Changing Cancer Data Collection: Creativity with Data Flows

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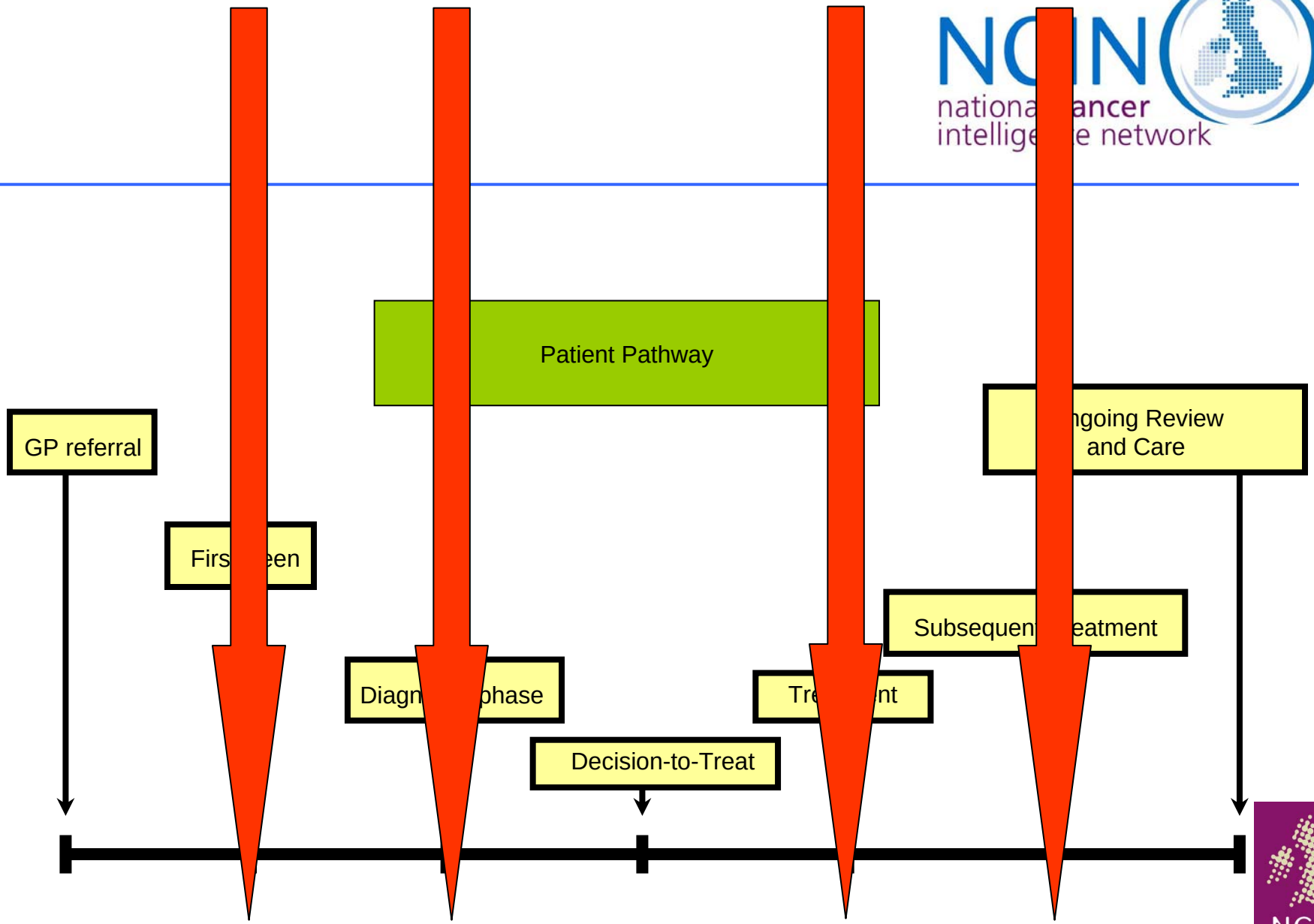
Lead for Clinical Outcomes

