NDRS
NATIONAL DISEASE REGISTRATION SERVICE

NDRS webinar: Breast screening After Radiotherapy Dataset (BARD)

7th October 12:00-13:00

Welcome! The webinar will start shortly

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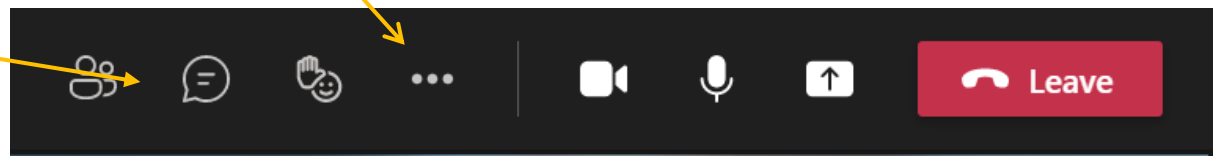
Welcome and Housekeeping

- Difficulties with sound/connection – log off and re-join
- Please put yourself on mute & camera off
- Set your own live captions in settings (the three dots on the top right)
- Post questions in chat box



- Webinar is being recorded – recording and slides on our website later:

www.ndrs.nhs.uk/breast-cancer-screening-after-radiotherapy-dataset-bard-webinar-october-2021/

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Speakers and Content

Speakers:

1. Elsita Payne, NDRS

2. Professor John Radford, University of Manchester and The Christie NHS Foundation Trust

2. Professor Richard Cowan, The Christie NHS Foundation Trust

3. Dr Joanna Williams, The University of Manchester, The Christie NHS Foundation Trust and NHS Digital

Agenda:

- An introduction to NDRS
- An overview of the Breast screening After Radiotherapy Dataset (BARD)
- Breast cancer and radiotherapy
- Implications for clinical practice
- Challenges / issues / future aims

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Overview of NDRS

The National Disease Registration Service (NDRS) collects data on patients with cancer, congenital anomalies and rare diseases.

The NDRS includes two disease registration services:

1. **NCRAS** – National Cancer Registration and Analysis Service
2. **NCARDRS** – National Congenital Anomaly and Rare Disease Registration Service

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The Data Journey

1 Patient journey

2 Data collection

NDRS support hospital teams to code and collate data throughout the patient pathway

3 NDRS

NDRS teams consist of - Technology, Data liaison & projects, Registration and Molecular

4 The data is then used by:

NDRS analysts, researchers, charity organisations, NHS policy makers and commissioners

Data outputs, knowledge sharing & communication

This includes evaluating service provisions, addressing health inequalites, environmental causes and improving outcomes for patients

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Putting security and confidentiality first

NDRS data is highly sensitive and patient level

- Security and patient confidentiality are paramount

NDRS has legal permission to collect patient information without consent

- Granted under Section 254 of the Health and Social Care Act 2012

  Must have a medical purpose
  - Be in the public interest or interest of improving care
  - Obtaining consent must be impractical
  - Be compliant with DPA/GDPR

Yearly review with the Confidentiality Advisory Group – Health Research Authority (HRA)

Data is aggregated, anonymised or de-personalised wherever possible

Patient can opt out at any time

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Patient Information

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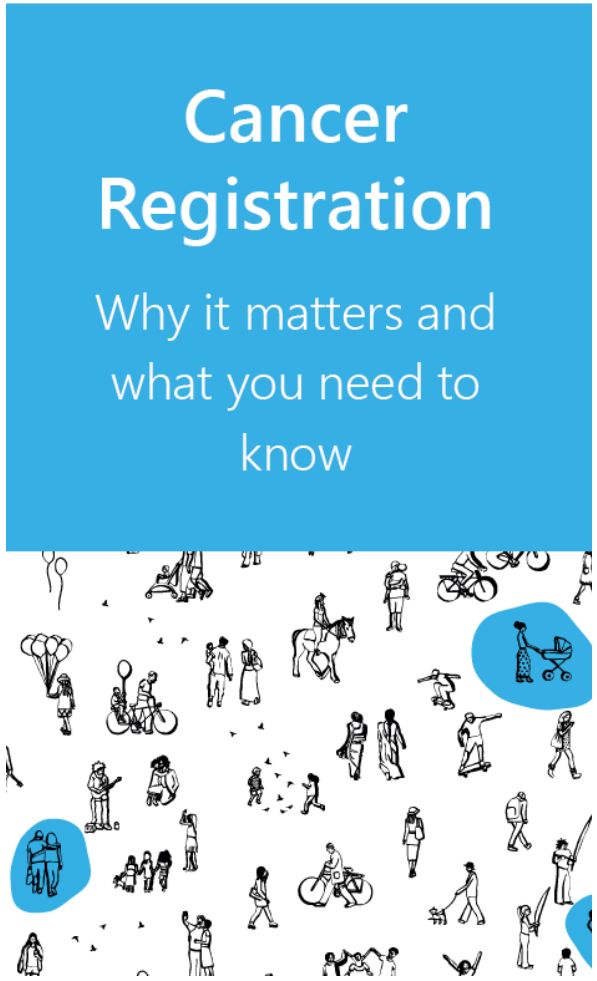

Patient leaflets are given to patients after a cancer diagnosis.

