DATA SHARING (FUNDER'S PERSPECTIVE)

Cancer Research UK

CRUK IS LARGEST CHARITABLE FUNDER OF CANCER RESEARCH IN THE UK

Our research spend is circa

£400m

We support research in over

130

institutions

We support Around

170

clinical trials

Since the early 1980s, we have taken

170

new drugs into early clinical trials

We support over

950

Principal Investigators

We support more than

4000

researchers, doctors and nurses

We support nearly

500

PhD Students

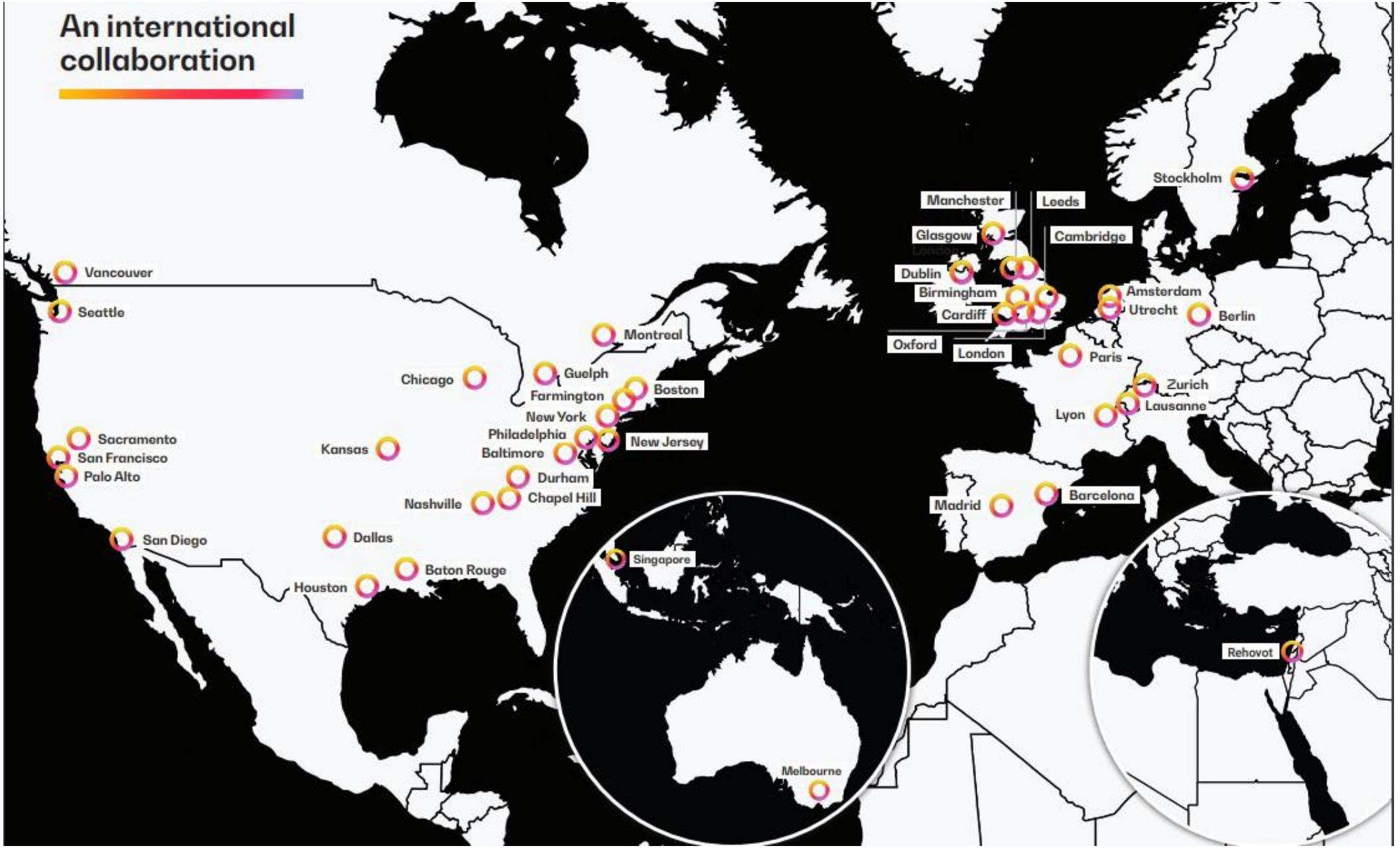
Each year our researchers publish an average of

2500

academic papers

A TRACK RECORD OF PARTNERING WITH GOVERNMENTS & INDUSTRY

CANCER GRAND CHALLENGES



10 challenges

11 global teams

10 countries

700+ researchers

£200+ to be invested

Our partners

Via Cancer Research Horizons, we provide unparalleled access to CRUK's innovative science portfolio & are the gateway for partners to connect with our cancer expertise, R&D capabilities, & enabling infrastructure across the CRUK Network.