NCIN

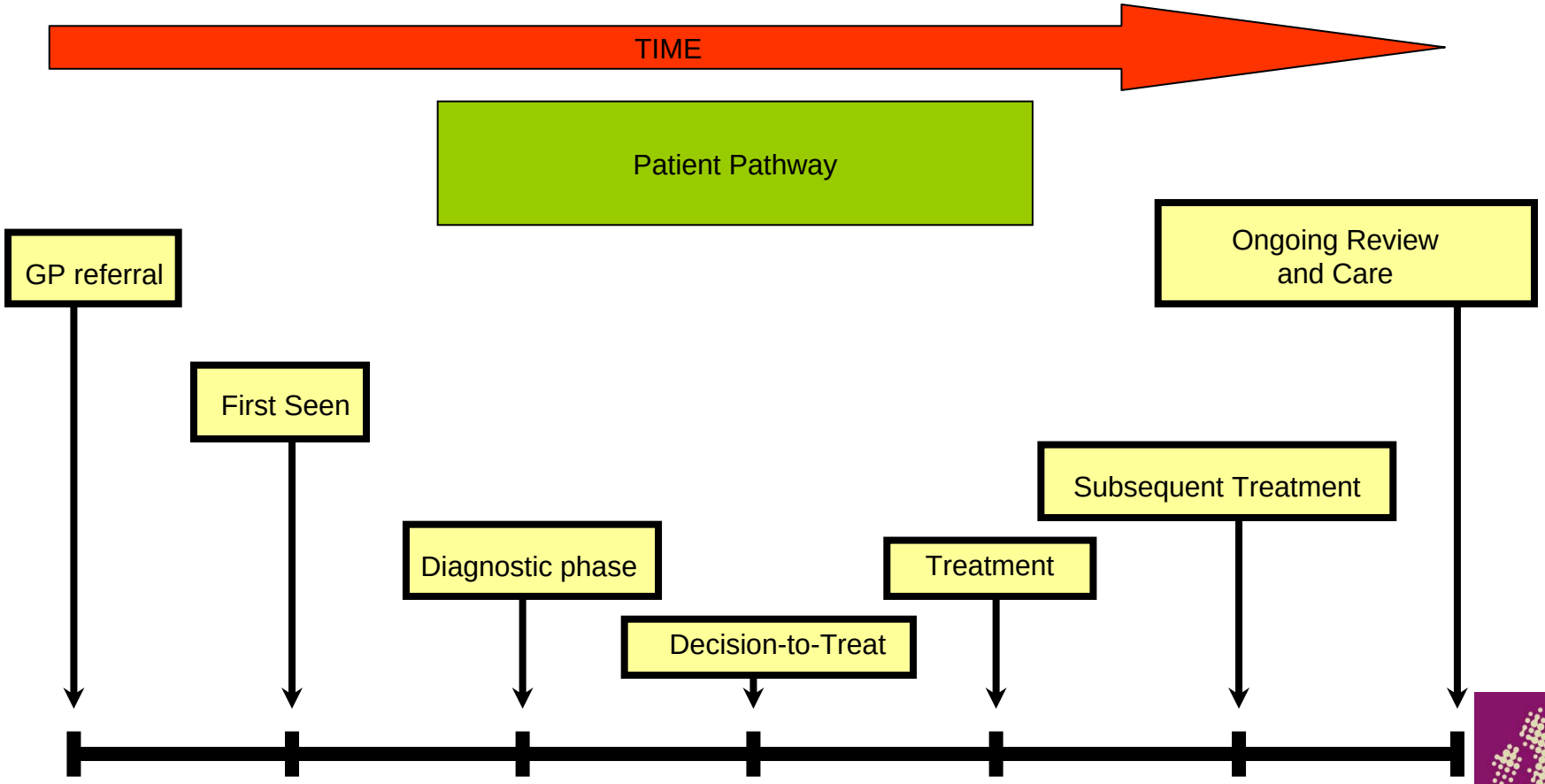
Core Objective #1:
Promoting efficient and effective data collection throughout the cancer journey

Calman-Hine 1995

- ...Framework for creating a network of cancer care in England and Wales...
- ...Development of cancer services should be patient focussed...
- ...Cancer registration and careful monitoring of treatment and outcomes are essential...



Using information to improve quality & choice


TIME
Patient Pathway
GP referral
First Seen
Diagnostic phase
Decision-to-Treat
Treatment
Subsequent Treatment
Ongoing Review
and Care

Since then…….

- Cancer Plan 2000
- Manual of Cancer Standards
- Peer Review
- MDTs
- National Cancer Dataset
- Cancer Waits
- National Clinical Audit Support Programme
- College datasets e.g. BASO, ACP, BAUS

Emphasis on cancer data

- Multiple datasets
- Multiple data sources
- Multiple data processes

- No strategy
- Parallel universes
- Who wants what and when!

DUPLICATION

Focus on…..