- Online PDF leaflet
- You can order print leaflets
- Visit our website: www.ndrs.nhs.uk

Contact: NDRSenquiries@nhs.net

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BARD

Breast screening after radiotherapy dataset

7th October 2021

MANCHESTER 1824
The University of Manchester

The Christie NHS
NHS Foundation Trust

NDRS
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ICR The Institute of Cancer Research

TEENAGE CANCER TRUST

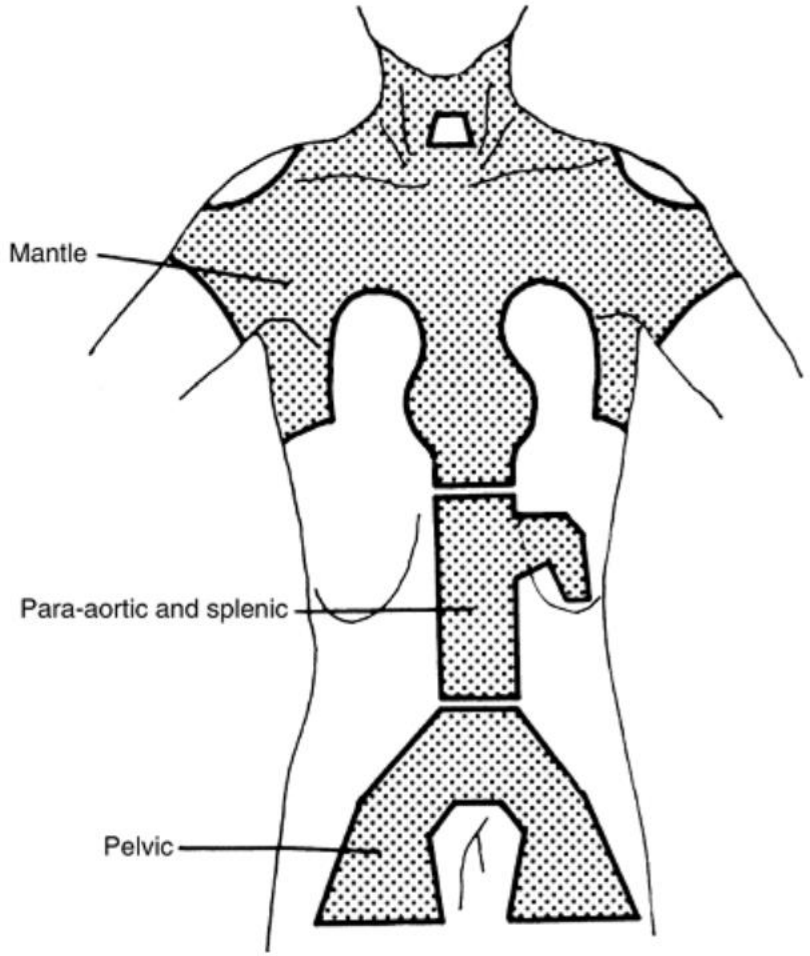
The evolution of Radiotherapy in Hodgkins Lymphoma

Radiotherapy – the only curative treatment

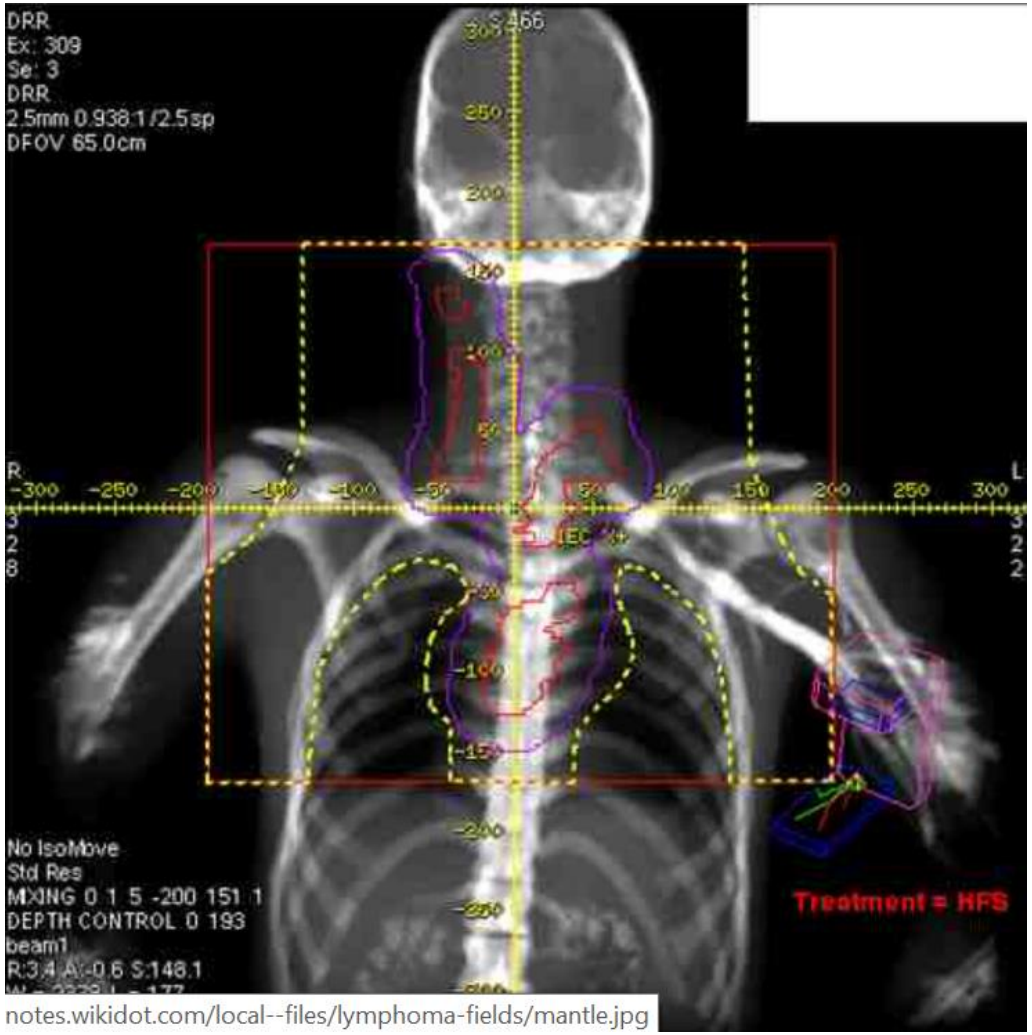
Radiotherapy – the only curative treatment

