

JOINT WORKING EXECUTIVE SUMMARY

Project Title: The Lothian Cancer Data Intelligence (LCDI) collaborative project

Organisations involved:

NHS Lothian Edinburgh Cancer Centre, University of Edinburgh, Usher Institute, IHDP Scotland, Roche (and other pharmaceutical companies) and the ABPI Scottish Collaborations Group.

Project description:

Focusing on the Breast Cancer Patient Pathway, from the point of diagnosis onwards, the objectives of the project are to:

- Better define the gap between what is on offer from data and what can be delivered, with the aim of informing the HTA data process for SMC.
- Describe the data completeness, data quality and scope of a comprehensive linked regional cancer dataset.
- Build an analytical framework for the quantification of population size, population characteristics, clinical and patient outcomes, tolerability, healthcare costs and value of recently adopted new technologies for cancer.

The project will also:

Develop appropriate governance by which researchers from academia, the NHS, industry and others can apply for access to the dataset.

Test the robustness and validity of the dataset.

Expected outcomes:

Benefits to Patients: Improved patient concordance, adherence and benefit from therapy through additional support of data to ensure optimal use of medicines. Better information as a basis for patient specific treatment decisions.

Benefits to NHS: A data audit framework as a basis for improved quality of care for breast cancer patients and improved capture of patient outcomes. Improved trusting and transparent professional relationship between NHS and the pharmaceutical industry.

Benefits to Roche: Improved reputation through working jointly with NHS to benefit patients. Improved trusting and transparent professional relationship between NHS and the pharmaceutical industry. Access to anonymized aggregated data to allow better disease understanding. The optimal use of medicines in appropriate patients which should mean better proactive treatment and management of patients.

Resource Breakdown:

Roche Products Ltd along with the three other companies each contributed £32,480.50, the NHS contributed £118,309.50 and the ABPI Scottish Collaborations Group paid £10,000.

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