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

COLLECT ONCE

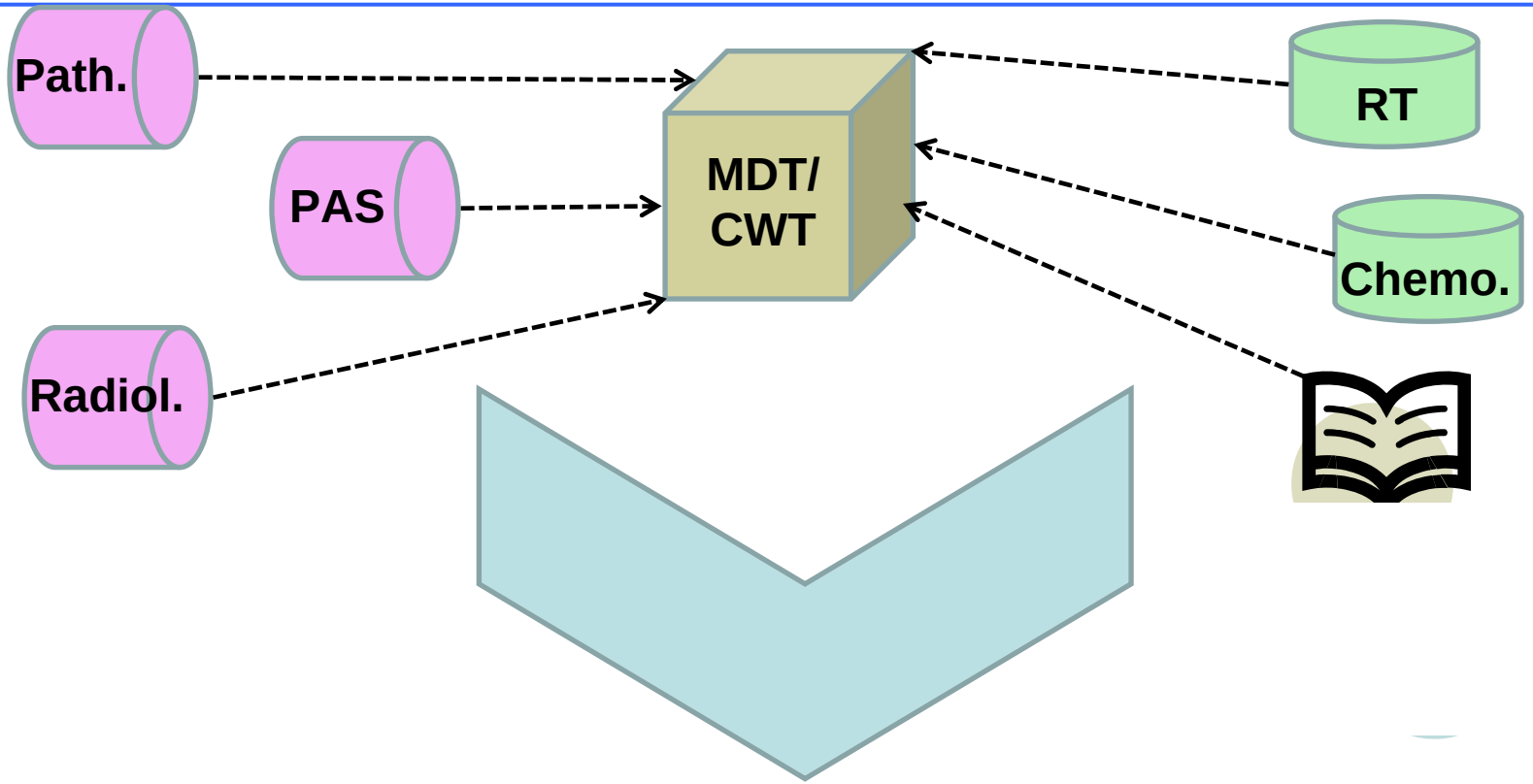
Cancer Reform Strategy

- Mandation of datasets
  - National Contract for Acute Services
  - Commissioning Datasets
  - Cancer Waiting Times
  - Cancer Registration
  - Radiotherapy
  - Chemotherapy

By 2011

- Electronic transfer of Cancer Registration dataset
- Recognise multiple data sources
- Capture ‘clinical’ data via MDTs
  - Staging
  - Co-morbidity
  - Recurrence, etc