Total Nodal

Radiotherapy

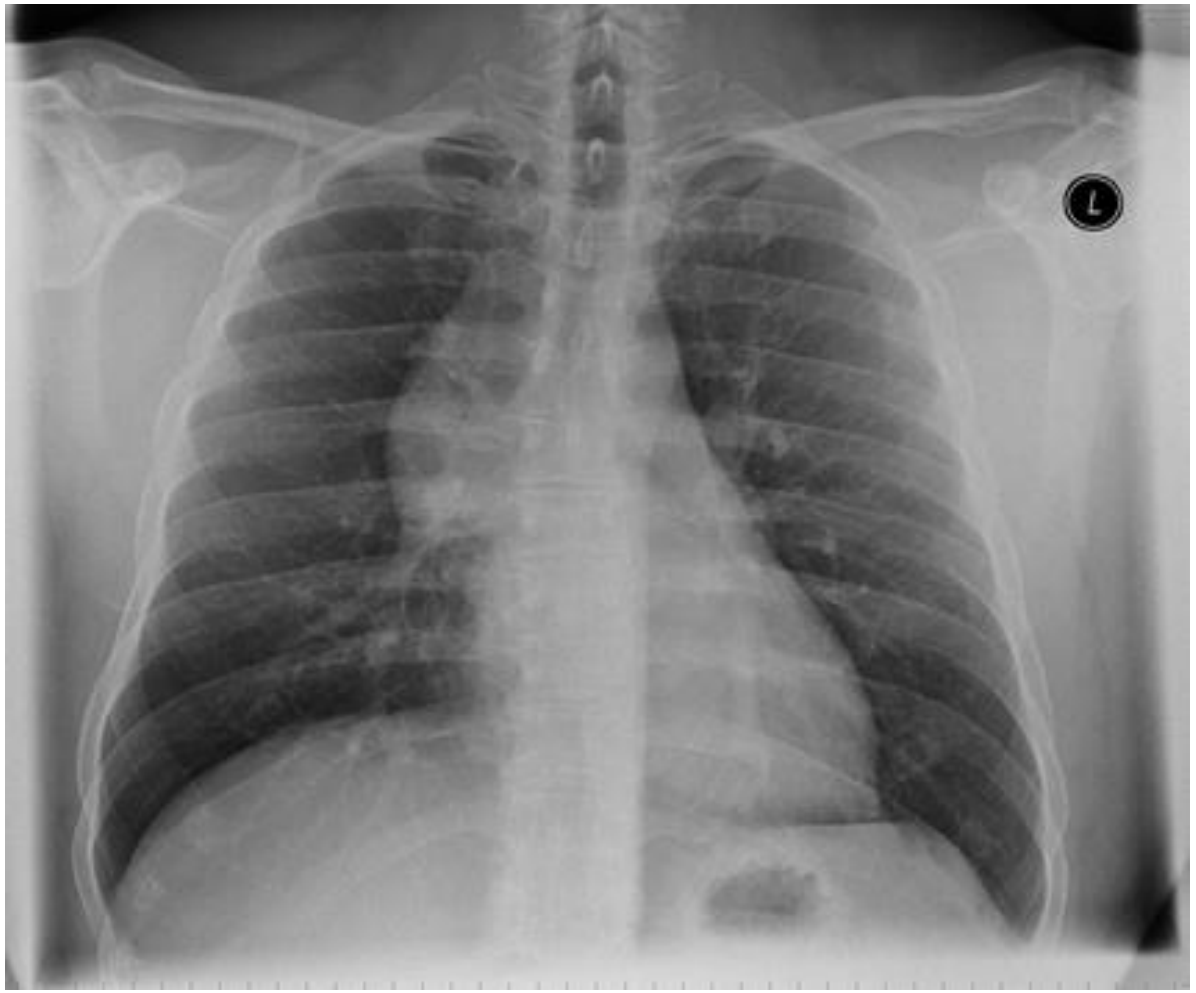


Mantle Radiotherapy

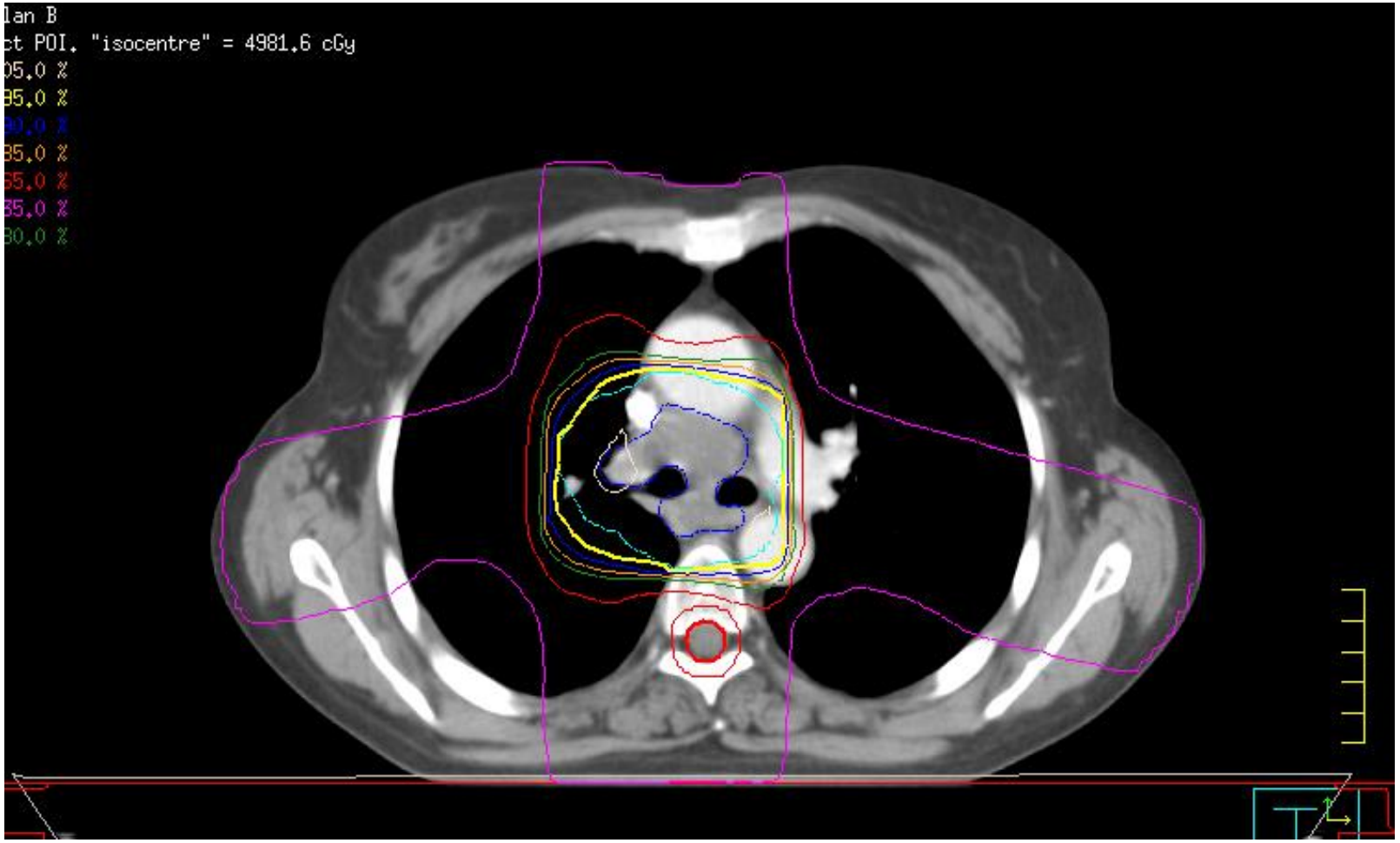


notes.wikidot.com/local--files/lymphoma-fields/mantle.jpg