Licences & collaborations

Spin-out formation & investment

Therapeutic discovery alliances

Clinical development partnerships

Strategic R&D initiatives

OUR RESEARCH DATA STRATEGY

CRUK'S FUNDING POLICY ON DATA SHARING

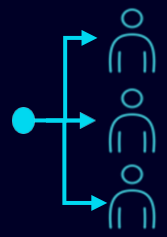
- CRUK is a signatory to the Corcordat on Open Data and DORA. Grants are covered the **Data Sharing & Management Policy**
- Applicants must submit a **Data Sharing plan** as part of their research proposal – it is part of the funding decision
- CRUK encourages wide sharing and **FAIR access** to research data, along with compliance with UK GDPR
- **Patient data must be appropriately anonymized & consented** (including ideally for secondary and commercial uses)
- Data must be **shared in a timely manner** - The Data Sharing Plan (DSP) must contain timelines to release the data. Acceptance for publication is the general trigger, but population based (long term) studies will be released in batches

CRUK'S FUNDING POLICY ON DATA SHARING

- We **do not specify data formats**, but expect to see common data standards, formats & metadata used to maximise access
- We expect to see a **plan to allow secondary use of the data** (long-term preservation plan – min 5 years), including a costs plan and any data archives to be uploaded to
- CRUK maintains a **data enclave** (Trusted Research Environment (TRE)/Secure Data Environment (SDE)) for researchers to upload a to if a suitable alternative is not found
- Publications should include a **Data Access Statement** setting out how to access data and any restrictions
- Data access is granted via requests to the **Data Access Committee/Access Review Group** - Any restrictions on access to the data must be made clear in the repository and in publications.

DATA IS AN INCREASINGLY IMPORTANT TOOL IN IDENTIFYING NOVEL INTERVENTIONS

Increases in analytical capabilities such as AI/ML mean data is increasingly valuable for:



DEVELOPING PATIENT STRATIFICATION TOOLS

Use data to better stratify patients to improve response rates & reduce side effects

IDENTIFYING NOVEL TARGETS

Identify novel biological vulnerabilities that could make new therapeutic targets

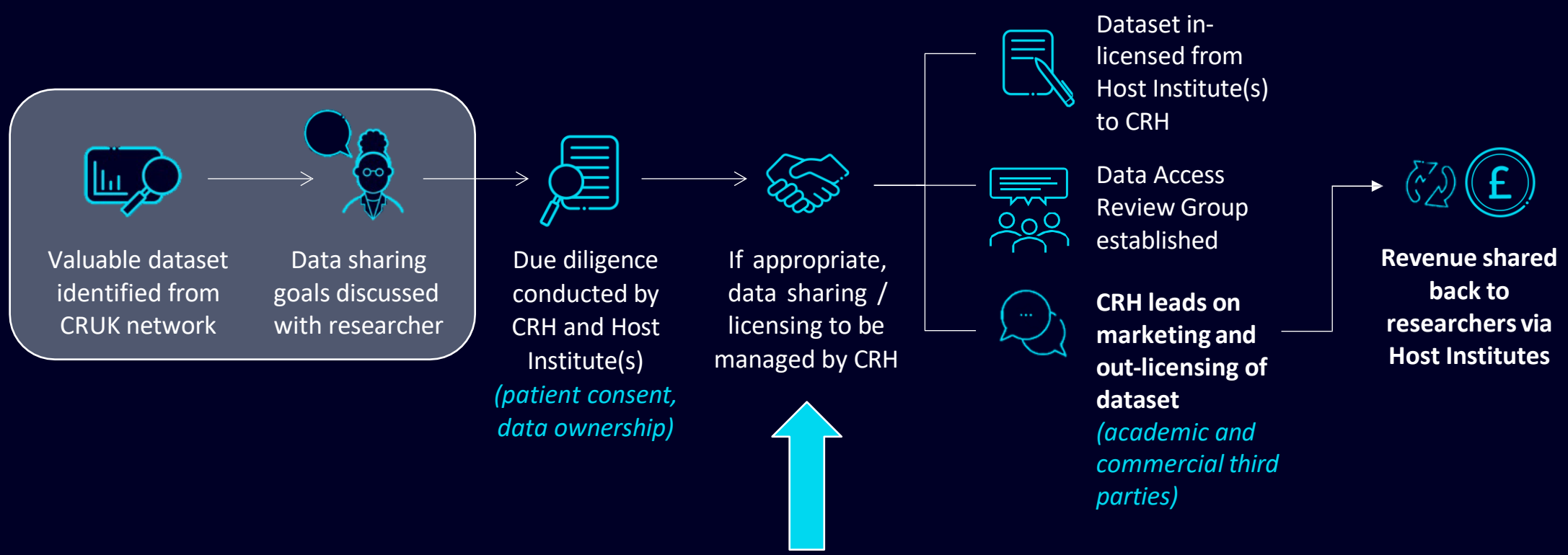
BUILDING RISK MODELS

Better predict individuals' cancer risks and contributing factors

AUTOMATING DIGITAL PATHOLOGY ANALYSIS

Reduce pathologist workload by automating pathology slide analysis

COMMERCIAL DATA PARTNERING NEEDS A CONTROLLED PROCESS



BUILDING TRUST AND MAINTAINING TRANSPARENCY

Patient Consent

- Developing improved consenting practices so it is clearly communicated from the start of a research how data will be used
- Offering patients the opportunity to allow their data to be shared for further academic and commercial research