Patient Management

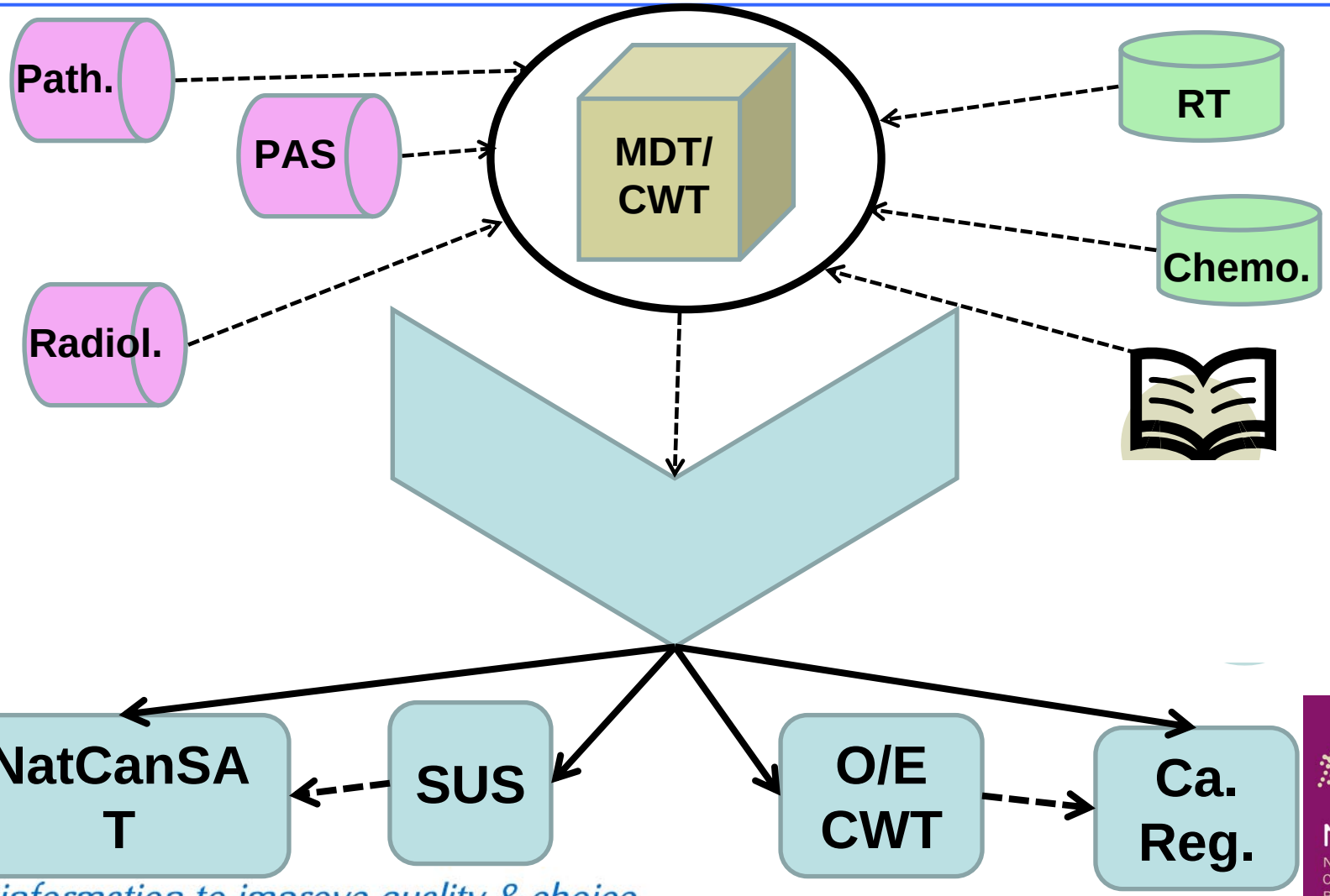


Link Data Sources for Patient Care

Challenges....

- Clinical data from MDTs?
- Transport via standard NHS data flows
  - SUS
  - Open Exeter (Cancer Waits)
  - To Cancer Registries & Nat. Repository
  - To NCASP
- Linking activity and ‘care record’ data
  - OPCDS + radiotherapy
  - CWT + ‘registration’

Data Transfer - 2



Using information to improve quality & choice

The role of NCIN

- Coordinate implementation of National Contract
- Support MDTs to coordinate data capture
- Oversee MDT training programmes
- Facilitate discussions re: data gaps
  - Staging & co-morbidity
- Support submissions to ISB and ROCR
- Work towards harmonisation of processes
- Strive for data quality and timeliness