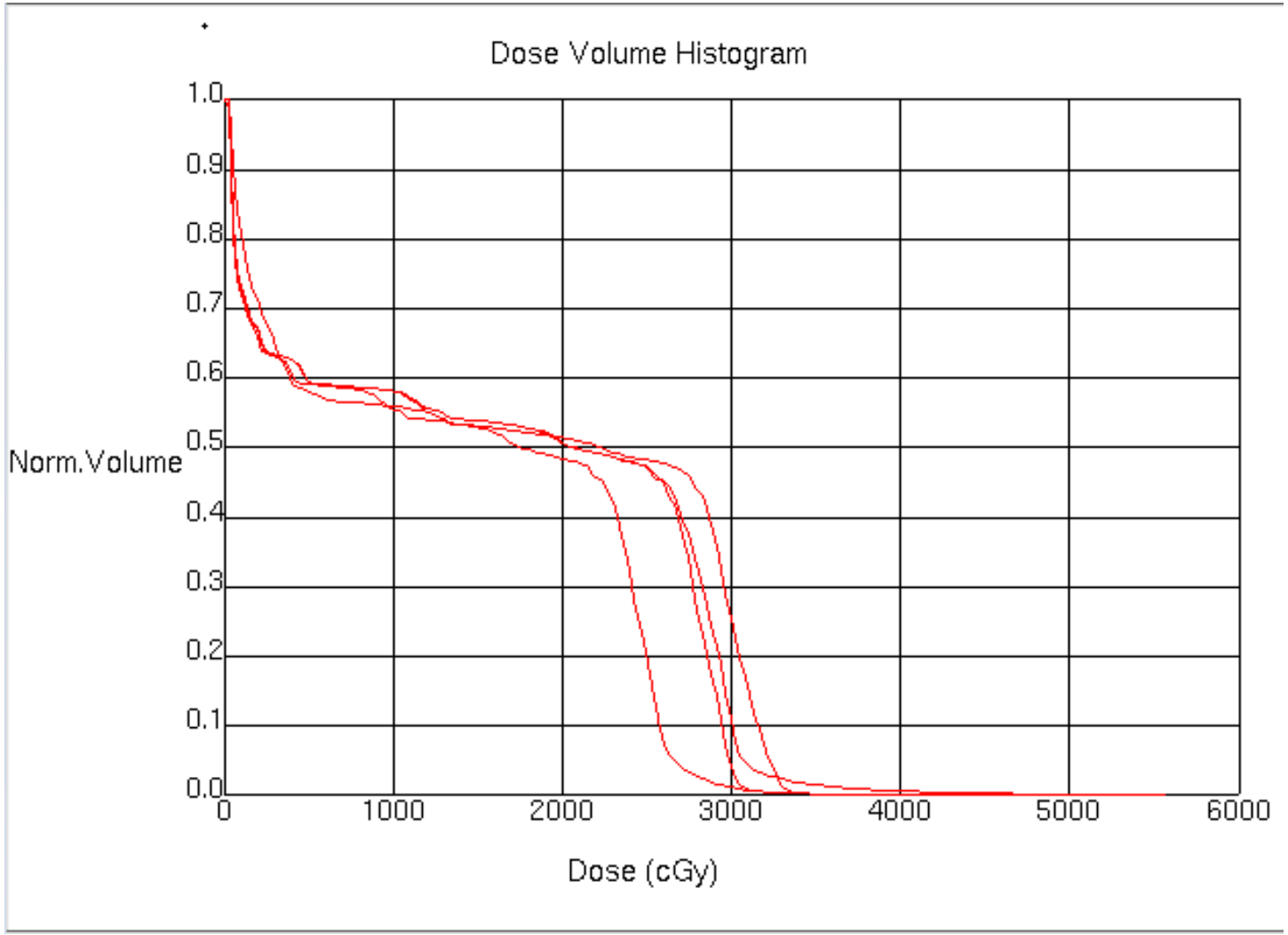
Plain film imaging



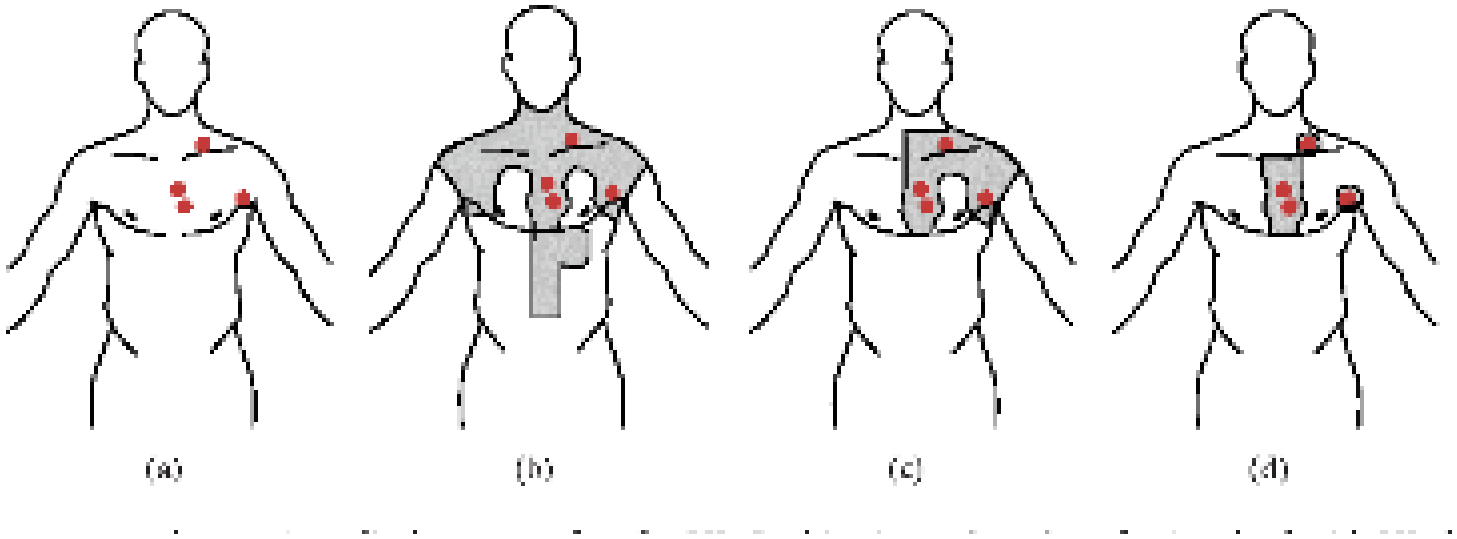
1990s



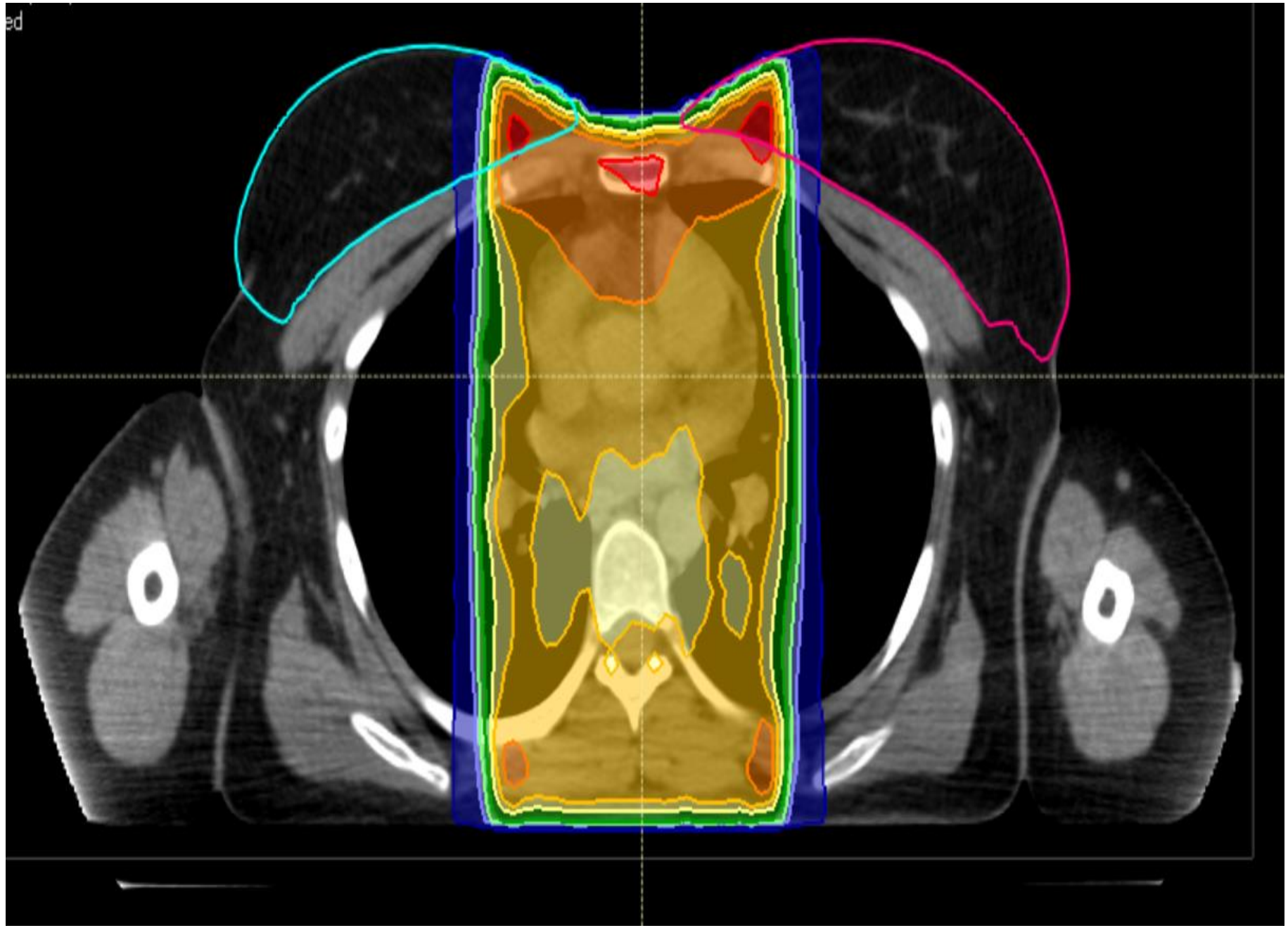
Calculate the dose to critical structures



Reduction in field irradiated



Regulation of movement during treatment



Accurate estimation of dose to the breasts

- This has not been carried out routinely
- We have yet to determine which is the most important parameter to record
- Prospective studies to correlate the volume of breast tissue irradiated, the dose and the risk of subsequent cancer

