chris Gibbs
- Adam Glaser
- Mike Hawkins
- Louise Hooker
- Anna Kelsey

- Ian Lewis
- Chris Mitchell
- Tony Moran
- Mike Murphy
- Kathy Pritchard-Jones
- James Salt
- Charles Stiller
- Jeremy Whelan

+ NCIN team
+ Vacant post – TYA 'user'

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Patient Pathway

GP referral

First Screen

Diagnostic phase

Decision-to-Treat

Treatment

Subsequent Treatment

Ongoing Review and Care

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Focus on…..

- MDTs
- Patient Management
- Aligning datasets
- Coordinate processes
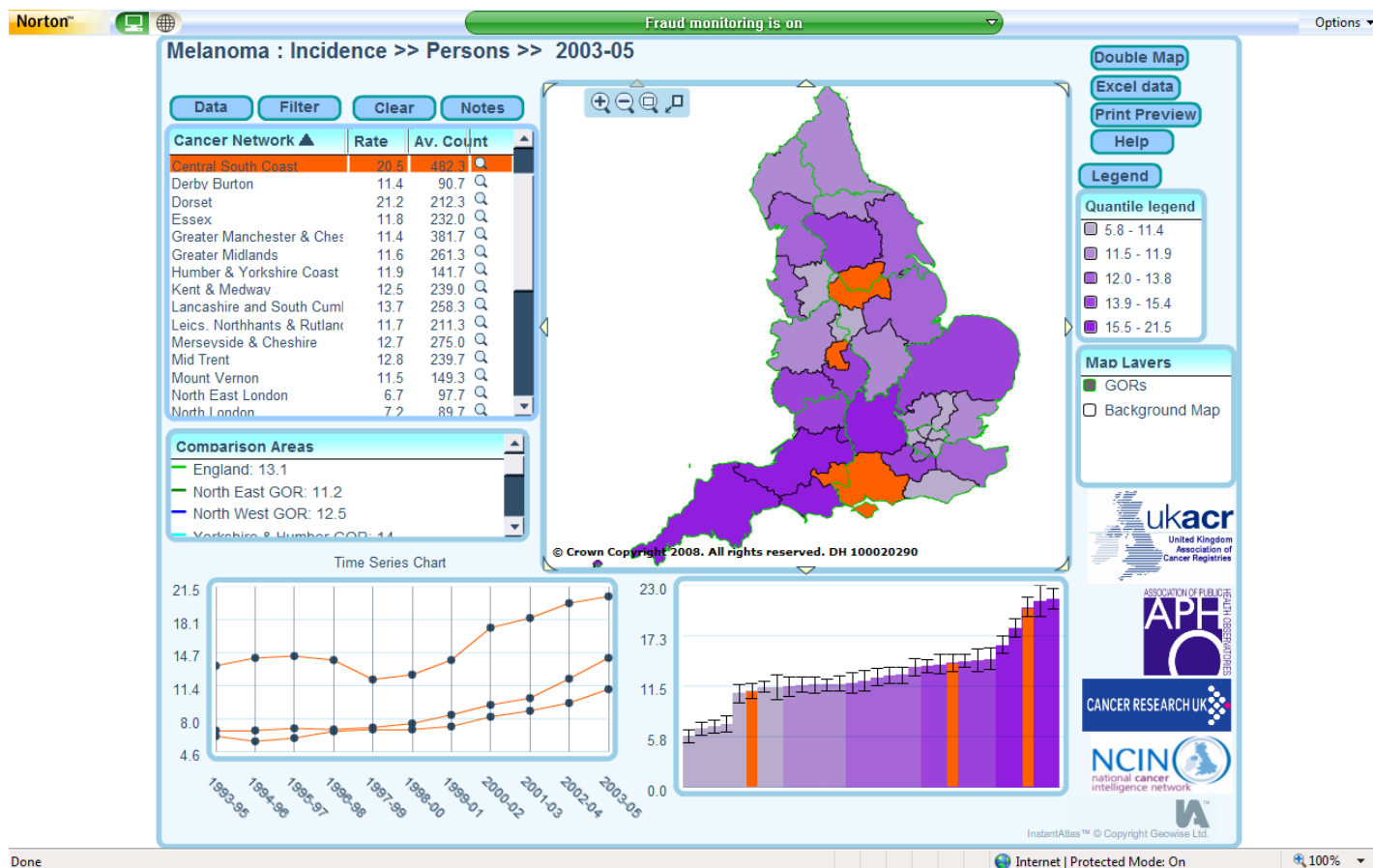- Gaps in knowledge and data

COLLECT ONCE

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National Cancer e-Atlas

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NCRN (Trials) Linkage

- Monitoring entry rates into clinical trials
  - comparing characteristics against population based incidence
  - Examining geographic, ethnic and socio-economic characteristics of patients in trials
  - comparing characteristics of trial entrants with non-entrants
- Potential for following up trials patients over long periods
- Assessing the quality, reliability and reproducibility of data available in the NHS datasets as compared with data collected in clinical trials
- NCIN data for follow-up (e.g.)
  - Can subsets of patients with more intensive follow-up inform interpretation of whole trial population datasets?

Summary...

Future perspectives:

- Massive potential of data linkages:
  - Service: clinical, primary care, end of life
  - Research: genetic, trials, informatics
- Scope to transform information landscape
  - New linked datasets as research tools
  - Clinical care and outcomes properly monitored for service improvement and patient benefit

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