- Developed a PPIE process to allow patients to input on overall data strategy and review specific commercial access requests
- Using a learning & development model, first proposed by Understanding Patient Data, to ensure that patients inform the evolution of policies and strategy

- Building reporting mechanisms into data access partnerships to capture information on impact
- Using this information work with PPIE groups to generate case studies that highlight the importance of commercial access to data with the aim of changing the public perception

OUR GUIDING PRINCIPLES

Our guiding principles have been developed through extensive consultation with people affected by cancer and research funder best practice.

Fair Partnership

Return fair value to the researchers who generated the data, with data access contingent on Data Controller consent

Data Security & Management

*Strong emphasis on security and management to ensure research is conducted in a responsible manner and all partnerships will be based on a **strict legal contract***

Transparency & Accountability

Maintain public trust by holding companies to account, ensuring data access is for defined projects and involving patients in decision making

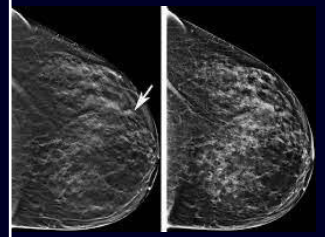
Protecting Academic Research

Protect academic interests while enabling commercial access, with academics maintaining data ownership

www.cancerresearchhorizons/collaborate-us/pharma-biotech/data-partnerships

CASE STUDY: OPTIMAM: UNLEASHING THE POTENTIAL OF BREAST SCREENING DATA

What is OPTIMAM?



>150,000
2D –FFDM Images

>3000
3D Tomosynthesis

- Image data associated with detailed clinical information & ground truth results
- Area of interest annotations
- Longitudinal data
- Enriched for abnormal cases

How has it been created?

Royal Surrey County Hospital NHS Foundation Trust

CANCER RESEARCH HORIZONS
FURTHER FASTER TOGETHER

Consortium of NHS Sites

- 9 NHS sites collect and share SOC data
- New sites added through deed of adherence for consistency
- Revenue share based on site contribution to dataset

RSNFT act as lead site

- Coordinate the automated collection of data and updates
- Manage storage and sharing with 3rd parties

CRH commercialise

- Right to CRH under background agreement
- Data shared with companies only after successful application to the OPTIMAM steering committee

16 commercial deals and more than 25 academic access requests, several high profile publications and multiple products on the market trained on OPTIMAM Data

CASE STUDY: STRATIFICATION IN CRC

The S:CORT consortium analysed the molecular profile of 2000 colorectal cancer patient samples creating a highly valuable clinically linked multi-omics dataset (incl. RNAseq, H&E, methylation data)

7 Academic partners | 1 Industry partner | 2 Funders

Barriers to data sharing	CRH intervention
Multi-institute consortium 7 different institutes involved in generating data	Dedicated CRH team member(s) leading discussions with Institute research groups, TTOs and legal teams
Complex ownership Each site separately owned the IP and data it generated	CRH is working with Institutes to establish a commercialisation agreement (that sits on top of the consortium agreement) to centralise the IP to allow effective commercialisation
Consent Historic consent only included 'further research use'	National and local ethics bodies and patient-public panel consulted, advised to allow access to academic and commercial applicants contingent on review by data access committee
Non-Consortium contributors Institutes outside of the consortium contributed samples to the project	Commercialisation agreement outlines revenue shares due to each contributor based on relative contributions to the dataset

S:CORT Stratification in COloRecTal cancer


CANCER
RESEARCH
UK
Together we will beat cancer


CANCER
RESEARCH
HORIZONS
FURTHER FASTER TOGETHER


CANCER
GRAND
CHALLENGES

THANK YOU

REFERENCES

- CRUK's data sharing policy is here - https://www.cancerresearchuk.org/funding-for-researchers/applying-for-funding/policies-that-affect-your-grant/data-sharing-and-management-policy#:~:text=CRUK%2Dfunded%20researchers%20must%3A,of%20the%20relevant%20research%20area

- Guidance around the generation of data sharing plans is here - https://www.cancerresearchuk.org/funding-for-researchers/applying-for-funding/practical-guidance-for-researchers-on-writing-data-sharing-plans

- CRUK's guiding principles for commercial data partnerships can be found here - https://www.cancerresearchhorizons.com/our-guiding-principles-data-partnerships