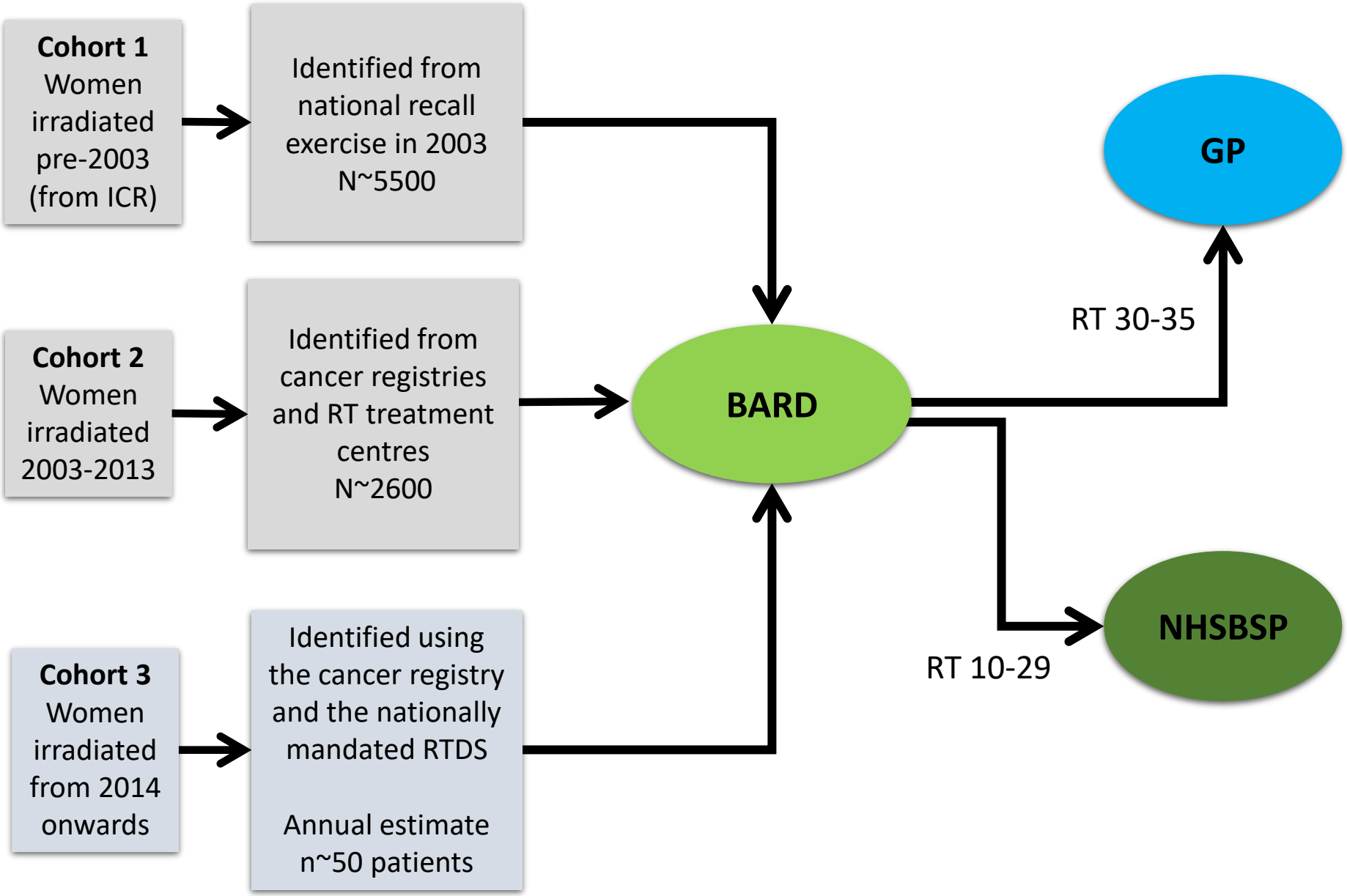
Breast cancer after RT

- Female survivors of lymphoma who received radiotherapy (RT) involving breast tissue at a young age are at increased risk of breast cancer
- In England this risk varies between 1:3 and 1:7 depending on age at RT, dose of RT and other factors
- National guidelines published by Department of Health in 2003 recommended women irradiated to a field including breast tissue under age 36 are offered annual breast screening starting 8 years after treatment or at age 25, whichever occurs later
- Pre-BARD, implementation of guidelines depended on individual physicians referring lymphoma survivors for screening at the appropriate time
- Strong support for a national database

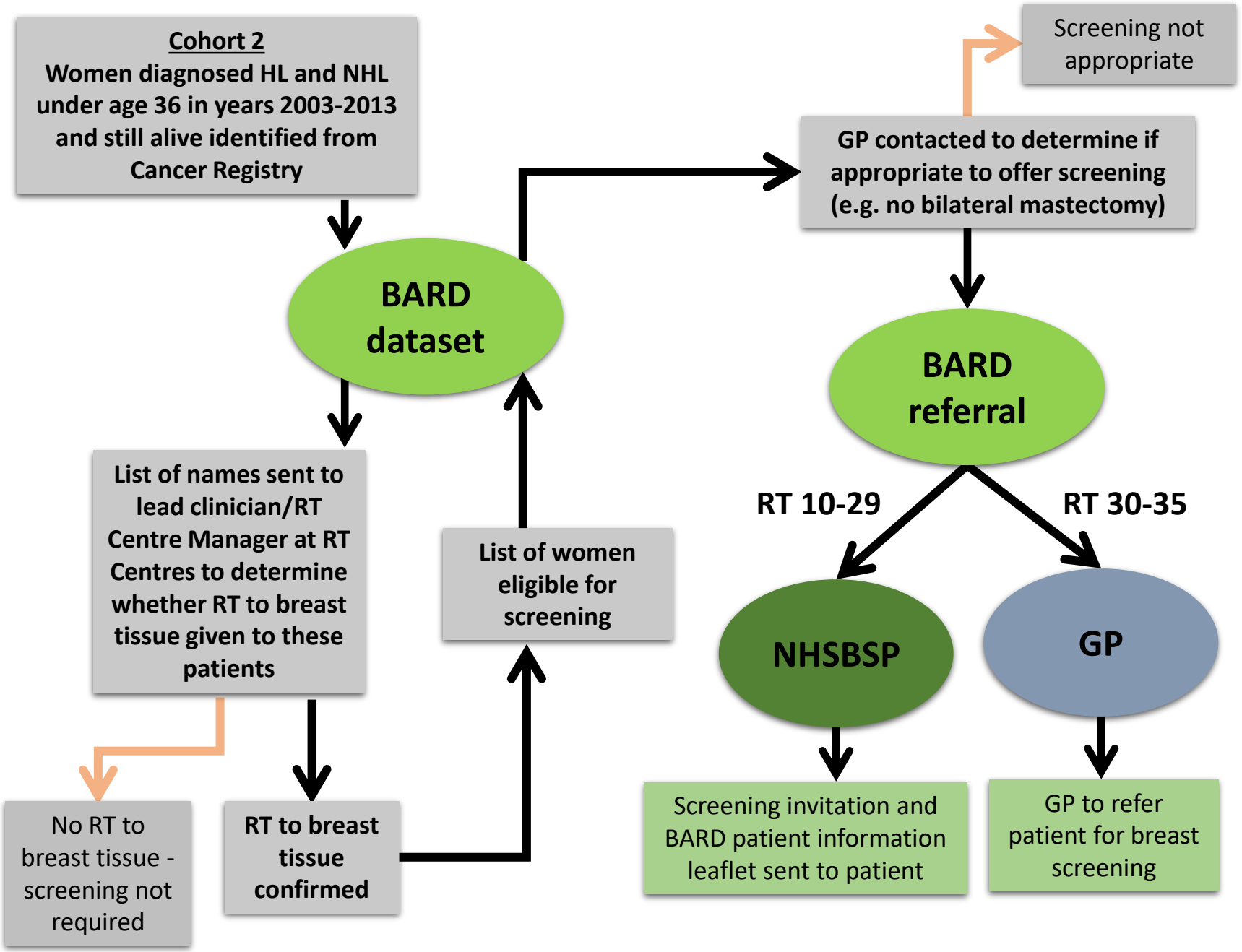
BARD project group

- Richard Cowan – Clinical Oncologist (lymphoma)
- Valerie Goode – Nurse Clinician
- Dipesh Gopal – General Practitioner
- Sacha Howell – Medical Oncologist (breast cancer)
- Jacquie Jenkins – National Breast Screening Programme Manager
- Aislinn Macklin-Doherty – Cancer Epidemiologist
- Martin McCabe – Paediatric Oncologist
- Elsita Payne – NDRS Health Services Data Manager
- John Radford – Medical Oncologist (lymphoma), Chair
- Kirstin Roberts – NDRS Data Analyst
- Mark Sibbering – Breast Surgeon
- Tony Swerdlow – Cancer Epidemiologist
- Ellie White – Data Manager
- Joanna Williams – Senior Project Manager
- Debbie Worthington – Patient representative
- Natalie Yates-Bolton – Patient representative

BARD cohorts 1-3



Identification of patients eligible for screening in cohort 2



Operational aspects of BARD

- Linkage of datasets to identify at risk patients

- The database
    - Planning / understanding structure and capabilities
    - Access and utilisation of data to inform screening referrals
    - Expansion

- Patient referrals

- Inclusion of different sub-cohorts of patients
    - Non-lymphoma diagnoses
    - Private healthcare
    - Diagnosis/treatment outside of England

- Liaison with numerous colleagues across the NHS

Learning

- Linking data in a central repository is required
- Inclusion in national guidelines
- Emerging sub-cohorts (i.e. TBI pts) are being discussed
- Analysis of the database to understand exact need, and screening uptake
- Research

Thank you!

- Contact us at: NDRSenquiries@nhs.net
- Feedback survey - link in chat box
- Next webinar: ‘Get Data Out – impact of cancer data’ – link in chat box
- Subscribe to our newsletter: www.ndrs.nhs.uk/newsletter/

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